Negotiating evidence-based and patient-centred approaches to the management of multimorbidity across the adult life span: The Australian general practitioner experience

By

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DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed..

Date......9/9/21......

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CHAPTER 1 CONTENTS

ABSTRACT

People with multimorbidity comprise an unprecedently large proportion of general practice patients. Increasingly, many will be of advanced age with life-limiting conditions requiring end-of-life care. Healthcare systems, policymakers, and patients themselves expect general practitioners to provide care that is both patient-centred and aligned with the tenets of evidence-based medicine. However, general practitioners may find this work challenging if constrained by system structures and research evidence oriented to single condition care. International studies suggest general practitioners are confronted with high levels of clinical uncertainty due to the complex nature of multimorbidity and needing to reconcile multiple drug risk/benefit ratios for each individual patient. There is currently little research describing Australian general practitioner perspectives on multimorbidity and their patient management experiences. Healthcare reformers require this knowledge if it reveals challenges jeopardising the safety of patients or the sustainability of general practice.

This research is the first to explore the Australian general practitioner experience of managing patients with multimorbidity across the chronic management and end-of-life phases of care. Furthermore, it is unique in examining the implications of multimorbidity for the normative evidence-based and patient-centred expectations on general practitioner decision-making. The research program used a mixed methods exploratory sequential design of three interdependent phases and four studies to examine the general practitioner experience. The studies comprised a systematic review of qualitative studies of general practitioner perspectives, a content analysis of Australian chronic disease guidelines, in-depth interviews, and a quantitative cross-sectional survey of Australian general practitioners.

Most Australian general practitioner participants considered research evidence to have limited generalisability to their patients with multimorbidity. However, they differed in the ways they acted on guideline recommendations. Some adhered closely to evidence in formulating care plans, despite concern for patient safety. More, however, said they relied on fostered knowledge of individual patients to inform their care deliberations. Concerningly, general practitioners perceived the fragmented sectoral structure of the Australian healthcare system and its fee-for-service model of payment as incompatible with a patient-centred approach to care. Fee-for-service appears to penalise them financially from taking the time required to provide adequate

care to complex patients. It also discourages residential aged care work and home visitations. Almost a third of general practitioners refer patients to other general practitioners or specialist palliative care at the end of life, not considering this as part of their role. The majority believed multimorbidity care became simpler at the end of life. However, multimorbidity could challenge prognostication and the timing of conversations around changing care goals.

General practice is at the frontline of multimorbidity care within the Australian healthcare system, yet it appears to be facing some significant resourcing and evidence challenges. According to general practitioners, these difficulties threaten the quality of the care they provide, their work satisfaction, and ultimately the sustainability of general practice. As Australia faces the reality of an ageing population with expanding needs for complex and costly care, the Australian Federal Government needs to attend to the concerns of those practitioners in its vanguard and invest in strengthening general practice. Guideline developers and research producers might also explore innovative ways to support clinical decision-making for patients with multimorbidity.

PUBLICATIONS ARISING FROM THIS RESEARCH

Peer-reviewed journal articles

Damarell RA, Morgan DD, Tieman JJ. General practitioner strategies for managing patients with multimorbidity: a systematic review and thematic synthesis of qualitative research. BMC Fam Pract. 2020 Jul 1;21(1):131. doi: 10.1186/s12875-020-01197-8.

Damarell RA, Morgan DD, Tieman JJ, Healey D. Multimorbidity through the lens of life limiting illness: how helpful are Australian clinical practice guidelines to its management in primary care? Aust J Prim Health. 2021 Jan 19. doi: 10.1071/PY20164

Damarell RA, Morgan DD, Tieman JJ, Healey D. Bolstering general practitioner palliative care: a critical review of support provided by Australian guidelines for life-limiting chronic conditions. Healthcare (Basel). 2020 Dec 11;8(4):553. doi: 10.3390/healthcare8040553.

Other publications

Damarell RA. General practitioner clinical decision making for patients with life-limiting illness: does the presence of complex multimorbidity make a difference? 2019 Apr 9 [cited 2021 May 28]. In: Caresearch, palliative care knowledge network. Caresearch Blog: Palliative Perspectives [Internet]. Adelaide: Caresearch. 2015- . [about 3 screens]. Available from: https://www.caresearch.com.au/caresearch/TabId/3781/ArtMID/6000/ArticleID/483/General-practitioner-clinical-decision-making-for-patients-with-life-limiting-illness-does-the-presence-of-complex-multimorbidity-make-a-difference.aspx

LIST OF ABBREVIATIONS

AMS	Aboriginal Medical Service
ACCHO	Aboriginal Community Controlled Health Organisation
AGREE-II	Appraisal of Guidelines for Research & Evaluation Instrument
AGS	American Geriatrics Society
CARPA	Central Australian Rural Practitioners Association
CASP	Critical Appraisal Skills Programme
COPD	Chronic Obstructive Pulmonary Disease
COREQ	Consolidated Criteria for Reporting Qualitative Research
EBM	Evidence-Based Medicine
ENTREQ	Enhancing transparency in the reporting of qualitative health research
GP(s)	General practitioner(s)
GPMP	General Practitioner Management Plan
GRADE	Grading of Recommendations, Assessment, Development and Evaluations
IRSD	Index of Relative Socio-economic Disadvantage
NHMRC	National Health and Medical Research Council (Australia)
NICE	National Institute for Health and Care Excellence
OECD	Organisation for Economic Co-operation and Development
PHN(s)	Primary Health Network(s)
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QOF	Quality and Outcomes Framework
RACGP	Royal Australian College of General Practitioners
SPICT	Supportive & Palliative Care Indicators Tool
TCA	Team Care Arrangement
WHA	World Health Assembly
WHO	World Health Organization
WONCA	World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians

GLOSSARY OF TERMS

Aboriginal Community Controlled Health Organisations (ACCHOs)	‘A primary health care service initiated and operated by the local Australian Aboriginal community to deliver holistic, comprehensive, and culturally appropriate health care to the community which controls it, through a locally elected Board of Management.’[1]
Burden of Treatment (BoT)	‘A patient's perception of the aggregate weight of the actions and resources they devote to their healthcare, including difficulty, time, and out-of-pocket costs dedicated to the healthcare tasks such as adhering to medications, dietary recommendations, and self-monitoring.’[2]
Bulk billing (Australia)	A clinical service that directly receives a patient’s Medicare rebate as full payment, with no additional fees charged.
Care sector, Primary	Provides first-line access to the health system and the gateway to the wider system in Australia. Includes general practice, pharmacy, community nursing, Indigenous health workers, dentistry, and allied health services, amongst others working in the community.[3] Excludes hospital or institutional care.
Care sector, Secondary	Comprises specialist providers working in private practice or in hospitals to whom a patient must be referred, usually by a primary care provider.
Carer	A person who provides personal care, support, and assistance with day-to-day living to another individual who needs it. Excludes employed carers, those working as a volunteer for an organisation, and people caring as part of a course.[4]
Chronic condition	A ‘condition with a pattern of recurrence, or deterioration, a poor prognosis, and one which produces consequences, or sequelae that impact on the individual's quality of life.’[5]
Clinical Practice Guidelines	‘Statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options’ [6]
Comorbidity	Any ‘distinct additional clinical entity that has existed or that may occur during the clinical course of a patient who has the index disease under study.’[7]
Complex (patients)	A medical morbidity burden interconnected with non-medical factors such as psychosocial challenges or cultural and economic context. Complexity might also incorporate dimensions such as biologic and genetic factors, environment, and behaviour.[8]
Comprehensive care	Healthcare providers or practices that ‘offer a range of health and medical services, including aged care, preventive care, palliative care, immunisation, women’s health, men’s health, children’s health, after-hours services, home care and hospital-in-the-home.’[9]

End-of-life care	'[T]he episode of life that starts once active disease management is no longer an option, the disease will lead to death sometime in the foreseeable future and the involved parties are aware of this.'[10]
Evidence-Based Medicine	The 'conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine requires the integration of individual clinical expertise with the best available external clinical evidence from systematic research and our patient's unique values and circumstances.'[11]
Evidence summaries	A regularly updated online resource that 'aims to integrate the body of evidence at a topic level for several related questions' and which provides 'actionable recommendations for practice.'[12]
Fee-for-service	A model of provider payment wherein consumers pay providers directly for services received with no interference from any other payer.[13]
General practitioner	'[P]ersonal doctors, primarily responsible for the provision of comprehensive and continuing care to every individual seeking medical care irrespective of age, sex and illness. They care for individuals in the context of their family, their community, and their culture, always respecting the autonomy of their patients. They recognise they will also have a professional responsibility to their community. In negotiating management plans with their patients they integrate physical, psychological, social, cultural and existential factors, utilising the knowledge and trust engendered by repeated contacts. General practitioners/family physicians exercise their professional role by promoting health, preventing disease and providing cure, care, or palliation and promoting patient empowerment and self-management' [14]
Goals of care	The 'overarching aims of medical care for a patient that are informed by patients' underlying values and priorities … and used to guide decisions about the use of or limitation on specific medical interventions.'[15]
Health Care Homes (Australia)	An Australian Government trial involving existing general practices or ACCHOs that commit to a 'systematic approach to chronic disease management' using a 'coordinated, multi-disciplinary model of care that aims to improve efficiencies …' Employs a bundled payment model.[16]
Life-limiting illness	An illness where 'it is expected that death will be a direct consequence of the specified illness. Such illnesses may include, but are not limited to cancer, heart disease, chronic obstructive pulmonary disease, dementia, heart failure, neurodegenerative disease, chronic liver disease and renal disease.'[17]
Medicare (Australia)	Australia's universal healthcare system which provides the population with access to essential healthcare services at no charge or for a subsidised fee.

Multimorbidity	'The presence of two or more chronic conditions in which each condition may influence optimal clinical management of the other condition(s) though interactions between the conditions and the related treatments, between the treatments, or through limitations of life expectancy.'[18]
Multimorbidity, Complex	Multimorbidity involving three or more body systems, each affected by at least one chronic condition.[19]
My Aged Care (Australia)	An online portal established by the Australian Government that serves as the entry point for older Australians to access government-funded aged care services.[20]
My Health Record (Australia)	An online summary of an individual's health information available to all Australians. Authorised healthcare providers may access this record to access information or add information for sharing with other healthcare providers.[21]
Palliative care	An 'approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'[22]
Palliative care, Generalist	'Clinicians who are not palliative care specialists are a core part of the multidisciplinary team closely involved in looking after people who are dying in both the acute care setting and community, where there are not complex symptoms. Nonpalliative care specialists collaborate with palliative care specialists. These clinicians nonetheless provide bereavement support and lead conversations about burdensome or futile treatment. These clinicians require training from specialist palliative care clinicians in basic palliative care principles.'[23]
Palliative care, Specialist	Clinicians with 'expertise in managing pain, prognostication, diagnosing dying and recognising dying as a natural part of life, and are highly skilled in communicating about death and dying. These clinicians manage conflict on decision making around benefits and burdens of treatment, complex symptom management and expert knowledge on medications and complex pharmacology while navigating the complex ethical regulatory aspects of care. Specialist palliative care clinicians support patients with high distress and complex needs and family dynamics and are involved in complex bereavement support.'[23]
Patient-Centred Care	Care that is 'respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.'[24]
Patient health priorities	The 'specific health outcome goals that individuals most desire from their health care given what they are willing and able to do to achieve those outcome goals (within the context of their healthcare preferences).'[25]

Patient outcome goals	The ‘health and life outcomes that people desire from their health care.’[25]
Patient preferences	The ‘healthcare activities … that people are willing and able (or not willing or able) to perform and the care they are willing (or not willing) to receive.’[25]
Polypharmacy	The regular use of at least five medications by an individual.[26]
Primary Health Networks (Australia)	Independent organisations funded by the Australian Government Department of Health to ‘coordinate primary health care in their region. PHNs assess the needs of their community and commission health services so that people in their region can get coordinated health care where and when they need it.’[27]
Residential Aged Care (Australia)	‘An Australian Government-funded and regulated service under the *Aged Care Act 1997* (Cth) that provides accommodation and aged care to people requiring ongoing health and nursing care.’[28]
Shared Decision-Making	An approach where ‘clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences.’[29]
Whole-person care	Considers ‘multiple dimensions of the person in an integrated way, values the therapeutic relationship, recognises patients’ individual personhood, acknowledges doctors’ humanity, views health as more than absence of disease and employs a range of treatment modalities.’[30]

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The treatment of a disease may be entirely impersonal; the care of a patient must be completely personal. The significance of the intimate personal relationship between physician and patient cannot be too strongly emphasized, for in an extraordinarily large number of cases both diagnosis and treatment are directly dependent on it, and the failure of the young physician to establish this relationship accounts for much of his effectiveness in the care of patients. (Peabody, 1927, p. 877)[31]

CHAPTER 1 INTRODUCTION

Multimorbidity, or 'the presence of several co-occurring long-term chronic conditions, being related or not, in a given patient',[32] is a state of health that has risen in prevalence worldwide in recent years.[33, 34] This represents an epidemiological shift for healthcare from treating mainly communicable diseases to managing long-term and frequently incurable chronic diseases.[35] The transition has been primarily driven by dramatic increases in longevity[36] attributed to modern therapeutic innovations and successful population health initiatives.[37] It has also coincided with the increased risks for developing chronic illness associated with less healthy lifestyles.[38, 39]

Although chronic disease has been steadily growing in prevalence since the 1950s, medical education, research, and care structures have remained focused on resolving acute, episodic and now largely curable health problems.[40] Policy-makers have, therefore, only relatively recently begun to address chronic disease through national strategies or frameworks.[41-43] This action, largely a response to the unprecedented level of strain chronic disease is placing on healthcare budgets,[40] recognises the poor fit of the existing acute care model for chronic disease management.[44] A common response has been to introduce 'disease management programmes',[45] often based on the Chronic Care Model[46] and usually focused on managing a single condition.[47] In the same way, the infrastructure for delivering and financing care and measuring its quality has not yet evolved to deal with more than one illness at a time.[48] Meanwhile, multimorbidity has begun climbing the political agenda and gaining attention as a problem without a mature or conclusive evidence base[49] and one which threatens the sustainability of health systems.[48, 50] Meeting the long-term needs of people with multiple conditions is likely to require more extensive reform of fragmented care structures, including the entrenched sub-specialisation approach with its vested interests in providing care one body system or disease at a time.[51]

The Triple Aim approach to improving the quality of healthcare systems requires reformers to address three simultaneous goals: the patient experience, the health of populations, and the per capita costs of care.[52] As with other complex health issues, multimorbidity threatens each goal within this agenda. Firstly, multimorbidity can impose a range of detrimental effects on individuals,[53] culminating in ‘escalating physical difficulties, often accompanied by psychological and/or social challenges … experienced as a virtual “cascade” of crises.’[54(p95)] Its negative impact on quality of life often exceeds the sum effects of single conditions as chronic diseases interact against a background of adverse drug-condition and drug-drug effects.[55] This puts people with multimorbidity at increased risk of poor quality of life,[56, 57] burdensome treatment regimens,[58] psychological distress,[59] and earlier mortality.[60] Families and carers of people with multimorbidity may be required to provide support, helping them meet their medical care requirements, or cope with the demands of everyday life.[61] This can affect their physical, mental, social, and economic well-being.[62-64]

Secondly, multimorbidity impacts the health of populations via seemingly non-random, complex patterns of interacting influences.[65-68] It is highly prevalent in older (65 years plus) populations,[65, 69-71] being a natural consequence of the 'chronic dysregulation of multiple organ systems' associated with ageing.[72(p2)] Moreover, multimorbidity in older populations is poised to create significant problems for health and social care systems with the worldwide gains seen in longevity.[72] In Australia, for example, approximately 15% of the population is currently aged over 65 years, and this is set to rise to 22% over the next 40 years.[73] However, multimorbidity is not only seen in older populations. Numerous prevalence studies across a wide range of communities reveal it to be increasingly common in younger populations,[74, 75] especially those living in socioeconomically deprived circumstances.[66, 76] One study has estimated that people living in low-income households are 4.4 times more likely to develop multimorbidity than those in higher-income circumstances, which suggests a strong role for social health determinants, as well as biological ones, in the aetiology of multimorbidity.[77] This makes it a growing concern across the whole life span and an important social equity issue for preventative and management population health strategies.[71, 78]

Thirdly, multimorbidity directly impacts the per capita costs of healthcare.[79, 80] People with multimorbidity are high users of healthcare resources across their multiple medications, numerous primary and secondary care appointments, and unscheduled emergency visits and hospitalisations.[81-84] Chronic conditions, in the main, are progressive and incurable, requiring ongoing management to alleviate symptoms or to prevent further complications or deterioration. Therefore, chronic care management occurs across a longer time span, from diagnosis up to when it becomes no longer possible to prevent deterioration. The longitudinal nature of chronic disease management makes it the most expensive aspect of healthcare[80] and places a substantial burden on healthcare economies worldwide.[50]

The complexity and demands associated with multimorbidity care also raise concerns for the well-being of the health practitioners charged with providing this care,[49] particularly frontline general practitioners.[85] When patient physical health burdens interconnect with non-medical factors such as psychological problems or socioeconomic difficulties, this can tax the health practitioner's personal and professional resources leading, in some cases, to dissatisfaction with their role.[85] However, patient complexity is only one part of the challenge ahead. The growing number of older people expected to require medical management in the future will place health systems under pressure to reduce costs and simultaneously demonstrate return on investment in terms of patient outcomes and quality of care. Health professional workloads are likely to increase, concomitant with a greater demand for accountability, potentially through more extensive imposition of pay-for-performance measures.[86] These requirements may place practitioners at risk of professional burnout, with flow-on consequences for patient care and health system resourcing.[87] Acknowledgement of the importance of improving health professionals' work life now comprises the fourth strand of the *Quadruple Aim*.[88]

In Australia, general practitioner encounters with patients with multimorbidity are now commonplace, comprising more than 50% of consultations.[89] In their role as gatekeepers to other sectors of the healthcare system, Australian general practitioners frequently share care of their patients with multimorbidity with a range of other specialists, each focused on a specific condition or body system. At the same time, they provide a more holistic, comprehensive form of care.[9] The general practitioner's *whole-person* (or *biopsychosocial*) approach acknowledges the patient's unique life circumstances and psychosocial needs alongside their need for medical treatment and customises care accordingly.[14, 90] However, the single disease approach dominant in health system design, the specialist agenda, and chronic disease research, can undermine general practitioner efforts to individualise care.[53, 91]

According to the Australian *Standards* for general practice, general practitioners are expected to conduct their consultations and decision-making processes according to the normative expectations of the Evidence-Based Medicine and Patient-Centred Care movements.[9] The patient-centred approach to care aligns well with the general practice ethos of care, emphasising understanding the whole person within a context and establishing a solid patient-doctor therapeutic relationship.[92, 93] Patients with multimorbidity and their carers may require a more patient-centred approach than those presenting with single and straightforward problems.[94, 95] However, patient-centredness requires an input of time.[96, 97] How general practitioners might successfully employ a patient-centred approach in the context of multimorbidity is unclear when the current Australian fee-for-service model of general practice was designed to deal with readily resolvable problems, thereby favouring and rewarding a high volume of short, uncomplicated consultations.[98]

Conforming with the tenets of Evidence-Based Medicine may also be problematic in the context of multimorbidity. To date, the evidence base for multimorbidity remains largely inconclusive across all levels of inquiry. There are still significant knowledge gaps in areas including aetiology, best practice pharmaceutical management, and optimal models of care.[49, 99] General practitioners may not be helped in their management decisions by clinical practice guidelines focused on treating single chronic diseases in isolation with little, if any, reference to what happens when diseases come in multiples.[100-102] On top of these challenges, many of the conditions contributing to multimorbidity will be progressive and non-curative, leading gradually or more rapidly to care needs within an end-of-life context. Ideally, prescribing or intervention decisions during this final phase of care should be weighed against concerns for limited life expectancy, quality of life, and an individual's personal goals and preferences.[103, 104] However, how the presence of multiple conditions impacts general practitioner management of a life-limiting illness and vice-versa remains largely unknown. If multimorbidity obscures the clinician's timely recognition of the approaching end of life or reduces the likelihood of activating a palliative care discussion, this may deprive patients and their families of the information they need to prepare for what is ahead. It may also impede the provision of effective symptom palliation.

This mixed methods programme of research seeks to examine the experiences of Australian general practitioners in their management of patients with multimorbidity, with a focus on the transition from chronic illness to palliative and end-of-life care. Although general practitioners are said to be the ideal professionals to provide whole-person multimorbidity care, [105, 106] a systematic review of first-hand perspectives of international general practitioners found they experience challenges in doing so.[107] Due to a paucity of studies involving Australian general practitioners, we currently have no empirical basis for knowing if they too experience difficulties fulfilling their central role in multimorbidity care across the adult life span. Further, we have little understanding of how they manage inherent challenges around evidence-based practice and person-centred care in providing complex care within the constraints of the primary healthcare financing model.

This first chapter provides the context of the study and the rationale for the research programme. It outlines what is known about multimorbidity and its impact on individuals, carers, healthcare systems and the management of life-limiting conditions. It also establishes the implications of multimorbidity for general practice before describing aspects of Australian general practice relevant to this thesis. The chapter concludes by presenting the research aim and questions and providing an outline of the thesis structure.

1.1 **Multimorbidity**

Multimorbidity is not a clinical diagnosis[32] and lacks a universal definition shared by clinicians, patients, researchers, and policy-makers.[108] This absence of conceptual clarity makes it difficult to determine the true scale and impact of the issue[49] and has impeded the development of a coherent evidence and practice base for multimorbidity.[109] Unless addressed, this problem may hinder future efforts to develop appropriate clinical and policy responses.[110]

1.1.1 Concepts closely related to multimorbidity

The concept of disease chronicity is important in multimorbidity definitions as it determines which conditions are included in any measurement of prevalence. This thesis adopts the consensus criteria of a chronic condition as one which lasts at least 6 months, impacts on a person's quality of life, and has a pattern of recurrence or deterioration and a poor prognosis.[5]

The term 'multimorbidity' is often used interchangeably with 'comorbidity'. However, these terms have different meanings based on context and viewpoint.[111] Comorbidity is defined as 'any distinct additional clinical entity that has existed or may occur during the clinical course of a patient who has the index disease under study.'(7(p456)) The priority implied here is a central index condition, with interest extending to additional comorbid conditions only insofar as they impact the index condition (Figure 1.1). This orientation corresponds well with the dominant medical specialisation model of care in secondary and tertiary settings based on diseases or body systems.[112] Multimorbidity, however, does not privilege any condition. It forces an examination of the effect of the whole disease constellation on the patient. For this reason, it appears to have more affinity with general practice where clinicians concern themselves with all of a person's conditions, shifting focus based on the patient's symptoms and priorities for care.[112]

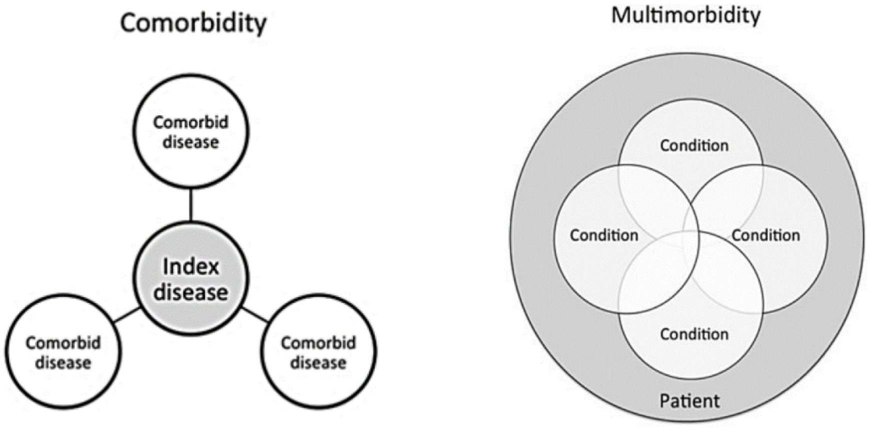

Figure 1.1 The comorbidity versus the multimorbidity construct

(Boyd C, Fortin M. Future of multimorbidity research: How should understanding of multimorbidity inform health system design? Public Health Rev. 2010;32(2):451-74. CC License: https://creativecommons.org/licenses/by/4.0/. Images not modified).

Multimorbidity is also frequently conflated with ‘frailty’, a geriatric syndrome, in describing vulnerable elderly patients.[113] As shown in Figure 1.2, multimorbidity and frailty are closely related and often overlap being 'complementary biomarkers of aging.'[55(p5)] They also exist independently of each other, having different prevalence rates[114] and requiring different approaches to management.[115] Research suggests that the relationship between multimorbidity and frailty is bidirectional. Having multiple chronic conditions may increase the likelihood of being frail,[116] while most people with frailty also suffer from multiple chronic conditions.[117] The interaction between multimorbidity and frailty can be especially problematic for individuals and may be a reliable predictor for functional disability and mortality.[118, 119]

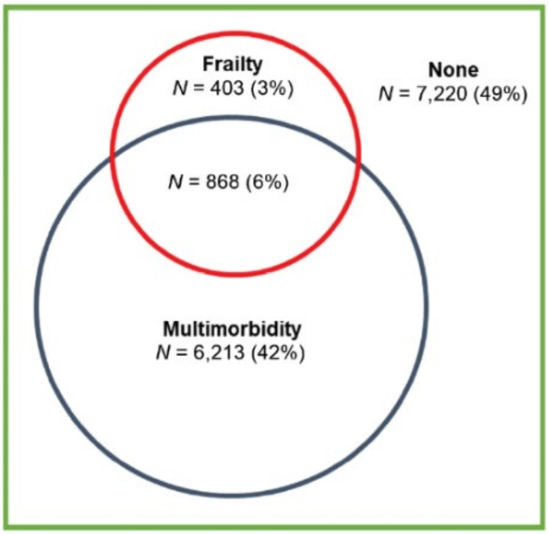

Figure 1.2 Overlap of frailty and multimorbidity from a pooled analysis of 9 prevalence studies

(Vetrano DL, Palmer K, Marengoni A, et al. Frailty and multimorbidity: A systematic review and meta-analysis. J Gerontol A Biol Sci Med Sci. 2019;74(5):659-666. By permission of Oxford University Press.)

Multimorbidity is also closely related to, but distinct from, the concept of 'complexity'.[120] As shown in Figure 1.3, complexity is a broader construct than either multimorbidity or frailty. It infers a medical morbidity burden interconnected with non-medical factors such as psychosocial challenges or cultural and economic context.[121-123] Complexity might also incorporate dimensions such as biologic and genetic factors, environment, and behaviour.[8, 124] When these factors interact, clinicians may experience patients as time consuming and resource intensive.[113] There will be problems outside the scope of medical practice or the doctor's expertise, and issues that cannot be managed effectively during a standard consultation.[125] This pressure on the clinician can put doctor-patient communication at risk and undermine the quality of the care provided.[124] There is growing evidence that patients with complex health needs contribute to general practitioner levels of stress and burnout.[85, 126]

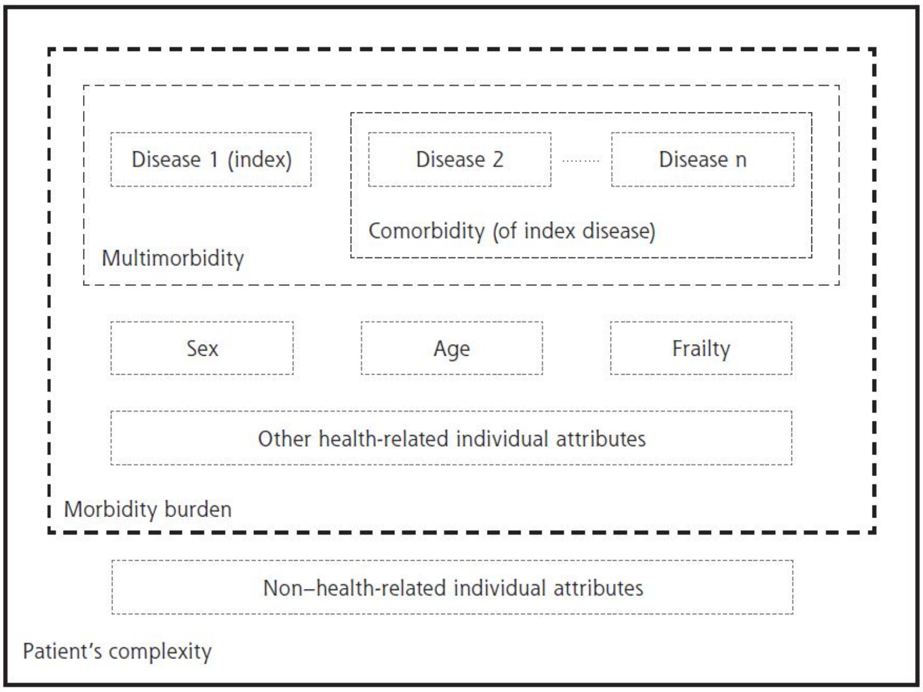

Figure 1.3 Relationship between comorbidity, multimorbidity and complexity

(Valderas JM, Starfield B, Sibbald B, et al. Defining comorbidity: Implications for understanding health and health services. Ann Fam Med. 2009;7(4):357-63. By permission of Annals of Family Medicine.)

Several models of complexity have attempted to conceptualise it in relation to multimorbidity. Schaink's Complexity Framework (Figure 1.4), derived from a scoping review of the literature, identified five interconnecting dimensions to patient complexity.[127] The first dimension is demographics, which includes a person's age, gender, ethnicity, and educational attainment. The second focuses on the individual's medical conditions, therapeutic regimen, and physical function. The remaining dimensions to this framework are the individual's health and social experiences (including quality of life and ability to navigate the health system), mental health concerns, and social capital.[127] A later ecological model by the Agency for Healthcare Research and Quality (AHRQ) Multiple Chronic Conditions Research Network[123] incorporated the personal, social, health and contextual approach of the Schaink model, but expanded it to give the health system and its services a more prominent contributory role within complexity. Here complexity is conceptualised as a malignment between a person's needs and the services available to them for meeting these needs.[123]

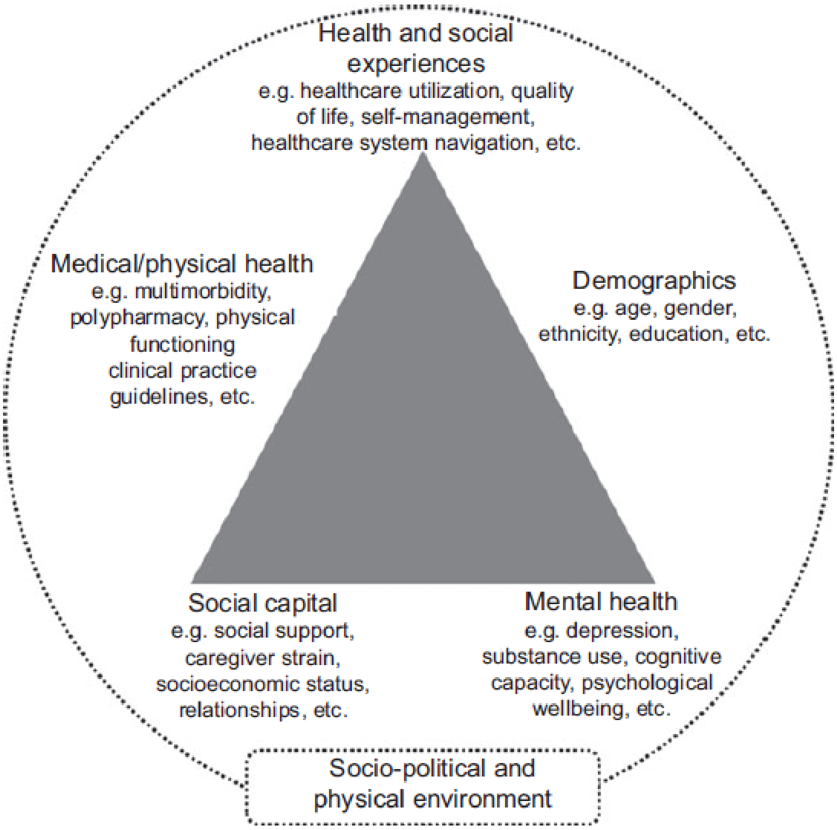

Figure 1.4 The five dimensions of Schaink's Complexity Framework

(Schaink AK, Kuluski K, Lyons RF, et al. A scoping review and thematic classification of patient complexity: Offering a unifying framework. J Comorb. 2012;2(1):1-9. CC License: https://creativecommons.org/licenses/by/4.0/. Image not modified).

Multimorbidity and polypharmacy are overlapping concepts insofar as people with multimorbidity are usually prescribed multiple drugs for prevention, therapy, or symptomatic relief. Like multimorbidity, polypharmacy lacks a standard definition. One systematic review identified 138 distinct occurrences of the term across the research literature,[128] making it challenging to compare studies. The most common definition in usage may be 'the regular use of at least five medications by an individual.'[26, 128, 129] Some definitions distinguish polypharmacy that is 'clinically appropriate' and beneficial for the patient from 'inappropriate polypharmacy' or 'potentially inappropriate polypharmacy' where potential harms may outweigh potential benefits.[130] It is usually left to the prescriber to decide which is which.[131]

According to one study, most participants taking five or more medications a day did not feel burdened by polypharmacy and may have experienced therapeutic benefits.[132] However, around 40% experienced polypharmacy as problematic as it was costly, inconvenient, or imposed a burden of treatment on them.[132] These problems might exceed the individual's capacity for self-management or fail to align with their goals and priorities for their health.[133] At its worst, inappropriate polypharmacy can increase the risk of adverse drug events and drug-drug interactions in older people and contribute to problems such as cognitive impairment, delirium, falls, urinary incontinence, and reduced functional capacity.[134] As well as being costly to the patient, inappropriate polypharmacy impacts resource use, mainly through unscheduled hospitalisations and visits to the emergency department.[134]

There is evidence that the prevalence of polypharmacy is increasing, particularly amongst the elderly and nursing home populations.[135, 136] In Australia, the proportion of people aged 70 years and over taking five or more prescribed medications increased by 52% between 2006 and 2017, equating to approximately one million people.[137] The older population is particularly vulnerable to adverse drug events due to the altered pharmacokinetics and pharmacodynamic changes associated with aging.[138] Patients receiving palliative care or in their final days of life may also experience polypharmacy when prescribers add medications to bring symptom relief without a comprehensive review of the total regimen.[104, 139]

1.1.2 The epidemiology of multimorbidity

Methods for measuring multimorbidity prevalence and patterning vary greatly.[140] They also depend on how investigators define multimorbidity.[65] Unsurprisingly then, prevalence estimates differ across reports[141] with a range of 12.9% to 95.1% suggested based on primary care data.[142] Despite this sizeable range, there are specific identifiable trends in multimorbidity across studies, countries, and settings.[143] First, prevalence increases in tandem with ageing populations,[65, 66, 69-71, 144-151] as shown graphically in Figure 1.5.

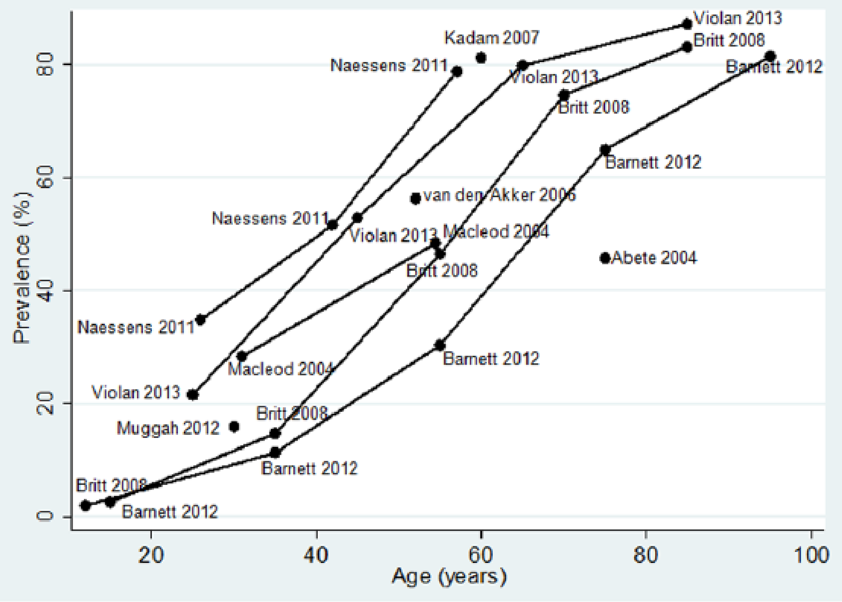

Figure 1.5 Prevalence of multimorbidity by age group

(Violan C, Foguet-Boreu Q, Flores-Mateo G, et al. Prevalence, determinants and patterns of multimorbidity in primary care: A systematic review of observational studies. PLoS ONE. 2014;9(7):e102149.
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Furthermore, the prevalence of multimorbidity in older populations is likely to rise further. United Kingdom modelling shows a two-fold increase in older people with four or more conditions over the next twenty years.[152] As this will include a high proportion of mental health conditions and dementia; this forecast has important implications for health and social care organisation and funding.[153]

While multimorbidity is more prevalent in older age groups, the absolute number of people with multimorbidity is largest amongst younger populations and increasing,[65, 71, 154-157] especially in areas of socioeconomic disadvantage.[66, 75, 158] There are other disparities in multimorbidity prevalence indicating that chronic conditions are not distributed equally across populations. First, multimorbidity is more prevalent in females than males.[34, 65, 75, 142, 151, 159] It is also socially patterned, with people living in socioeconomically deprived areas experiencing higher rates of multimorbidity than those living in less disadvantaged neighbourhoods.[76, 147, 151, 160-162] Moreover, deprived populations tend to accumulate chronic conditions around 10-15 years earlier than more affluent ones.[66]

Increasingly, longitudinal studies are able to reveal differences in multimorbidity onset and progression between population subsets living within the same socioeconomically deprived regions.[163] This includes differences between ethnic groups. Several United States studies involving middle-aged participants have identified a higher rate of multimorbidity for Black American participants at baseline compared to White participants.[74, 164-166] Meanwhile, prevalence of multimorbidity in Dutch ethnic minority groups is comparable to prevalence in non-ethnic minority people aged 10 to 30 years older.[167] Within Australasia, Australian Aboriginal Peoples[168] and New Zealand Māori and Pacific Islanders[169] have a higher prevalence of multimorbidity compared to the rest of the population. As strong ethnicity patterning remains after controlling for sociodemographic factors such as education or socioeconomic status, this seems to suggest that there are yet unknown cultural differences at work impacting on the physical and mental health of certain population subsets.[165]

Mental-physical comorbidity is also patterned, disproportionately affecting younger people (18-44 years) and those of lower socioeconomic status.[66, 75] Furthermore, there is a clear dose-response relationship between the number of chronic physical conditions a person has and the presence of a mental disorder such as anxiety or depression.[66, 75, 162, 170-172] The particular relationship between physical disease and depression appears to be bidirectional, with a history of physical disease associated with subsequent depression[170] and a history of depression positively associated with future disease onset.[173] Moreover, certain chronic disease clusters appear to associate more closely with mental disorders, with arthritis, lung disease, heart conditions, and diabetes shown to frequently co-occur with elevated depression and anxiety.[172] Despite this patterning, depressive symptomatology associated with a chronic physical condition is often not recognised in primary care.[174] This finding underscores the importance of screening people with multimorbidity for mental health disorders.[175]

Currently, around 23% of Australians have two or more chronic diseases, based on a list confined to eight common conditions and self-report.[176] This figure rises as high as 73% in those aged 65 or over in the population.[177] Multimorbidity is also prevalent in Australian homeless and marginalised populations,[178] people from non-English speaking backgrounds,[179] and regional or remote communities.[176]

1.1.3 Impact of multimorbidity on patients and their carers

For some people, but not necessarily all, multimorbidity will have a deleterious and disruptive impact on most aspects of their lives.[180] Complex interactions may occur between treatments or treatments and conditions, making it clinically challenging to predict how multimorbidity will affect any individual based on a straight disease count.[55, 181] Some studies stress the importance of specific clusters of conditions,[182] or the number of body systems affected[57] in determining likely impact. Multimorbidity can often impart a heavy and additive symptom burden.[183] For patients, this can translate to reduced health-related quality of life,[56, 57, 184-186] functional decline,[187-191] and disability.[192, 193] Everyday tasks may become a struggle,[194, 195] ultimately affecting the ability to work and earn an income.[180, 196] In Australia, people with chronic conditions which involve at least three different body systems appear to be the most negatively affected.[19, 151] Around half will experience functional restrictions or disability, and 47% will be unable to work.[151]

People with multimorbidity may also experience a range of psychosocial challenges such as the psychological distress associated with living with painful, chronic illnesses with uncertain trajectories,[59, 197] social isolation or loneliness,[54, 198] or a sense of loss of personal autonomy, life purpose and productivity.[199, 200] This distress can increase the severity of the multimorbidity itself[59] and may lead to, or intensify, depression in patients.[171] People with physical-mental multimorbidity are also at increased risk of unplanned hospital admissions[199, 201, 202] and emergency department visits.[203] Ultimately, multimorbidity can impact survival[60, 204-206] with an estimated 7.5 years of life lost.[207]

For carers, physical assistance with activities of daily living can impact their physical health through injuries and reduced capacity to look after their own health needs.[62, 63] Furthermore, the work of facilitating access to care, managing appointments,[208] assuring continuity of care,[209] and communicating with health professionals on behalf of someone else can take a mental toll on carers[63] which may go unnoticed within general practice consultations.[210] Some carers will have made financial sacrifices to fulfill the carer role, such as giving up paid employment.[64] The practical difficulties of looking after a person with restricted function can also put carers at risk of social isolation[62, 208] and limit their ability to participate in meaningful, valued activities.[64] Some carers report challenges in accessing carer support or respite services.[208] Others may themselves be ageing with multimorbidity or experiencing functional or cognitive decline. [211]

People with multimorbidity report significant troubles interacting with the health system.[200, 212] Fundamental to their difficulties is its structure built around disease-based specialisation[199, 213] which, from the patient's perspective, creates an experience of care that is fragmented, uncoordinated[214, 215] and associated with considerable 'hassles.'[212] There are also financial challenges associated with healthcare use for this population[58, 216, 217] which may jeopardise adherence to treatment goals. Even with Australia's universal health coverage, people report a high cost burden for their treatment.[218, 219] This is particularly problematic for older people[220-222] and people who are socioeconomically disadvantaged.[223] Together, these challenges have the potential to create a range of substantial quality and safety issues for patients and their carers.[213, 215, 224]

Conversely, some studies show multimorbidity to be associated with more, rather than less, appropriate care.[225, 226] This might occur when one condition shares common pathophysiology with another and therefore receives a 'collateral benefit' from a single management plan.[227] It might result from an increased level of patient contact with health services.[228] Clinicians might also be more vigilant in the provision of care when confronted by complexity. For example, patients receiving treatment for long-term physical conditions are more likely to receive attention for comorbid depression.[229]

1.1.3.1 Burden of treatment

When the workload of healthcare begins to affect a person's functioning and sense of well-being,[230] the person is said to be experiencing *burden of treatment*.[231] Burden of treatment is the perceived cumulative weight of all the activities and resources individuals must devote to their healthcare to comply with health provider recommendations.[2] It may involve the complexities of dealing with the healthcare system,[61, 231] as well as the energy, time, travel, and financial cost expended on performing the self-care tasks necessary for successful management of long-term chronic conditions.[2] Burden of treatment is imposed on top of, and may be antagonistic to, an already heavy burden of disease.[232, 233]

People with multiple chronic conditions are at risk of a high burden of treatment.[234] Clinicians themselves may be unwittingly contributing to this burden in providing care adherent to clinical practice guidelines.[234] As guidelines remain focused on single conditions, a person with multiple conditions is likely to be bombarded with pharmacological and non-pharmacological management recommendations taken from across multiple clinical practice guidelines.[100] When numerous health professionals are involved, potential interactions between recommendations may be overlooked. Several studies based on hypothetical patients with only a few conditions demonstrate the potential dangers of this additive approach to care.[102, 235, 236] For three conditions, a patient with moderate disease would need to take 6-13 medications per day,[235] significantly increasing the risk of adverse drug-drug interactions.[102] They would also be required to attend 1-6 healthcare visits per month[235] and spend 5-8 hours per day on self-care activities.[236] These figures rise as the number of conditions increases or if the disease burden includes a mental health condition.[237]

The consequences of burden of treatment for patients include confusion, poor adherence, or avoidance of self-care work altogether.[218] People may also make their own decisions about what they will prioritise, which may not be the most pressing concern from the clinician's perspective.[58, 238] Clinicians should therefore keep in mind any potential to over-medicalise problems, over-prescribe,[218, 238] or add further burden to carers.[239] Currently, few guidelines quantify the workload implicit in their recommendations and any impact on a person's quality of life.[238, 240]

Several models and theories are available to help us understand the concept of treatment burden. These include the Cumulative Complexity Model[241] and Burden of Treatment Theory[239] out of which has come the approach to patient care called Minimally Disruptive Medicine.[234, 242, 243] These models and theories acknowledge the work delegated to the patient by healthcare systems in the interests of self-care. They also postulate a counterbalancing component called 'capacity', which is the combined total of the internal and external resources patients can call on when needed to help cope with healthcare demands. These resources include personal resilience, information and knowledge, and support networks.[239]

Figure 1.6 illustrates the individual nature of coping thresholds and their impact on work-capacity equilibrium.[231] As each person possesses different capacities and burdens, it makes sense for clinicians to examine the burden of treatment at the level of the individual.[58]

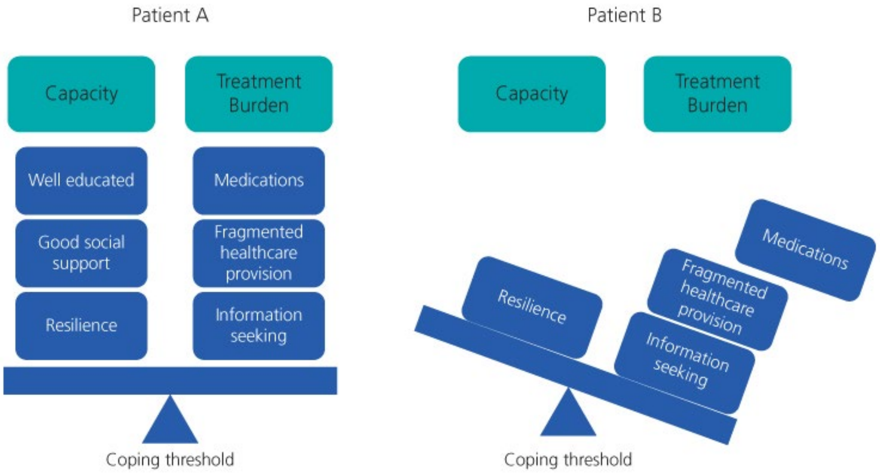

Figure 1.6 Achieving a balance between capacity and treatment burden: Two patient examples

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Validated tools for application in primary care can also help clinicians assess burden of treatment for patients with multimorbidity.[244] These include the ICAN Discussion Aid,[245, 246] the Treatment Burden Questionnaire,[247] and the Multimorbidity Treatment Burden Questionnaire.[248]

1.1.4 *Impact of multimorbidity on healthcare systems*

A United Kingdom study has estimated that people with multimorbidity use healthcare 2.56 times more than people without multimorbidity.[79] An exponential relationship between each additional chronic condition and healthcare expenditure is also evident, indicating that the overall cost for managing multimorbidity can be higher than treating each condition separately.[249, 250]

Despite the considerable impact of multimorbidity on healthcare expenditure, healthcare services continue to conform to a legacy twentieth-century structure focused on curing acute illnesses and infections[251] or treating people disease-by-disease.[47] As Salisbury[252(p7)] states:

> Management of patients with several chronic diseases is now the most important task facing health services in developed countries, which presents a fundamental challenge to the single-disease focus that pervades medicine.

This approach, and the medical super-specialism it has created are arguably major contributing factors to healthcare's high usage and costs.

1.1.5 *Multimorbidity with a life-limiting illness*

For many patients with multimorbidity, at least one chronic condition will be life-limiting, non-curable, and progressive. A 'life-limiting illness' is defined as an illness where:

> [I]t is expected that death will be a direct consequence of the specified illness. Such illnesses may include, but are not limited to cancer, heart disease, chronic obstructive pulmonary disease, dementia, heart failure, neurodegenerative disease, chronic liver disease and renal disease.[253(p6)]

Multimorbidity is commonly associated with these life-limiting chronic conditions and might be considered the rule in the final year of life[200] where a heavy burden of restrictive symptoms may accompany it.[254-256] Despite its prevalence, there is scant research currently available on how to prioritise and manage symptoms in late-stage patients with multimorbidity.[187, 257] For clinicians, awareness of a symptom burden, on top of an advancing life-limiting chronic index condition might prompt consideration of limited life expectancy and the changing goals of care. A shift to a palliative care approach should ideally ensue to enhance quality of life in the time left to the person.[258]

The World Health Organization defines palliative care as:

> [A]n approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[22]

The recognition of limited life expectancy should necessitate a re-evaluation of the patient's medications as the risks of harm and the promise of therapeutic benefit become less clear with the physiological changes that accompany declining health.[259] This includes the possibility of deprescribing or reducing preventive medications with a long *time to benefit*, defined as 'the time until a statistically significant benefit is observed in trials of people taking a therapy compared to a control group not taking the therapy.'[260(p655)] Deprescribing might also target medications with known risk factors for poor outcomes such as accidental falls or urinary incontinence.[259] Furthermore, existing medications for long-term conditions may no longer be metabolised in the same way as before as patients with advanced disease experience alterations to their body mass, pharmacokinetics, and pharmacodynamics.[261] To alleviate the burden of treatment, clinicians might also consider reducing diagnostic testing, lifestyle preventive tasks such as weight control and exercise prescriptions, and intrusive self-management activities such as blood glucose monitoring.[258] However, burden of treatment can be a problem in other ways. As people with multimorbidity approach the end of their life, they may be at risk of high intensity care involving interventions such as chemotherapy or haemodialysis.[262, 263] Such invasive care at the end of life can increase the likelihood of hospitalisation,[263, 264] of being admitted to intensive care, and of dying in the hospital.[265] Furthermore, treatments for symptoms experienced at the end of life may themselves induce new symptoms requiring management.[139, 266] As many patients with an advanced life-limiting illness receive care at home for as long as possible, carers and family can be placed under a considerable strain to make sense of medications which may change after each hospitalisation.[267] They may also struggle to continue to coordinate care across the person's various conditions or between health providers who may not communicate well with each other.[262]

Clinician recognition of the approaching end of life is vital for ensuring that the needs of patients and their families do not go unrecognised. When this recognition leads to an open and sensitive discussion of prognosis with patients and their families, this opens up the possibility of anticipatory planning.[268] Studies of prognostic disclosure tell us that most patients with a cancer diagnosis want an honest discussion of prognosis to help them face challenging decisions, to reduce uncertainty as to what might lie ahead, and to have the chance to pursue personal goals within a realistic time frame.[269-271] Goals of care discussions, which should follow a disclosure of prognosis, are ideally initiated early (6 to 12 months before death),[272] outside of a crisis such as hospitalisation, and continued over time.[273] They should also be 'as much about how the patient wants to live'[273] as end-of-life treatment intent.[274]

From the health provider's perspective, discussing prognosis and goals of care can facilitate more timely initiation of palliative care, medicines optimisation, and advance care planning. It might also provide an insight into the potential future support needs of carers. However, it appears clinicians are often reluctant to initiate prognosis or goals of care conversations with their patients, even when patients have prognostic awareness or desire these discussions.[275-278] This can leave older people to view their progressive deterioration as a sign of getting old rather than nearing death, leaving carers and families unprepared.[200] Eligible patients, especially those with non-cancer diagnoses, are also at risk of being overlooked for referral to specialist palliative care, from which they could derive benefit.[279, 280] Conversely, clinician reluctance to discuss prognosis has been linked to significantly more aggressive medical care in the final week of life, worse patient quality of life near death, and a higher risk of problematic bereavement for carers.[281] The reasons for clinician hesitancy include discomfort with breaking bad news and not wanting to destroy hope or inflict psychological harm.[282] Some clinicians may also believe disclosure will compromise the therapeutic relationship, although the evidence shows this relationship is more often strengthened through this honest communication.[283]

A major reported barrier to communicating prognosis to patients is clinician difficulty in determining life expectancy,[284] particularly for patients with non-cancer diagnoses[285-287] such as dementia[288] and heart failure.[289-291] Recognising a transition point between the active disease management and end-of-life phases of care is further challenged by there being no agreed definition of 'end of life' in practice, nor when this phase is considered to have started.[292] Definitions vary by country, or organisations within the same country, and may be dictated by financial, legal, or practical reasons.[292] For example, Palliative Care Australia regards the end-of-life phase as 'the few weeks of life in which a patient with a life-limiting illness is rapidly approaching death'[293] while other key Australian health organisations define this phase as the last 12 months before death.[294, 295] One conceptualisation of 'end of life' that does not refer to a specific timeframe is:

> [T]he episode of life that starts once active disease management is no longer an option, the disease will lead to death sometime in the foreseeable future and the involved parties are aware of this.'[10(p2222)]

The relationship between this phase and other phases of care are shown in Figure 1.7.

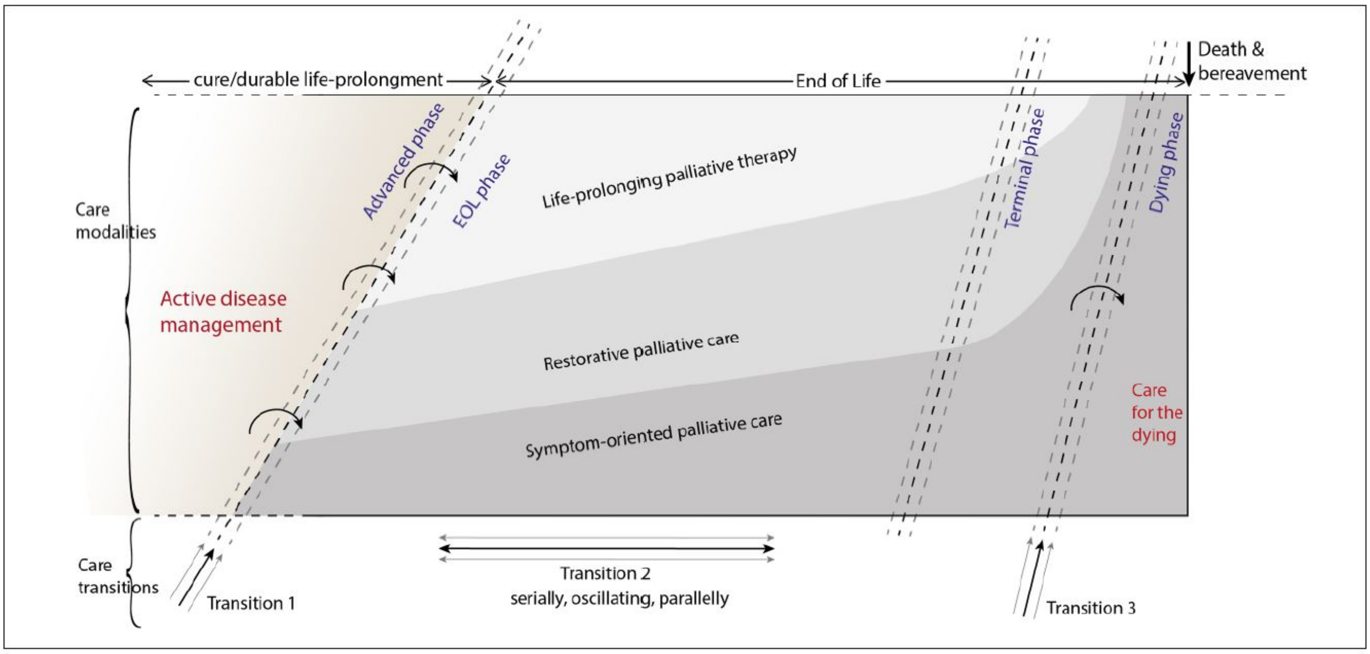

Figure 1.7 A 'layered' model of end-of-life care showing the transitions between care phases

(Sercu M, Beyens I, Cosyns M, et al. Rethinking end-of-life care and palliative care: Learning from the illness trajectories and lived experiences of terminally ill patients and their family carers. Qual Health Res. 2018;28(14):2220-38. By permission of Sage Publishing.)

Multimorbidity may further confound clinician efforts to determine when a person is approaching death.[82] Overlapping symptoms such as dyspnoea in both heart failure and chronic obstructive pulmonary disease,[296] frailty, or escalating acute events attributed to comorbidities or adverse drug effects may mask indicators of terminal deterioration, challenging efforts to ascertain life expectancy. Furthermore, although some life-limiting index conditions may follow an identifiable, if not entirely predictable trajectory towards death,[297] the effect of overall multimorbidity on these trajectories is not known as patients may have two or more trajectories running concurrently.[298] The archetypal trajectories of the different types of life-limiting illnesses are shown in Figure 1.8.

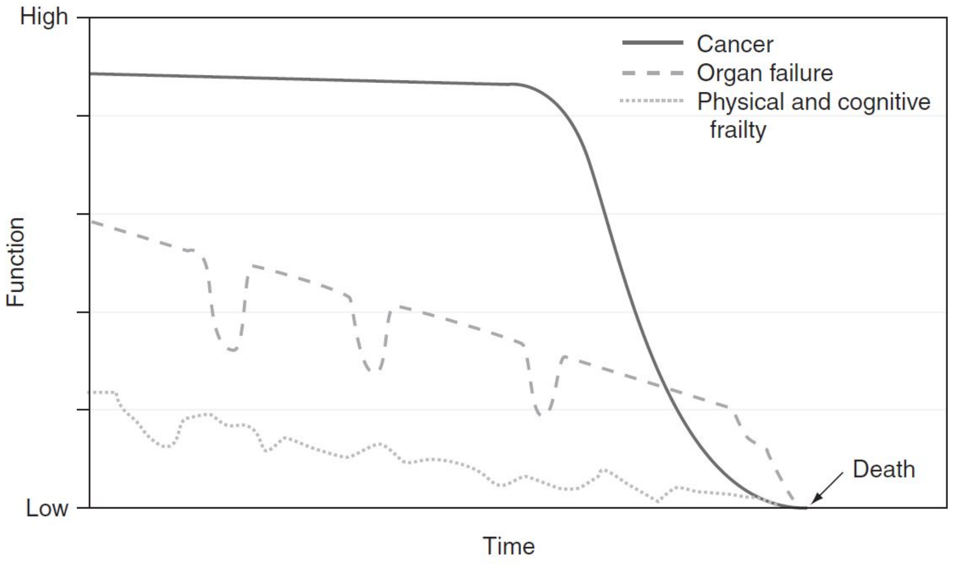

Figure 1.8 Three major trajectories of decline at the end of life

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Each life-limiting index condition will have its own considerations around comorbidities at the end of life. Some of the management implications associated with five major life-limiting conditions in Australia are outlined here.

1.1.5.1 Cancer

Cancer is currently the main cause of disease burden in Australia.[299] Although certain cancers contribute to the leading causes of mortality in Australia,[300] ongoing improvements in cancer screening and therapies have increased the numbers of people living longer with the condition post-diagnosis.[301] As a result, cancer can now be considered a condition with chronic characteristics, requiring ongoing monitoring, medical treatment, and self-management over the longer term.[302, 303] Older people with cancer are likely to have comorbid conditions as cancer and chronic illness risks increase with age.[304] Prevalence of comorbidity ranges from 14% to 81% across certain cancers,[305] with the upper end of this spectrum perhaps reflective of shared causal pathways between some cancers and comorbid conditions, for example, smoking-related lung cancer and chronic obstructive pulmonary disease.[304] However, people living with cancer have a higher prevalence of multimorbidity than people of the same age *without* cancer,[306, 307] indicating that non-age factors are also at play. Some cancer therapies have demonstrated the ability to induce new conditions or exacerbate pre-existing ones.[302] Furthermore, comorbidities can influence the cancer survivor's functional status and quality of life.[308] Comorbidities may also negatively affect cancer survival,[305] either directly or via the withholding of active treatments from patients.[309, 310]

Although cancer survivors may eventually die of a recurrence of cancer, they are more likely to die earlier than the general population of other non-cancer causes such as cardiovascular disease.[311] For this reason, survivors often face a heavy burden of treatment, not just in managing the acute effects of cancer and being vigilant to recurrence, but also staving off late and long-term non-cancer outcomes.[312] This might involve pharmacological and non-pharmacological interventions, as well as major lifestyle modifications.[313]

1.1.5.2 Heart failure

Heart failure is another condition highly associated with ageing.[314] Most heart failure patients (92%-99%) have at least one additional chronic condition,[148, 315, 316] while 53% have six or more requiring management.[316] Coronary artery disease, chronic obstructive pulmonary disease, hypertension, diabetes, chronic kidney disease, depression, and cancer frequently co-occur with heart failure.[148] Heart failure with comorbidities is associated with a high degree of therapeutic complexity and polypharmacy[317] which can result in exacerbations of the condition requiring hospitalisation.[318] It also carries a high symptom burden, with breathlessness, oedema, and fatigue common.[317] Clinicians may observe heart failure as gradual functional decline with intermittent acute episodes of deterioration, recovery to a lower level of functional capacity, followed by a sudden and often unexpected death.[319] Heart failure has a five-year mortality rate of 43.3%[320] and was ranked the eleventh leading cause of death in Australia in 2019.[300] It is 1.7 times more prevalent in Indigenous Australians than in the non-Indigenous Australian population[321] where it develops as a complication of rheumatic fever or rheumatic heart disease.[322]

1.1.5.3 Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease (COPD) is an umbrella term for progressive lung conditions such as emphysema, chronic bronchitis, and chronic asthma.[323] It is characterised by the narrowing of bronchial tubes, impairing a person's ability to breathe without difficulty.[323] COPD was ranked the fifth leading cause of death in Australia in 2019.[300] An estimated 86% of people living with COPD in this country have comorbid chronic conditions,[159] including cardiovascular disease, heart failure, lung cancer, metabolic syndrome, diabetes, osteoporosis, anxiety, depression, asthma, and obstructive sleep apnoea.[324] Comorbidities can negatively impact COPD, worsening the experience of breathlessness, increasing functional impairment, and reducing survival.[325] The typical combination of COPD and heart failure is particularly problematic for diagnosis as both conditions share similar symptoms. The combination is also known to increase the risk of hospitalisation and death.[326] Like heart failure, the relapsing and remitting nature of COPD progression can make prognostication difficult for clinicians.[327] This generally results in clinicians overlooking patients for palliative care,[328-330] which has demonstrated effectiveness in alleviating symptoms and improving quality of life for this population.[331, 332]

1.1.5.4 Chronic kidney disease

Chronic kidney disease is an age-related condition characterised by a gradual decline in renal kidney function.[333] Diabetes and hypertension can hasten its onset.[334] At the same time, chronic kidney disease is an independent risk factor for cardiovascular disease[335] with stroke, heart failure, and myocardial infarction often causing death before a person reaches end-stage kidney disease requiring renal replacement therapy.[336] Chronic kidney disease is estimated to affect 11% to 13% of the population worldwide[337] and projections suggest it will become the fifth highest cause of mortality by 2040.[338] In Australia, chronic kidney disease-related mortality was estimated at 11% in 2018.[339]

As chronic kidney disease impacts multiple organ systems, many comorbid conditions associate with it, some of which are highly symptomatic, resulting in a reduced quality of life.[340-342] Conditions most associated with chronic kidney disease include hypertension, diabetes, pulmonary disease, heart failure, coronary artery disease, atrial fibrillation, myocardial infarction, and stroke. However, unrelated conditions such as depression and dementia are also prevalent.[341] There is, therefore, an onus on primary care to identify and manage known risk factors early to avoid further progression of kidney damage.[343]

Like other organ failure conditions, chronic kidney disease progresses along an unpredictable trajectory[344] and is associated with high health costs in its later stages through frequent hospitalisations.[340] The minority of people who do not die before end-stage renal failure may receive dialysis or transplantation.[340] However, there is some doubt about the benefits conferred by dialysis to older, frail people with comorbidities.[345, 346] People managed supportively without dialysis have similar survival outcomes as those on dialysis but with fewer acute hospitalisations and a greater likelihood of dying at home.[347] They also show less deterioration in functional status.[348] Furthermore, common symptoms of severe pain, fatigue, breathlessness, and insomnia appear to be frequently overlooked and undertreated during end-stage renal failure.[349] These findings attest to the need for better and earlier initiation of a general palliative care approach or improved access to specialist palliative care to alleviate symptoms and initiate frank discussions of treatment benefits versus risks.[350]

1.1.5.5 Dementia

The prevalence of dementia, including Alzheimer's disease, is increasing in tandem with the aging of populations[351] and has a substantial effect on health and social care, communities, and families.[352] Dementia is a neurodegenerative disease that impacts memory, executive function, speech and language comprehension and a person's ability to perform activities of daily living,[353] frequently leading to disability and dependency.[352] It is also a terminal condition, although often not recognised as such, with a median survival time of 1.3 years.[354] It was the second leading cause of death in Australia in 2019, which constitutes an increase in mortality of 66.8% since 2010.[300]

Multimorbidity is extremely common in dementia where people experience, an average, four additional chronic conditions.[72] These include other conditions associated with ageing such as chronic kidney disease, heart failure, osteoarthritis, osteoporosis, heart failure, stroke, and diabetes.[148, 355] Increasing cognitive impairment and complex self-care regimens associated with multimorbidity can make it challenging for people living with dementia to keep their comorbid conditions in check without carer support.[356] Furthermore, comorbid conditions such as stroke[357] and diabetes[358] have been shown to exacerbate the progression of dementia.

The presence of dementia may result in lower-quality healthcare for comorbid conditions or reduced access to services.[359] This includes treatment for pain that can be severe but uncommunicated,[360] visual impairments, and monitoring of diabetes and its complications.[359]

Furthermore, ongoing treatment of comorbidities, on top of medications for the management of behavioural and psychological dementia symptoms, can drive inappropriate polypharmacy in this population,[361] often resulting in adverse outcomes such as falls and fractures.[362] People living with advanced dementia have palliative care needs equivalent to people with terminal cancer.[363] Despite this, care at the end of life can be comparatively suboptimal.[364]

1.2 General practice and multimorbidity

According to the World Organization of Family Doctors (WONCA),[14] general practitioners (or 'family doctors') provide biopsychosocial, comprehensive, and continuing care to all individuals within a population, regardless of their illness, and within the context of a family, community and culture. They also recognise their own professional responsibility to their community and their role in 'promoting health, preventing disease and providing cure, care, or palliation.'[14(p9)] General practitioners work within the primary care sector, alongside other professionals from allied health, nursing, community health and dentistry.[365] As established with the Declaration of Alma-Ata[366] and reasserted with the Declaration of Astana,[367] primary care has four main principles which clearly align with the aforementioned WONCA definition of general practitioner work. These are: provision of first-contact, equitable access to healthcare within the community; long-term person- rather than disease-focused care, comprehensive care across most health problems; and the provision of coordinated care.[368] Countries with strong primary care demonstrate better outcomes for their populations at lower costs.[368-370] Furthermore, countries that invest in preventing and managing chronic diseases are shown to be more likely to have a better social and economic return on their investment.[371, 372]

The principles and characteristics of general practice, therefore, differentiate it from other medical specialties. They also make it especially well-suited to providing care for people with multimorbidity.[47] First, general practice takes a whole-person approach, viewing presenting conditions as part of a complex combination of contextual, biological, psychosocial, and cultural factors.[14, 30] A whole-person approach acknowledges the interplay between individuals and the ecosystems in which they exist and grasps the association between multimorbidity and social disadvantage. Unlike relationships with other specialists, a patient's relationship with their general practitioner is not dependent on the type and duration of the condition they have.[373] As general practitioners form relationships with patients before they know what their problems are, general practice has been called the only medical specialty that defines itself in terms of relationships.[374]

Furthermore, patients often experience a continuous therapeutic relationship with their chosen general practitioner which may even extend to the patient's family.[87] This *relational continuity* can produce a sense of partnership, affiliation, and mutual commitment over time through repeated contacts.[375, 376] Studies of relational continuity have demonstrated benefits such as fostering trust, respect, and open communication while promoting better patient adherence to treatment recommendations.[377] For the practitioner, knowledge of the patient accumulated over time may be clinically helpful in formulating tailored, individualised care plans[375, 377-379] and identifying when clinical changes have taken place. There is also evidence of an inverse relationship between continuity of care and unplanned hospital admissions[380-382] and mortality.[383]

For patients with multimorbidity, seeing the one primary caregiver means being understood without having to repeat a complex medical history.[376] For the practitioner, it clarifies that responsibility for an individual lies with them and not the other clinicians involved in care,[384, 385] perhaps leading to better efforts at coordinating care for patients.[377] Older patients especially value relational continuity[377, 386] and express a desire for one trusted clinician to guide them and coordinate their interactions across complex healthcare systems.[387-389] Many patients even demonstrate a willingness to sacrifice the convenience of access to care in favour of maintaining continuity with their general practitioner.[386, 390]

Patients with multimorbidity also report wanting to feel listened to by their doctors and receiving care that is individualised to their specific needs and flexible enough to adapt as their conditions fluctuate over time with disease progression.[386] General practice strives to meet these needs through its defining quality of patient-centredness.[87] Patient-centred care—defined more fully in the next chapter—is 'care that is respectful of and responsive to individual patient preferences, needs, and values, and ensures that patient values guide all clinical decisions.'[24(p6)]

Several other characteristics of general practice, however, may constitute challenges for high-quality multimorbidity care provision. First, people with multimorbidity require multiple and ongoing appointments to have their conditions assessed and monitored. While general practice can provide socially equitable care to the community it serves by being relatively accessible and inexpensive,[368] out of pocket costs can still mount for patients through frequent contact, deterring people from seeing their general practitioner at potential risk to health.[391]

Secondly, accessibility to general practice, while highly valued by patients with multimorbidity,[386] can come at the cost of having adequate time within the consultation. The fee-for-service model of general practice in Australia can place pressure on practitioners to prioritise the volume of appointments over spending more time with complex patients to explore their problems.[392] This tension can create stress for the general practitioner[393] and a poor experience for the patient with multiple competing concerns.[194, 394] Managing uncertainty under pressure can be particularly demanding for general practitioners operating in areas of high socioeconomic deprivation. Multimorbidity appears to exacerbate the 'inverse care law',[126, 395] meaning there can be a large disparity between the needs of patients with significant multimorbidity and the personal and organisational resources available to them for meeting those needs.[97, 396]

Thirdly, general practice alone is charged with providing comprehensive care whereby '[a]ll aspects of human existence are legitimate concerns of the general practitioner provided that they are presented as a problem by the patient.'[397(p26)] This view of general practitioners as interested in a universe of clinical problems may be under threat from increasing specialisation within general practice itself in the form of general practitioners with special interests (GPwSIs). A GPwSI acquires specialist knowledge and skills through extra training which can then be shared with colleagues within the practice or employed in the care of patients with the specific health issue of interest.[398] As of 2021, there were 31 Specific Interests groups registered with the Royal Australian College of General Practitioners (RACGP) in areas as diverse as breast medicine, dermatology, diabetes, musculoskeletal medicine, and pain management.[399] Notably, however, this list excludes chronic diseases and multimorbidity. While GPwSIs may take the pressure off other specialists, cut waiting-list times, and provide underserved areas with much needed access to specialist care, they also have the potential to reduce access to generalist care overall and create fragmentation within the speciality.[400] Specialisation may also weaken the generalist role, by emphasising interests in specific diseases rather than a general biopsychosocial concern for individual patients.[398] Furthermore, it remains to be seen how this diversification will impact on care of increasing numbers of older, complex patients.

Comprehensive care also means that patients can present with a vast range of undifferentiated, not yet fully developed, problems that the general practitioner must gather, sift, and prioritise for action in the limited time available.[401] The complexity and diversity of problems seen in general practice have led its practitioners to report higher rates of clinical uncertainty than other specialities, apart from psychiatry.[402] However, general practitioners appear to develop tactics to grow increasingly comfortable with clinical uncertainty throughout their careers.[403] The consequences of not doing so include a high level of personal anxiety, stress,[402, 404] and burnout.[405]

It might also lead to excessive ordering of tests[406] and referrals,[407] with an ensuing burden on the healthcare system and the patient. Clinical uncertainty, however, is likely to be intensified in the presence of multimorbidity,[408] affecting deliberations from diagnosis through care planning and goal setting to therapeutic management.[55]

While international studies have examined the problem of multimorbidity management from the general practitioner's perspective, including one systematic review,[107] we know very little of the Australian general practitioner's experience. As the Australian general practitioner perspective is the focus of this research programme, the following section describes the context of general practice in Australia, highlighting features that may impact multimorbidity care provision.

1.2.1 The Australian general practice model

Australian general practice sits at the centre of the country's primary care system, which is considered one of the strongest in the world, albeit not without room for improvement.[409, 410] General practice is the most accessed health service in Australia, with almost 90% of the population seeing their general practitioner at least once a year.[411] Although people in Australia are free to visit any general practice, 75.5% reported having a preferred general practitioner in 2018-19.[412] Accessibility differs by geographic location, with people living in regional and remote areas of Australia having access to far fewer general practitioners per capita than those living in inner regional areas or major cities.[411]

Most general practices operate as privately-owned businesses, varying in size, ownership model, and work team composition, but responsible for managing indirect costs such as wages, rent, insurance, supplies, and information technology systems.[413] Around half of general practitioners work in a group practice comprising two to five other general practitioners.[411] Practices may also employ other health professionals such as practice nurses, allied health practitioners, and pharmacists.

Australia's universally available healthcare insurance scheme, Medicare, is funded by national tax revenue. Money is then allocated to general practice by the Commonwealth Government via a fee-for-service model.[414] This model reimburses general practitioners for activities they undertake for patients according to a set schedule, the Medicare Benefits Schedule, which stipulates the types of services attracting a rebate and their corresponding fees.[415] The Government then subsidises patients for their general practice visits at the fee stipulated in the Schedule.[352] If general practitioners choose to charge only the subsidised amount, patients have no out-of-pocket expenses (*bulk billing*).[414] However, practices can also charge more than Medicare will reimburse, leaving a gap amount for the patient to pay. Practices can choose to bulk bill a subset of their patients, such as pensioners and people on a low income.[416] In 2018-19, 66% of patients had all their general practice fees bulk billed.[417] However, patient costs continue to rise, with the average out-of-pocket cost for a standard consultation now higher than the rebate amount and increasing faster than the general inflation rate.[411]

Australian general practitioners can choose to provide care to people in residential aged care, either by continuing the long-term care of existing patients once they have moved into a facility or accepting new patients within nearby facilities.[418] The Commonwealth Government provides an annual payment incentive, the Aged Care Access Incentive, to practices registered with their Practice Incentives Program to encourage sustained general practitioner services within residential aged care.[419] Despite this fee, the Australian Medical Association estimated in 2014 that as few as 21% of Australia's general practitioners were engaging with residential aged care.[420] This reluctance may be due to the poor fit between an inflexible fee-for-service reimbursement model and the amount of work involved.[421] In 2021, a Royal Commission heard testimony of the poor quality and unsafe care received by older Australians in residential aged care. One of the systemic failures highlighted by the Commission was a disconnect between aged care and medical services with general practitioners found to be particularly inadequate in the quality and quantity of their service provision. In the words of the report: ‘Medicare is designed for people going to the doctor, and does a poor job of encouraging doctors to go to people living in aged care.’[28(p25)] In acknowledging inadequate funding for general practitioners to provide this care, the Commission proposed a trial of a new model of primary care for aged care involving voluntary practice accreditation, patient enrolment, capitation payments, and formalised after-hours arrangements.[28, 421]

While funding for general practice is the Federal Government's responsibility, Australia's state and territory governments administer funding for public hospitals, community health services, and mental health services.[422] This split in funding and regulatory responsibility has tended to foster silos, rather than integration, between sectors[423] while limiting coordination and continuity of care for patients.[424] Neither level of government has overall responsibility for system performance, and both write health policy without coordinating with the other.[425] Furthermore, running alongside Australia’s publicly funded services is a private health insurance system that around half the population purchases for broader choice and faster access to non-emergency care.[426]

This overlapping, mixed model of public and private care can create additional complexity for patients.[424]

Each Australian general practice has the support of a regional Primary Health Network (PHN).[27] These organisations can help general practices align their services to the needs of the local community, especially in the areas of disease prevention and the management of specific chronic conditions.[427] Thirty-one Primary Health Networks span Australia, created by the Australian Government in 2015 to run as non-profit, independent organisations.[27] Their purpose is to identify and prioritise health service needs specific to the population of their catchment area and to then commission services to meet them.[27] This might involve improving the accessibility of primary care, especially to ‘those at risk of poor health outcomes,’ or collaborating with regional hospital networks to improve coordination of care for patients.[428] Theoretically at least, PHNs have the potential to integrate primary care and public health to create more accessible healthcare better tailored to community needs.[427] Current broad priority areas for PHNs include mental health, aged care, and digital health, amongst others.[27]

A unique part of Australia’s primary care sector is the Aboriginal Community Controlled Health Organisation (ACCHO), whose core business is to provide a range of services needed within specific Indigenous communities[429] as part of efforts to reduce the ongoing disparity in health between Indigenous and non-Indigenous Australians.[430] These organisations, operated by the local Aboriginal community, offer ‘holistic, comprehensive, and culturally appropriate health care to the community which controls it, through a locally elected Board of Management.’[1] There are around 143 ACCHO organisations distributed across Australia in metropolitan, regional, and remote areas. Each employs diverse personnel, including salaried general practitioners, nurses, social and emotional well-being workers, pharmacists, and Aboriginal health practitioners.[431] The ACCHO model has similarities with the successful patient-centred medical home model in the United States with its integrated, comprehensive, team-based approach to caring for individuals and families within a community.[430] By addressing social and health issues, ACCHOs 'function as community spaces through which Indigenous people attempt to deal with their immediate health needs and the underlying structural causes that produce very poor health outcomes.’[432(p472)] ACCHOs have increased Aboriginal peoples’ access to primary care and attendance at clinics.[433, 434] They have also demonstrated improved health outcomes for Australian Aboriginal peoples across various target areas, including chronic disease management.[433, 434]

1.2.2 Australian Government initiatives for managing multimorbidity

The *National Strategic Framework for Chronic* Conditions (2017-2025) directs Australia's policy response to preventing and managing chronic disease.[42] Although this document does not explicitly focus on multimorbidity, it acknowledges the importance of tackling shared health determinants and risk factors across chronic conditions and suggests the Australian Bureau of Statistics uses 'prevalence of chronic condition multimorbidities' as one indicator against which to measure progress.[42]

The Australian Government provides a 'Chronic Disease Management—GP Services' package of incentives within the Medicare Benefits Schedule.[435] This package acknowledges the vital role of general practice in chronic disease management.[410] However, its prime purpose is to encourage more coordinated and systematic, rather than reactive, care of people with chronic conditions or a terminal medical condition.[435] The package includes a fee for preparing and routinely reviewing time-limited general practice management plans (GPMP). It also includes a Team Care Arrangement (TCA) payment for coordinating and reviewing a multidisciplinary care team involving at least two other types of health professional and providing patients with subsidised access to five allied health appointments per year.[435] Additionally, general practitioners can refer patients at risk of inappropriate polypharmacy to a pharmacist for a Medication Management Review[436] and provide patients aged 75 and older with a once-yearly comprehensive health assessment (the 75+ Health Assessment).[437]

It is still unclear if these incentives result in better outcomes for patients. In at least two studies, the GPMP demonstrated reduced rates of unexpected hospitalisations for patients with heart failure[438] and diabetes.[439] Other studies, meanwhile, suggest these tools have a negligible effect on avoidable hospitalisation rates[440] or were indeed strong predictors of emergency department presentation.[441] However, uptake of these incentives by general practitioners also appears to be low, with only 6.8% of eligible patients signed up for a Medication Management Review and 35.8% for the GPMP.[437]

Another national response to the burden of chronic disease is the current trial of the Health Care Homes primary care model, due to conclude in 2021.[442] In this model, general practitioners coordinate multidisciplinary care for each enrolled patient based on care plan needs.[443] Reimbursement is by partial capitation for each patient enrolled rather than the usual fee-for-service.[89] The impact of this model on Australian general practitioner workload and patient experience is as yet unknown. A systematic review of similar models internationally has reported positive clinical outcomes for depression, health-related quality of life, and self-management.[444] In another review, patient adherence to treatments and attendance rates at emergency rooms also improved.[445]

1.2.3 Palliative care and the Australian general practitioner

Death is an inevitable outcome for many of the chronic conditions associated with multimorbidity. In Australia, palliative and end-of-life care can be provided by both specialist and generalist palliative care providers, with generalist palliative care providers including general practitioners, nurses, and specialists such as oncologists and geriatricians.[446] Palliative Care Australia (PCA) defines palliative care somewhat differently to WHO as:

> [P]erson and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life.[253(p6)]

Palliative Care Australia also emphasises the timing of palliative care which may commence as early as when a person receives a diagnosis of a life-limiting illness and run concurrent with active disease management.[293] According to Palliative Care Australia, most palliative care needs are straightforward, therefore most palliative care patients can be ably managed by generalists such as general practitioners.[253] This preserves specialist palliative care teams for dealing with a smaller subset of patients with complex, refractory issues.[253] Alternatively, the generalist can call upon the specialist for advice or share care responsibility.[447] In Australia, access to specialist palliative care is needs-based rather than based on diagnosis or prognosis. However, specialist palliative appears to be consistently out of reach of specific populations,[253] such as people with a non-cancer diagnosis such as dementia or COPD,[328] and Australian Aboriginal Peoples.[253]

There is an expectation that Australian general practitioners will provide palliative and end-of-life care to their patients. The RACGP gives palliative and end-of-life care central position within the general practitioner scope of practice and the meaning of 'comprehensive care' in their *Standards* for general practitioners[9] and guidelines for aged care (the *Silver Book*).[448] Meanwhile, Palliative Care Australia expects that general practitioners will 'have minimum core competencies to manage physical symptoms, to provide or refer to psychosocial support services, and to discuss the goals of treatment and a person's prognosis.'[253(p12)]

Over the next twenty years, the number of people projected to require palliative care is expected to increase somewhere in the range of 25% and 42%.[449] There is, therefore, an expectation that general practitioners will increasingly provide more palliative care as demand outstrips the capacity of specialist palliative care services.[450, 451] The World Health Assembly (WHA) underscored this pragmatic expectation in its unanimous resolution to strengthen palliative care as a component of comprehensive care across the life course, 'especially at the primary care level …'[452(p2)] The resolution added a humanistic argument to the need for more generalist palliative care in the community by stating:

> [A]voidable suffering of treatable symptoms is perpetuated by the lack of knowledge of palliative care, … highlighting the need for continuing education and adequate training for all hospital and community-based health care providers …'[452(p2)]

There are other arguments for strengthening general practice palliative care in Australia. First, it offers benefits that patients and their families value, including accessibility, local knowledge, and relational continuity.[453-455] Secondly, there is growing empirical evidence that general practitioner involvement in palliative care provides measurable, tangible benefits to patients. These include improved quality of life,[456-458] maintenance of functional status,[459, 460] increased likelihood of dying at home,[461] and reduced health service use[457, 462] with attendant cost-savings to the health system.[463]

To date, there is no centralised mechanism for capturing Australian primary healthcare data detailing the amount of palliative care provided by general practitioners.[446, 464] Even the Medicare Benefits Schedule does not contain palliative care-specific items against which general practitioners can charge for their services.[446] What current information we have comes from general practitioner self-reports. These suggest that most Australian general practitioners are already providing palliative care,[465, 466] with general practitioners in rural and remote areas seeing themselves as primarily responsible, despite being more poorly funded and resourced than their urban colleagues.[467] However, what is not known is the impact of multimorbidity on general practitioner willingness to provide palliative care and on their decision-making when doing so.

1.3 Problem statement

The Australian healthcare system faces considerable challenges over the next few decades with a growing number of older people with multimorbidity set to put pressure on the primary care and aged care sectors. Following closely behind older people will be an even larger population of younger people from deprived socioeconomic backgrounds, who will have developed chronic conditions at an earlier age due to unmanaged risk factors. General practice will rightly be the first and most accessible part of the health system for people with multiple chronic conditions facing an uncertain but incurable disease trajectory. However, based on its current design, funding model and processes, it is likely to be ill-equipped to manage the complexity and volume of problems it can expect to confront. Within Australia, older people are already experiencing substandard healthcare within residential aged care settings, and this is set to worsen in the immediate future with more general practitioners stating their intentions to stop this part of their practice. Furthermore, already around a quarter of general practitioners do not engage in palliative or end-of-life care for their patients.

Driving this reduction of services is the combination of the general practice small business model, whereby practices pay their own operating expenses, and the Australian Government's method of remunerating clinical activities on the assumption that most patient interactions involve simple, resolvable problems. At the same time, there is enormous pressure on general practice to prevent illness and support patient self-efficacy through health promotion and patient education. Together these factors may be unfriendly to more time-consuming patients as they threaten the sustainability of a practice. There may be other pressures on Australian general practitioners that are less evident, such as high levels of uncertainty in dealing with complex health and social issues, or areas where medical training has been inadequate. Alternatively, general practitioners may be gradually adapting to the prevailing systems in which they work or finding solutions to the complex patients they are likely to be encountering more frequently. Either way, it is important to understand the experiences of Australian general practitioners charged with providing high quality, evidence-based, patient-centred care if their health and the future strength of Australia's primary care sector are of concern.

1.4 Contribution made by this research

The production of research on multimorbidity has been called an international priority.[49] This programme of research heeds this message by being the first to investigate the frontline experiences of Australian general practitioners in managing adults with multimorbidity. It is also the first to ask how multimorbidity management changes, or if indeed it does, across the chronic and palliative phases of care when one condition is life limiting. By adopting a conceptual framework comprising the principles of evidence-based and patient-centred care, the research also interprets the impact of its findings on these two important requirements of medical practice today.

The research is unique in that it uses data and methodological triangulation to gain a richer understanding of general practice ecosystem features that either support or impinge on care efforts. Triangulation through adoption of the mixed methods approach has arguably conferred credibility and validity to the research[468] by enabling verification of findings from one sample of participants or source of data to others.

The findings from this research will constitute evidence of if and how multimorbidity impacts on general practitioners, as it does on everything from healthcare policy and economies to patients and their families. It is hoped these findings will contribute to fruitful debate around suitable primary care models for managing multiple, rather than single conditions, and better integration of primary care with other parts of the healthcare system.

1.5 Aim and research questions

General practitioners are well suited to provide care for adults with multimorbidity. The aim of this research is to investigate the experiences of Australian general practitioners in doing so, according to our expectations for evidence-based and patient-centred care, and particularly as people progress from a stable, chronic phase to the end stages of a condition.

The overarching research question posed by this thesis is: *What is the Australian general practitioner’s experience of negotiating evidence-based and patient-centred approaches in managing multimorbidity across the adult life course?*

In answering this question, the thesis will consider the following sub-questions:

1. If general practitioners experience challenges in managing patients with multimorbidity, particularly when a life-limiting condition is involved, what are the challenges, and what strategies do they use to circumvent them? (Chapter 4)
2. Do Australian clinical practice guidelines and evidence summaries for life-limiting chronic conditions support Australian general practitioners to provide care to people with multimorbidity in both the chronic and end-of-life phases? (Chapter 5)
3. What is the Australian general practitioner experience of managing patients with multimorbidity across the adult life course, including the palliative and end-of-life stages? (Chapters 6 and 7)
4. What are the implications of any findings for general practitioners, general practice, and the healthcare system in Australia? (Chapter 8)

1.6 Structure of this thesis

Figure 1.9 provides an overview of the thesis structure.

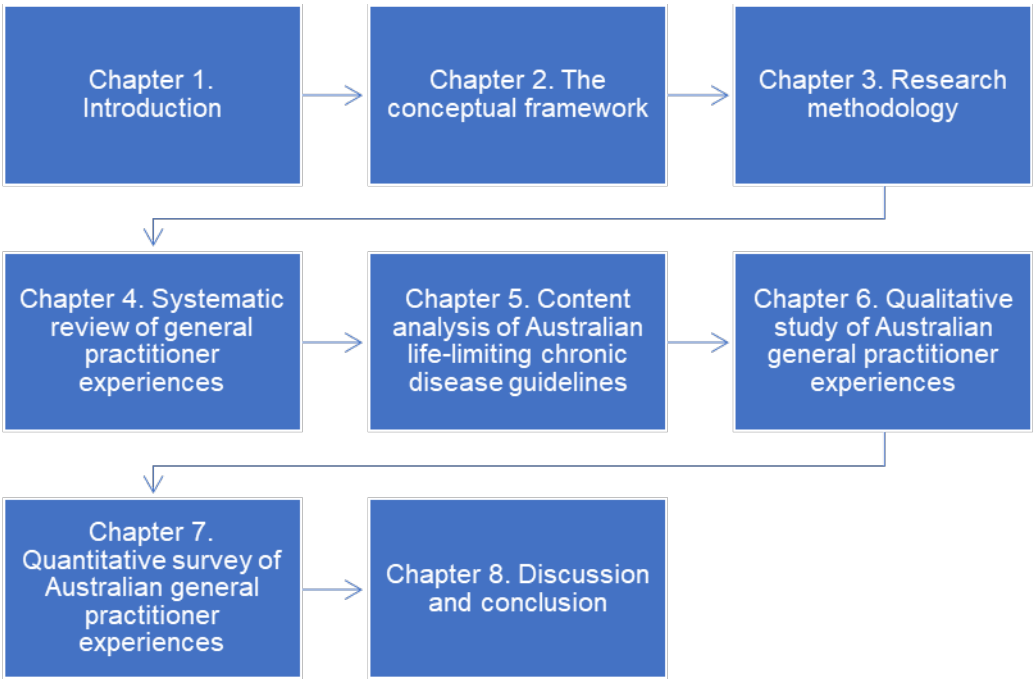

Figure 1.9 Overview of the thesis structure

Chapter two provides an overview of the contextual framework used to guide the thesis. It outlines the importance of Evidence-Based Medicine and Patient-Centred Care to clinical practice, the evidence for each, and the likely impact of multimorbidity on the general practitioner's ability to conform to their normative expectations.

Chapter three restates the research questions and describes the mixed methods methodology and pragmatic worldview directing the research programme.

Chapter four presents the methods and findings of a systematic review and thematic synthesis of qualitative studies which have individually explored general practitioner experiences of managing multimorbidity. The focus here is international; however, limited to countries with similar general practice characteristics as Australia.

Chapter five presents a content analysis of current Australian evidence-based clinical practice guidelines for life-limiting chronic conditions. It seeks to understand the extent to which these important syntheses of evidence acknowledge the high prevalence of multimorbidity in their target populations and support general practitioners in their management of conditions across the treatment and palliative phases of care.

Chapter six describes the methods and results of a qualitative thematic analysis of in-depth interviews with Australian general practitioners on their first-hand experiences of managing patients with multimorbidity.

Chapter seven presents the methods and results of a survey of Australian general practitioners on their experiences of managing patients with multimorbidity across the life course.

Chapter eight presents and integrates the findings of all four studies (Chapters 4-7). It discusses the implications of the findings along with suggestions for proceeding to address the issues it highlights. The strengths and limitations of the research project are also acknowledged and outlined.

CHAPTER 2 THE CONCEPTUAL FRAMEWORK

2.1 Chapter preface

Chapter 1 outlined the rationale for this research project, presented the background concepts, the research aim, and questions. It also provided a brief overview of the thesis content and structure.

This chapter describes the conceptual framework through which the researcher will interpret the overall findings in the Discussion chapter—the principles of Evidence-Based Medicine and Patient-Centred Care. It provides a brief history of these two influential approaches which have shaped healthcare over the past thirty or so years. It also describes some of the tensions between them in their operationalisation and outlines the implications of multimorbidity for them both in clinical practice.

2.2 The conceptual framework

A conceptual framework acts as a lens or 'blueprint' for a research project, providing the work with a common thread that gives structure and cohesion.[469] It also directs the researcher's attention, offering a means to differentiate between concepts of importance and issues falling outside the scope of the work.[470] The conceptual framework for this research was created by drawing together the existing literature on Evidence-Based Medicine and Patient-Centred Care; both dominant movements in healthcare imposing normative expectations on how clinicians should make patient care decisions. This framework did not impose a deductive approach on the research by restricting the range of questions asked and the interpretations made. Instead, it provided a flexible overarching scaffold within which each study could be inductive and exploratory.

2.2.1 Other theories of potential interest to this thesis

As this thesis research followed an inductive, exploratory design, the issues and concerns of Australian practitioners were not clear at the start of the research project, but rather became apparent over its full course. This made it challenging to identify a single medium- or long-range candidate theory at the outset capable of giving explanatory shape to what was not yet known. None of the multimorbidity-specific theories described in Chapter 1 were considered a suitable fit as they centre on the patient experience, rather than that of the clinician. However, the focus of this thesis on evidence-based and patient-centred care approaches to general practitioner decision-making suggested there may be value in exploring theories around decision-making, complexity, uncertainty, and perhaps professionalism within the context of medical socialisation. The candidate therefore undertook a preparatory literature search to find theories that might unify and explain some of the relationships between these major concepts.

A few theories could explain singular facets of these issues but were insufficient overall. The first of these was dual-system theory of cognitive reasoning in medical decision-making (or System 1 and 2 thinking).[471] This theory distinguishes between quick, accessible, and effortless intuitive thinking (System 1) and more deliberative, slower, and sequential reasoning processes (System 2).[472] For clinicians operating under conditions of uncertainty, trying to account for multiple conditions, their treatments, and their unseen combined outcomes, System 2 thinking permits more conscious, abstract, and hypothetical reasoning as the deliberator makes mental models of future possibilities.[472] However, System 1 thinking processes, which rely more on associative learning processes, prior knowledge, narratives, and emotions,[473] might lead the clinician to base decisions on accumulated knowledge of the individual patient or pattern and context recognition.[474] This dual-process psychological theory can offer an understanding of *how* medical reasoning might operate. However, it seems distant to the idea that clinical judgement is a more practical form of reasoning (or 'phronesis') that enables clinicians to 'combine scientific evidence, clinical skill, and collective experience with similar patients to make sense of the particulars of one patients' illness …'.[475] Psychological theories of reasoning also have nothing to say about the complex interrelationships between the social, environmental, and system factors within which medical reasoning and decisions occur.

A second theory considered for its applicability to this research was Bronfenbrenner's Bioecological Model of Human Development which explores the multifactorial and bi-directional interactions that might impact on the individual.[476] Applying this model to general practice means situating the general practitioner within a working microsystem of peers, colleagues, and patients, interacting with professionals operating within other settings of care (the mesosystem), while being impacted, less directly, by service and system-level factors (the exosystem), and the prevailing cultural, societal, and political norms (the macrosystem).[477] This theory appears to have utility in portraying a network of interacting systems where the individual clinician is acted upon by contextual drivers operating at multiple levels. Nevertheless, it may be less suited to describing the adaptive behaviours of individuals and system components over time as chronic conditions accumulate and fluctuate, and complexity wanes or intensifies. This might be better explained by complexity science which focuses on the interconnections between components in a system rather than on the individual components themselves.[478]

Complexity theory is increasingly applied to health services research[479] where it encourages a view of healthcare as 'an eco-system of co-evolving elements' rather than as mechanistic and subject to linear forces.[480] The multiple elements within this ecosystem experience positive and negative feedback loops which results in non-linear and unpredictable effects.[481, 482] Applying the theory to multimorbidity care in Australia, the patient-GP dyad might be described as existing within a complex system comprising interacting components. Together and individually the patient and the GP interact with multiple health professionals across the various sectors and funders of care (private/public, state/national, inpatient/outpatient). At a more local level, the fluctuating nature of the patient's chronic conditions, the unpredictable course of cumulative comorbidity, and changes in a patient's capacity and workload balance[122] might also be conceived as components in this system. So too might the economic and organisational constraints of the GP's practice environment.

How the GP, the patient, and the practice adapt to find dynamic, if not altogether perfect strategies to resolve some of the pressures and ambiguities might be explained by complex adaptive systems theory. However, the candidate considered it pre-emptive to label the experiences GPs were yet to describe as 'complex'. Furthermore, the highly metaphorical nature of the theory did not seem to complement the pragmatic worldview of the research project. Complexity theory might explain the complex ecosystem surrounding multimorbidity care and the complicated interactions between each of the system's parts, yet its explanatory power would be at an intellectual remove from the everyday experiences of general practitioners at the level of personal encounters and relationships with uniquely individual patients. As the research question focuses on the GP experience in negotiating evidence-based and patient-centred approaches to care provision, the fundamental concepts comprising these ideals needed to provide the conceptual scaffold for this work.

Evidence-Based Medicine and Patient-Centred Care came to prominence almost contemporaneously at the end of the twentieth century and have continued to evolve in parallel.[483] Despite both movements being primarily concerned with improving the quality of patient care, their advocates have rarely engaged in purposeful dialogue over the years.[484] Some commentators see these approaches as complementary, even necessarily interrelated, if either is to reach its full potential.[485-488] In Australia, both approaches to care form core standards for general practice and essential care quality indicators.[9]

The term 'patient-centred' has now evolved into 'person-centred' to emphasise the person rather than the disease state.[489, 490] According to Starfield,[491] the latter term is a better fit for primary care, and multimorbidity in particular, as it connotes knowledge of a person accrued over time and not limited to specific disease-oriented episodes of care. While the researcher agrees with this statement, the thesis will use 'patient' and 'patient-centred' throughout for consistency.

2.3 What is Evidence-Based Medicine?

In 1992, an Evidence-Based Medicine Working Group, primarily based at McMaster University in Canada, announced Evidence-Based Medicine as a 'new paradigm' for teaching the practice of medicine.[492] In doing so, the group urged clinicians to make greater use of clinical research evidence in their decision-making and to be less reliant on the subjective opinions of eminent physicians. They also promoted a diminished role for intuition, clinical experience, and pathophysiologic rationale[492] within decisions.[11] According to the Working Group, Evidence-Based Medicine was:

> The conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine requires the integration of individual clinical expertise with the best available external clinical evidence from systematic research and our patient's unique values and circumstances.[493(p71)]

From this foundation as a medical education initiative for increasing research literacy,[494] Evidence-Based Medicine rapidly broadened its scope over the next two decades.[495] It soon spread to other healthcare disciplines and activities,[496] leading to the introduction of the more inclusive names 'Evidence Based Practice' and 'Evidence Based Health Care'. As the Evidence-Based Medicine concept continued to evolve, proponents continued to reassert its purpose,[486, 496] often in response to considerable critical debate and controversy.[488, 495, 497-503] Its intention might be summarised as moving clinical practice, and the clinical research that should inform it, towards greater objectivity, transparency, and accountability.[504, 505]

Today Evidence-Based Medicine is generally understood to have two meanings: (1) a set of formal principles and techniques for generating and assessing research evidence usually, but not exclusively, on the efficacy of interventions; and (2) a model of decision-making in the clinical encounter.[506] Together, these two interpretations of Evidence-Based Medicine currently influence many aspects of healthcare.[494] This includes health system quality assurance and improvement activities where Evidence-Based Medicine is a tool for addressing variation and quality in care,[507] policy-making,[508] and healthcare resource allocation.[509]

2.3.1 The tools of Evidence-Based Medicine

Beyond encouraging prospective and practising clinicians to 'develop independent views regarding medical claims and controversies,'[510(p990)] Evidence-Based Medicine has championed a range of tools and methodologies to support clinicians in keeping up to date with a vast and growing body of research.[507] This includes checklists for appraising the quality and applicability of research and pre-appraised forms of evidence such as the single study synopsis and online point-of-care databases, of which UpToDate is an example. By identifying and appraising the totality of the evidence, evidence-based syntheses spare clinicians the labour of doing this for themselves,[499] as well as from having to reason from scratch each time they encounter a clinical problem.[511] There is evidence that clinicians find this 'bottom line' presentation of evidence preferable and convenient.[512] They also make different decisions based on the ready availability of evidence at the point of care,[512] leading to improved patient outcomes.[513]

One of the most important and prolific sources of synthesised evidence is the clinical practice guideline. Clinical practice guidelines are:

> [S]tatements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options.[6(p4)]

They are often produced at a national or regional level by officially sanctioned guideline development organisations (for example, the National Institute of Health and Care Excellence), non-governmental disease-specific organisations, or specific professional bodies. Guidelines serve several purposes. Firstly, their potential to reduce inappropriate variations in clinical practice has made them valuable instruments of policy-makers for improving healthcare quality and safety.[6] Furthermore, guidelines can be an effective means of quickening the pace by which practitioners translate research evidence into clinical practice.[514-517] As critically appraised syntheses of best available research, often covering the full breadth of their clinical topic, guidelines are also a conveniently accessible distillation of information for clinician decision-making.[518]

Clinicians can also access a range of decision aids based on the same evidence underpinning guidelines. These tools are designed to help clinicians communicate evidence of treatment harms and benefits to patients in a more transparent, friendly way.[496, 519] They might, for example, illuminate trade-offs between various treatment options, often using graphics, to help people prioritise the approach that suits them best.[520] A recent Cochrane review found that clinician use of these aids can lead to greater patient participation in decision-making processes, improved knowledge about risks, and more value-congruent choices.[521] However, despite these known benefits, decision aids are rarely implemented into clinical practice.[519, 522]

2.3.2 Evidence-Based Medicine as a model of individual clinical decision-making

In a later restatement of Evidence-Based Medicine, its founders presented it as a 'prescriptive rather than descriptive' model for decision-making within the clinical consultation.[523] This revised model of Evidence-Based Medicine advocated that clinicians consider three components when deciding on a course of action: (1) the patient's clinical state and the clinical setting itself; (2) the best research evidence available; and (3) the patient's own, unique preferences and likely mode of action.[523] According to this model, these three domains should be considered through the lens of a fourth concept—clinical expertise—when a clinical judgement is required.

There is considerable ongoing debate as to the meaning and nature of terms such as 'clinical expertise' and 'clinical reasoning'.[524] However, clinical expertise might be considered the combined force of a clinician's clinical and reasoning skills, interpersonal abilities, accumulated experiential knowledge, and intuitive capacity.[11] In operational terms, *interpersonal* expertise embraces humanistic, narrative processes, such as carefully exploring individual patient circumstances, values, and treatment preferences. It might also be engaged to determine a patient's level of willingness to be involved in care decisions.[523] Clinical *reasoning* expertise, while variably conceptualised,[525] may comprise all the cognitive and contextual factors involved in determining a diagnosis or devising a management plan.[526] In the context of Evidence-Based Medicine, clinical reasoning includes assessing the applicability of different evidence sources to the individual patient.[527] Clinical expertise might then play an adjudicating role between these humanistic and deductive forms of reasoning by weighing and balancing the requirements imposed by each component.[501] Figure 2.1 shows the relationship between components in this model.

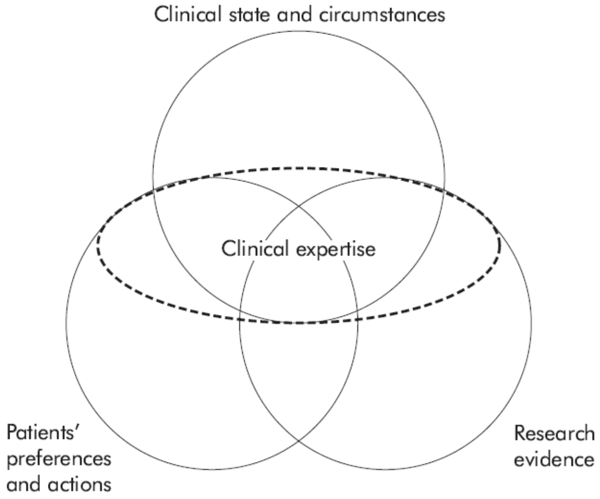

Figure 2.1 The EBM prescriptive model of clinical decision-making

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Several aspects of this decision-making model remain contentious. Principally, critics consider the rationale for the model to be belief-based rather than founded on evidence or theoretical principles,[506, 528] as there is no description of the design process explaining why these components were included or if others were considered and rejected.[506] This absence of detail has led some to view Evidence-Based Medicine as founded on motivational and persuasive rhetoric, making it ideologically strong but philosophically weak.[529] Others object to the model's appearance as a 'self-evident truth', making it 'disproof-proof' and 'virtuous' and therefore failure to adopt it 'not just stupid but wicked'.[530(p932)]

2.4 What is Patient-Centred Care?

Patient- (or *person-*, *client-*, *family-*, or *consumer-*) centred care is an approach to care whose influence cuts across all levels of health, from organisational policy and practices to the interactions between clinicians and patients.[531, 532] In the United States, Patient-Centred Care is considered one of six pillars of quality healthcare.[24] In Australia, its importance is upheld within the Australian Charter of Health Care Rights[533] and the National Safety and Quality Health Service Standards.[534] It is also considered a core value of Australian general practice. [87]

The term 'patient-centred care' was first used by Balint in 1969 as part of a plea to general practitioners to understand their patients as 'unique human beings.'[535] This departure from a disease-centric view of patients was later to resonate with Engel, who, in his biopsychosocial model, urged clinicians to attend to not just the biological but also the psychological and social dimensions of illness.[536] Elsewhere, general practitioners were being asked to 'enter the patient's world, to see the illness through the patient's eyes.'[537] These ideas eventually coalesced and reached the level of policy at a time of rising concerns for patient care quality and safety and dissatisfaction with disease-focused, paternalistic medical practices. They also coincided with a growing recognition of the patient's right to autonomy as healthcare 'consumer'.[531, 538] For some, however, the value of patient-centredness lies in its moral and ethical necessity. It is simply considered the right thing to do.[539-541]

However, despite this contemporary importance, patient-centred care still lacks a universally understood definition, as well as consensus on what it entails and how it might be measured.[491, 542-544] It is most often accepted as 'care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.'[24(p6)] At the global level, the sixty-ninth World Health Assembly of the World Health Organization ratified a framework on integrated people-centred health services in 2016. In doing so, it described 'people-centred' as:

> [A]n approach to care that consciously adopts the perspectives of individuals, families and communities, and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways. People-centred care requires that people have the education and support they need to make decisions and participate in their care. It is organised around the health needs and expectations of people rather than diseases.[545(p2)]

As this description reveals, patient-centredness can be both a dimension of healthcare design and delivery,[546] and a desirable characteristic of the patient-clinician encounter. Within the context of a clinical interaction, it means patients should be encouraged to be active rather than passive participants in decisions about their health.[547] The approach also emphasises to clinicians the 'value of the individual with their own unique history, experiences, values and culture that have shaped who they are.'[548(v)] These ideas are captured within the motto 'nothing about me, without me.'[549]

While patient-centredness has intuitive appeal as an aspirational goal, it may be challenging to operationalise.[542, 550] For some commentators, there remains a significantly wide gap between the organisational rhetoric around the concept found within policy statements and its actual implementation at the patient care delivery level.[55, 551-553] According to one study, this gap results when an organisation's leaders fail to define what they mean by the concept or instigate incentives and metrics that do not align with it.[553] Some organisations may even pursue goals that are inharmonious with patient-centredness, such as prioritising meeting their financial bottom line by reducing staffing levels,[553] or imposing a standardised checklist approach to patient care.[532] A recent and vivid example of a system-wide patient-centred care failure is Australia's aged care industry. The Royal Commission inquiry into this system highlighted 'the "time-clock"-driven nature of much care delivery to the exclusion of engagement with older people, and the failure of providers to prioritise care levels above financial motivations and profits.'[28(p39)] As significant investments continue to be made to improve the quality of health services through a reorientation towards patient-centredness, systems must be in place to appropriately monitor performance and reward those who achieve a high standard of patient-centredness.[551]

Compared to executive and clinical decision-makers, healthcare professionals are more likely to consider patient-centredness as core to professional identity, grounded on humanism and therapeutic alliance values, rather than a conception of patients as consumers and themselves as providers within a healthcare marketplace.[550] However, studies show that clinicians can also find it challenging to enact patient-centred principles for various reasons. Firstly, they might struggle to find a compromise when their professional agenda for improving someone's health conflicts with the need to respect and support an individual's autonomous agency. [554, 555] Some clinicians may eschew patient-centredness through concern for the loss of professional autonomy or income.[556] Others may find their ability to be patient-centred depends on the reason behind a consultation. As one study in general practice observed, patients and general practitioners alike perceived lower levels of clinician patient-centredness when the patient raised mental health issues or non-somatic problems, or when the patient presented a list of problems to be addressed.[557] Of interest to medical educators is the repeated finding that the patient-centred attitudes and behaviours of medical students deteriorate across the medical school years and into residency.[558-561]

2.4.1 The Patient-Centred Clinical Method

The Patient-Centred Clinical Method is a long-established, comprehensive model of patient-centred care, designed for teaching and training medical students to attend to both the patient's and the doctor's agendas.[92, 562] In Australia, this approach currently informs the general practice supervisor's guide to practice-based teaching.[563] The model integrates both the biomedical and the psychosocial using four interconnected components.[92] (Figure 2.2.) The first component is 'Exploring health, disease and the illness experience'.[564] This element distinguishes the model from the traditional biomedical approach to care by urging clinicians to focus on both the signs and symptoms of disease and the subjective experience of illness that accompanies it.[564]

The general practitioner evaluates the unique meaning each patient makes of what is happening to them[490] and acknowledges any associated emotions or expressions of suffering.[565] They might also take the opportunity at this point to explore the individual's expectations and aspirations for resumed health.[564]

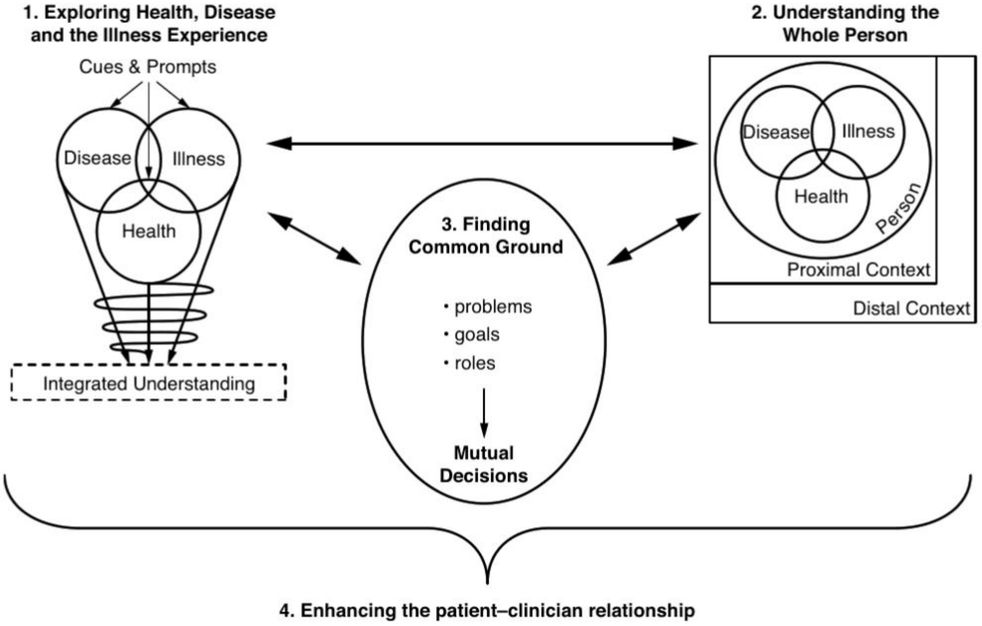

Figure 2.2 The Patient-Centred Clinical Method

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The second component of the model is 'Understanding the whole person.'[566] Here the clinician integrates knowledge of the disease and the subjective illness experience with 'an awareness of the person's position in the life cycle and his or her life context.'[566(p67)] It requires gathering knowledge, over time, of the contextual nuance in which people live, including factors of family, environment, culture, spirituality, social support, and employment status.[567] This information is crucial as it prevents the clinician from making 'contextual errors,' resulting in an inappropriate or unfeasible treatment plan for their patient.[568, 569] Contextual errors arise when clues (or 'red flags') are missed, such as a person's lack of resources, inability to access transportation, or a demanding caregiver role preventing them from attending to their own health.[568]

Contextual errors can represent a failure to individualise care or ask the question, 'What is the best next thing for *this* patient at *this* time?'[570(p281)] These errors are as important as biomedical errors, as they also threaten patient safety and quality of care.[571] They may also be commonplace. One study has shown general practitioners probe contextual red flags when explicitly presented with them but may then fail to incorporate this information into care plans.[572] Furthermore, they may be less likely to pay attention to contextual information handed to them than to information they elicit on their own.[573]

The third component of the Patient-Centred Clinical Method model is 'Finding common ground', which corresponds to the concept of shared decision-making. Shared decision-making, arguably the crux of patient-centred care,[574, 575] is the process whereby clinicians and patients 'jointly participate in making a health decision, having discussed the options and their benefits and harms, and having considered the patient's values, preferences and circumstances.'[576(p35)] Shared decision-making distances itself from the traditional paternalistic model where the clinician decides for the patient. It is also at a remove from the informed decision model at the other extreme whereby the patient is made entirely responsible for the decision.[577] Shared decision-making also stresses a unique approach to each patient on each visit,[92] and may be expressly appropriate where there is more than one reasonable therapeutic option available, each with balanced harms and benefits.[578] It has also demonstrated significant improvements in outcomes for patients with lower literacy, education, and socioeconomic status.[579]

The fourth component of the Patient-Centred Clinical Method model, and the one that integrates all others, is 'Enhancing the patient-clinician relationship'.[580] This describes the therapeutic alliance that can be 'accomplished through a sustained partnership with a patient that includes compassion, caring, empathy, trust, sharing power, continuity, constancy, healing and hope.'[580(p159)] Constancy and continuity, and the sense of safety and security they provide, are fundamental aspects of the general practitioner-patient relationship for older people and those with multiple conditions struggling to navigate complex health systems.[581] Furthermore, in a meta-analysis of 13 randomised controlled trials, the patient-clinician relationship showed a small but statistically significant effect on patient outcomes.[582]

2.5 Tensions between the evidence-based and patient-centred approaches to care

Clinicians need to reconcile Evidence-Based Medicine with Patient-Centred Care approaches in clinical practice.[583] To date, however, there is no unifying model to guide them in this task.[483, 485] While both these dominant discourses share a common goal in wanting to achieve optimal patient care, they continue to emphasise different pathways to this objective. The conceptual anchor for Evidence-Based Medicine is ensuring the best quality evidence available is included in the decision-making equation.[487] This requires a more deductive approach, applying generalised abstractions in the form of population research evidence to individuals as 'specific cases'.[584] Patient-Centred Care, meanwhile, is more anchored in medical care,[487] promoting the centrality of the patient in any deliberations, and using inductive methods to elicit the patient's unique story and circumstances. Furthermore, through the pivotal, unifying role granted clinical expertise, the clinician remains central in the Evidence-Based Medicine model. The clinician is arguably less conspicuous in the Patient-Centred Consultation Model, where the therapeutic relationship and shared decision-making take precedence.

Each approach, however, has been criticised for lacking what the other purports to value.[485] Evidence-Based Medicine stands accused of needing to be more patient-centred owing to the tokenistic role it appears to give to patient values and preferences in decision-making. Meanwhile, Patient-Centred Care is charged with having 'empirical stubbornness,' being a 'fuzzy concept' whose elements cannot be readily measured, and a multidimensional 'container concept', with each element requiring explanation via a different theory.[485(p21)] Certainly, assessing patient-centredness at the level of the individual consultation can prove difficult. It depends on myriad factors such as the quality of interactions,[585] the patients' expectations for trust, empathy, and being heard,[586] and personal qualities of the clinician, including attentiveness, empathy, patience, and openness.[586] However, perceptions of empathy[587] and communication quality[588] are shown to vary widely between clinicians and their patients. Factors beyond the clinician's control might also influence interaction quality, for example, time pressures[589, 590] or patient communication or functional health literacy.[544, 591] The following few sections outline some specific areas of difference and tension between evidence-based and patient-centred approaches to care.

2.5.1 Evidence for patient-centred care and shared decision-making

Patient-Centred Care has been researched as an intervention where findings of its impact on patient satisfaction and outcomes appear to be mixed.[540, 592, 593] Some studies have recorded an increase in patient satisfaction with patient-centred care,[95, 594-596] while others have found little or no effect on this same measure.[540, 597, 598] This may be due to the heterogeneity of the elements researched and the outcomes measured across studies.[598] At the level of consultation, however, there is some evidence suggesting individual elements of the interaction, such as the quality of the clinician-patient relationship[582] and the degree of trust patients place in the clinician,[594] may positively influence objective and subjective patient outcomes. Benefits have also been observed in patient adherence to treatment plans,[593, 599, 600] reduced symptom burden,[601] maintenance of functional performance,[602] and self-efficacy.[603] Patient-centred care has also demonstrated an impact on healthcare costs, with several studies showing a reduction in test ordering and referrals to specialists.[604, 605] Furthermore, patient-centred care may reduce the length of hospital stays[602] and readmission rates.[601]

Although the idea of shared decision-making holds appeal and has the support of many clinicians,[606] evidence suggests a perception-reality gap often exists between clinician attitudes and their actual practice.[607, 608] Certainly, with older patients, general practitioners have demonstrated a disinclination to discuss options and preferences and a tendency to make decisions unilaterally.[608] Effective shared decision-making also relies heavily on individual clinician interpersonal and communication skills. In the first instance, these are needed to ascertain personal patient willingness to participate in decision-making.[609] However, clinicians appear to have difficulty anticipating how involved their patients wish to be[610, 611] and have been unsupported, to date, by tools to help with the process.[612] What may be most important in shared decision-making is a clinician's ability to tailor information and their manner of communicating it to the person receiving it,[613] taking into account factors such as low literacy,[614] cognitive impairment,[615] and dementia.[616] As Winefield et al.[597(p821)] suggest:

> … the true therapeutic essence of ‘patient-centredness’ may have less to do with the relative quantity of specific behaviours than with the doctor’s ability to successfully match communication style to the particular needs of the patient. Sometimes this might mean power-sharing, sometimes directiveness, and sometimes deference.

2.5.2 The importance of patient values and preferences

A long-running and arguably unjustified criticism of Evidence-Based Medicine is that it disregards individual patient and humanistic concerns in its quest for optimal healthcare decision-making. From the start, proponents of Evidence-Based Medicine stressed the importance of putting patient values and circumstances at the centre of the clinical decision[496, 510, 617, 618] However, discussions on this point have been less visible in published statements of its founders than discourses on what constitutes high-quality evidence.[619] This perception has not been helped by proponents' continuing reluctance to define what it means by these concepts[506, 620] and whether they are confined to health concerns only or include the person's values and preferences for their wider life. This lack of conceptual clarity may go part way to explaining why a recent systematic review could identify 'surprisingly few' validated tools for eliciting patient preferences and priorities in primary care.[621]

If Evidence-Based Medicine has not provided a consistent definition of this component, it is unsurprising that it does not advise on how clinicians might elicit values and preferences from patients.[622, 623] As Haynes[523(p38)] once explained, 'determining what the patient wants and factoring this into the decision process is a growing responsibility of clinical expertise, currently limited by our understanding of how to determine patients' preferences.' This statement implies that the clinician must decide how to bring these elements to the fore during the consultation, even though clinicians have demonstrated poor perceptions of patient priorities and preferences for their care.[624]

Elsewhere Evidence-Based Medicine has explored quantitatively-derived population averages of patient values and their application to individual patients.[625-627] By endorsing health economic approaches such as decision trees, decision analysis, and utility assessment for determining values, Evidence-Based Medicine has drawn censure for dismissing 'the patient's own perspective on the illness in favour of an average effect on a population sample or a column of quality-adjusted life-years … calculated by a medical statistician.'[628(p236)] This statistical view of values is antithetical to the idea that values are highly individualistic and unstable[629] and are therefore perhaps best explored narratively and holistically within the context of an empathetic doctor-patient relationship.[620]

The Patient-Centred Clinical Method approach to patient values is somewhat more muted than that of Evidence-Based Medicine. Values are part of the initial exploration of the person's illness experience and are individualistic, experienced uniquely, contextualised by social determinants, and fixed on the health realm.[564] The task of eliciting values is also a pragmatic one for, as Stewart[564(p58)] states:

> The practitioner needs to discover the patient's worldview of health and corresponding health-related values and priorities as one of many competing values in order to assess the patient's commitment to its pursuit.

In recent years, there is growing acknowledgement of the importance of embedding patients into the centre of the guideline development process, so that guideline topics and recommendations better reflect the values and preferences of the target group.[630, 631] More extensive patient involvement in the development stages has been linked to more visible patient-preference recommendations within guidelines.[632] However, an analysis of guideline methodology documents has shown that guideline panels lack explicit methodological advice on how to involve patients, certainly in a way that encourages active contribution to the process.[630] The Grading of Recommendations, Assessment, Development and Evaluations (GRADE) system for grading the quality and strength of evidence within guidelines has, however, acknowledged that certain decisions should rely more on patient values and preferences than others, expressly those with a close balance between desirable and undesirable outcomes.[633] GRADE therefore advises guideline developers to classify decision points of this kind ('preference-sensitive') as weak, or conditional, recommendations.[634] Weak recommendations should then trigger a discussion of patient values, goals, and preferences as part of a shared decision-making process.

2.5.3 Randomised controlled trials versus real-world patients

From the outset, the Evidence-Based Medicine model of decision-making has been underpinned by the precepts that 'evidence is never enough'[635(p26)] and that the purpose of Evidence-Based Medicine is to 'encourage practitioners and patients to 'pay due respect—no more, no less—to current best evidence in making decisions.'[497(p1350)] However, these messages have been somewhat overshadowed by the epistemological outrage surrounding Evidence-Based Medicine's second principle of evidence.[636-642] This states that 'not all evidence is equal'[643] and that the best forms of evidence for answering clinical questions sit at the top levels of a vertical Evidence-Based Medicine hierarchy of evidence.[496]

This hierarchy, along with the many variants it has spawned, espouses the superior trustworthiness of certain types of empirical study designs over others based on the ability to minimise confounders and other forms of bias, and therefore maximising internal validity.[643, 644]

As Sackett[493(p72)] explains:

> Because the randomised trial, and especially the systematic review of several randomised trials, is so much more likely to inform us and so much less likely to mislead us, it has become the 'gold standard' for judging whether a treatment does more good than harm.

This high status granted evidence from randomised controlled trials may be contradicted by the difficulties in generalising it to individual patients.[502, 645-647] Somewhat paradoxically, the quest to maximise internal validity requires such tight control against bias and confounders (commonly older age, comorbidities, and lower social status) that trial participants often bear little resemblance to the people most likely to benefit from the intervention.[485] The influence on outcomes of individual differences and naturalistic contexts have been rooted out to give primacy to questions of efficacy over effectiveness.[648] Subsequently, findings can only suggest how the intervention is likely to work across a population or for the 'average' person.[636, 640, 649] Evidence-Based Medicine does not guide on translating evidence directly from populations into decisions for individual patients.[570] It is left to the clinician's expertise under conditions of 'epistemic uncertainty'[650(p508)] to determine the extent to which differences in treatment or patient characteristics may affect estimates of benefit or risk and ultimately treatment effects in patients seen in everyday clinical practice.[651]

Other patient-centred concerns regarding randomised controlled trials focus on frequent trialist disregard for outcomes that matter most to patients. These outcomes include quality of life, mortality, and morbidity.[508, 583] For example, a study of diabetes intervention trials found that only 18% measured patient-important outcomes affecting the quality of life, for example, amputations, stroke, and loss of vision.[652] Clinicians must frequently extrapolate findings based on surrogate endpoints (lowered cholesterol, for example) that have little importance for patient symptomology. Moreover, researchers measure these endpoints across short timeframes, rather than those implicit in definitions of 'chronic.'[642, 653] Furthermore, clinicians need to determine if a statistically significant finding translates into a clinically significant finding from the patient's perspective.[654]

Pragmatic controlled trials are proposed as a more appropriate way to assess the effectiveness of interventions when generalisability is a concern.[655] These trials have broad inclusion criteria and take place in real-world settings, under usual clinical conditions, rather than strictly controlled circumstances.[656, 657] They can therefore produce clinically meaningful results that are immediately applicable and more easily generalisable to the relevant clinical population,[658, 659] especially when conducted across multiple heterogeneous practice settings.[655, 656] However, this design also has its limitations. When used to evaluate complex and multifactorial interventions, pragmatic trials rely on the skills, understanding, and ongoing commitment of various time-pressured health professional groups for component implementation fidelity.[660] Pragmatic trials can also involve complex ethical approval processes and require large sample sizes to allow for subgroup analyses.[655] Furthermore, it may be harder to attribute a neutral or negative trial finding to the effect of an intervention in the presence of population heterogeneity and less strictly controlled trial processes.[656]

2.5.4 Clinical practice guidelines as tools for standardisation

Patient-Centred Care again comes into conflict with Evidence-Based Medicine when randomised controlled trials are codified into resources such as clinical practice guidelines, which can serve to regiment decision-making. The original purpose of guidelines, and indeed Evidence-Based Medicine, was to help reduce the practice variability that was rife at a time when clinicians relied on the opinions of authoritative experts to make decisions, rather than scientific evidence or individual patient circumstances.[661] According to the National Health and Medical Research Council which oversees guideline development in Australia, guidelines are not mandatory but 'advise people on how something could be done or what course of action can be taken in a particular circumstance.'[662] Elsewhere, where regulatory agencies impose adherence to guideline recommendations upon clinicians in the form of targets to be met (such as in pay-for-performance systems),[663, 664] clinicians can feel pressured to provide standardised rather than individualised care to patients. Under these conditions, an incentivised checklist-based, medical audit culture can take hold[665, 666] with the potential to inhibit, or even penalise, individualised care approaches and the exercise of professional discretion and patient autonomy.[508, 664, 667-669] As England's Quality and Outcomes Framework has shown, providing financial incentives to clinicians for adhering to guideline recommendations also requires extensive and highly standardised documentation.[670]

This can turn consultations into 'bureaucratic encounters, primarily oriented to completing data fields',[671(p1)] thereby undermining genuine patient care. These incentives also have the potential to impose a biomedical agenda on the consultation as clinicians prioritise more measurable aspects of the consultation while deprioritising attention given to patient concerns and cues, verbalised or otherwise.[671-673]

Changes to clinical targets within guidelines based on new evidence can also drive overdiagnosis and overtreatment and, therefore, higher resource costs.[674] A recent example is the significant lowering of the systolic blood pressure target within the American Heart Association/American College of Cardiology's guideline for hypertension management,[675] mainly on the basis of one large randomised controlled trial.[676] Clinicians have voiced concern that getting older people to reach this new target may result in adverse outcomes such as dizziness and falls. Furthermore, if this target were embedded in a quality measure, clinicians who did not follow the protocol, but made exceptions based on individualised patient concerns, could be required to account for their decision or may be penalised.[677]

A further problem with guidelines is that strong, unequivocal randomised controlled trial evidence is only available for a very small proportion of the decision points and actions covered by guidelines.[514, 644] Most decisions made by clinicians are, therefore, only ever supported by lower-level evidence[518] or expert consensus.[678] On this basis, individual patient values and preference-sensitive decision points should be made even more pronounced within guidelines. However, studies show that patients and their perspectives are not always considered during the guideline development process[679] and flagging of values-relevant decision points is often limited.[632]

Studies show that general practitioners are unlikely to make clinical decisions based on clinical practice guideline evidence.[680-685] Furthermore, this behaviour is not modified by a personal belief in the value of guidelines for improving care quality and safety.[686] Researchers provide diverse reasons for this. [687, 688] Chief amongst them is general practitioner awareness that guideline evidence is often based on higher-risk study participants than those seen in primary care.[689, 690] Furthermore, when guideline developers do not make the patient cohort explicit, general practice patients may be at risk of overtreatment and adverse outcomes.[689] General practitioners also cite lack of awareness of guidelines[691] or guideline overload[686] as reasons not to follow guidelines evidence.

Specific general practitioner characteristics also work against guideline adherence, including older age,[692] resistance to extensive practice changes, and reluctance to invest in new skills.[693] General practitioners may also be opposed to guidelines if they deem adherence to them as compulsory rather than discretionary[668] or recommendations as controversial or incompatible with their values or the preferences of their patients.[693] Attitudes held towards guidelines by peers and leadership figures are also influential.[687, 694]

2.6 Multimorbidity's challenges to Evidence-Based Medicine and Patient-Centred Care

The clinical reality of multimorbidity magnifies the tensions between Evidence-Based Medicine and Patient-Centred Care and presents some unique challenges for practising according to the tenets of both.[695] Firstly, clinical practice guidelines continue to focus on the care of a single index condition[696-698] and often lack advice on managing additional, comorbid conditions,[100, 515] even those that co-occur with high frequency. Over the last 15 years, there have been multiple systematic assessments of comorbidity acknowledgement in guidelines. Some have focused on guidelines for specific conditions.[517, 699-701] Others have assessed the guidance explicitly provided for older people.[100,702, 703] Several studies have examined guidelines issuing from a particular organisation such as the National Institute of Clinical Excellence[240] or those developed for a specific national context such as Canada.[101] Without exception, these studies have found little explicit guidance on the management of comorbidities, even when guideline quality was deemed high.

Clinicians also confront patient safety concerns when conscientiously applying 'best evidence' from multiple single disease guidelines to individual patients. Here, decision-making is made more challenging by balancing benefits and risks for each condition separately and in combination.[704] As Wallace[53(p1)] states, 'every individual recommendation may be rational and evidence based, but the sum of all recommendations in an individual is not.' One outcome from aggregated care of this kind may be adverse drug-condition interactions with the therapeutic approach for one condition affecting the progress of another condition.[100] Other consequences include inappropriate polypharmacy with its associated harms, or an unmanageable burden of treatment.[224, 234, 235, 240, 705, 706] A single clinician working across guidelines might impose a burden of care, but it is more likely to arise when a patient sees multiple specialists within a fragmented health system, with each focusing on a subset of the person's conditions.[552]

Lack of guidance on managing comorbid conditions is understandable considering the scarcity of primary empirical evidence available on what works in managing multimorbidity.[18, 49, 707] Most research to date has focused on multimorbidity's epidemiology, rather than its pharmacological[49] or behavioural[708] management, as intervention study designs have proven unable to deal methodologically with the complexity and heterogeneity of this population.[709] One Cochrane systematic review identified 17 randomised controlled trials of complex interventions for people with multimorbidity in primary care and community settings.[99] These interventions made little or no difference to clinical outcomes for patients, leaving investigators to conclude that it is difficult to improve outcomes for people with multiple conditions.[99]

Furthermore, where drug treatment trials are concerned, the myriad conditions of people with multimorbidity would most likely interact in innumerable ways with the intervention under investigation, potentially attenuating benefits and increasing intervention harms.[710] It follows then that people with multimorbidity are commonly excluded from clinical trials in favour of relatively young patients with single conditions only.[711] For example, from 1994 to 2006, 72% of trials reported in 9 major journals excluded older patients.[712] As older people metabolise drugs differently from younger people due to physiological changes with age, generalising evidence from these trials to older patients becomes risky and often associated with uncertainty as to benefit or harm.[18, 713] These trials also tend to focus on single disease outcomes rather than outcomes of value and relevance to multimorbid populations.[714-716] This includes quality of life which has been ranked as multimorbidity's highest research priority.[717, 718] Generalisability must, therefore, always be considered alongside the potential for harm whenever applying evidence to patients with multimorbidity.[18, 711, 719]

2.6.1 New approaches to multimorbidity management

Two guidelines explicitly addressing the care of people with multimorbidity were developed by the United Kingdom's National Institute for Health and Care Excellence (NICE)[720] and the American Geriatrics Society.[715] These guidelines provide comprehensive but mostly generic care strategies (or 'guiding principles') without focusing on specific diseases and their combinations. Both emphasise a patient-centred approach to care over a rigidly evidence-based one. Furthermore, they advocate for attention to treatment burden, individualised care plans, thorough assessments of potentially harmful interactions, elicitation of patient preferences, prioritisation, and goal setting.[117, 721]

The Royal Australian College of General Practice recently incorporated the pragmatic approach to multimorbidity management of the NICE guidelines in redesigning its clinical guideline for general practitioners working in aged care (or the *Silver Book*).[448] This guiding principles approach is also core to the Ariadne Principles—a tool for the goal-oriented management of patients with multimorbidity in general practice.[722] This tool focuses on four patient-centred core elements: the assessment of any drug-drug, drug-disease, or disease-disease interactions, elucidating patient's preferences and their prioritisation, agreement on realistic goals, and individualised management and follow up.[722]

Despite this evidence of growing international consensus around these patient-centred principles, their impact on patient outcomes still needs to be established. A recent, large pragmatic randomised controlled trial, the ‘3D trial’, attempted to do this.[596] It translated the recommendations of the Patient-Centred Clinical Method,[92] the NICE and American Geriatric Society multimorbidity guidelines,[715, 720] and the Ariadne Principles[722] into a model of primary care. This model, which embedded continuity of care, comprehensive assessment, and longer appointments, was implemented across 33 general practices in the United Kingdom. After a 15-month follow-up period, this complex intervention demonstrated no impact on patient illness, treatment burden, or health-related quality of life.[596] This finding appears to challenge the long-held assumption of a causal link between patient-centred care and improved quality of life and health outcomes.[723] However, it should not be overlooked that the intervention group indicated higher satisfaction levels with their care, which they perceived as attentive to their problems and providing continuity.[596] As an economic analysis showed no increased costs associated with the 3D patient-centred model, this raises the question of whether gains in patient satisfaction alone might justify implementation.[724]

Another emerging approach to achieving more patient-centred outcomes for people with multimorbidity is patient-priority directed, or goal-oriented care.[552, 725] This approach uses the goals people wish to achieve in their lives as the foundation for co-creating care plans.[552, 726] According to Vermunt et al[726], the role of goals in decision-making has been largely overlooked in definitions of shared decision-making to date. However, a goal-oriented approach has the potential to simplify decisions by focusing discussion on concrete and actionable outcomes of importance to the individual, rather than abstract concepts of risk/benefit ratios, numbers needed to treat, or disease- or symptom-specific concerns.[727] Patient goals, which ideally should be realistic and measurable,[25] might be as specific as attending an upcoming family event, or more global such as maintaining independence. Once goals are made explicit, clinicians can narrow treatment options to those best able to help the person achieve those goals. Modifiable factors impeding goals can also be identified and managed.[728]

The goal-oriented approach is specifically advocated for older people with multimorbidity as it concentrates care efforts on outcomes that span conditions rather than on treating each condition separately.[725] Aligning healthcare with goals in this way has demonstrated benefits such as reducing treatment burden and unwanted or unnecessary healthcare.[729] Furthermore, this alternative approach to patient-centred care for patients with multimorbidity has also proven acceptable to general practitioners (with training) and patients.[730, 731]

2.7 Conclusion

Modern day healthcare is pervaded by the two orthodoxies of Evidence-Based Medicine and Patient-Centred Care. They dominate discourses on how research and clinic practice should be conducted and interest policy-makers for their potential to reduce healthcare costs whilst improving its quality. Historically, these two approaches have been considered incompatible and serving opposing goals. However, their joint concern for patient goals, priorities, and values in decision-making appears to have brought them closer into alignment over time with guidelines and standards increasingly stressing the importance of both approaches.

General practitioners, like other health professionals, are judged on how well they integrate evidence-based and patient-centred approaches in their everyday practice. When a person has an uncomplicated, single, or acute condition, it may be occasionally challenging to reconcile evidence-based recommendations with patient preferences—the patient with a cold wanting a prescription for antibiotics being a case in point. However, multimorbidity threatens to compound any challenges by involving more problems and their consequences, requiring the general practitioner to integrate multiple sources of evidence with highly individual patient concerns, circumstances, abilities, and goals. How general practitioners negotiate the tension between providing evidence-based and patient-centred care forms the central thread to this thesis. It informs the approach to each study in terms of the topics explored. It will also serve as the lens through which Australian general practitioner experiences of multimorbidity will be interpreted in the Discussion.

The following chapter (Chapter 3) reports on the overall methodology and guiding pragmatic worldview of the thesis. It details the three-phase exploratory sequential mixed methods design used to integrate findings iteratively throughout the research project.

CHAPTER 3 RESEARCH METHODOLOGY

3.1 Chapter preface

The previous chapter introduced the conceptual framework for this research. This was evidence-based and patient-centred care approaches as normative expectations of the healthcare system. This framework will provide the lens for interpreting general practitioners’ experiences and answering the overarching research question.

This chapter introduces the mixed methods research methodology for the thesis. It provides background to the mixed methods approach and describes its applicability to the research's pragmatic worldview. It also introduces the overarching plan for conducting the research and integrating the findings across studies. The individual study chapters provide the detailed methods particular to each study.

3.2 Restatement of the research questions

This mixed methods research program sought to answer the overarching question: *What is the Australian general practitioner's experience of negotiating evidence-based and patient-centred approaches in managing patients with multimorbidity across the adult life course?* This question required a sequential approach to building understanding using a series of questions focused on different aspects of the issue.

Question 1. If general practitioners experience challenges in managing patients with multimorbidity, particularly when a life-limiting condition is involved, what are the challenges, and what strategies do they use to circumvent them?

Question 2. Do Australian clinical practice guidelines and evidence summaries for life-limiting chronic conditions support Australian general practitioners to provide care to people with multimorbidity in both the chronic and end-of-life phases?

Question 3. What is the Australian general practitioner experience of managing patients with multimorbidity across the adult life course, including the palliative and end-of-life stages?

Question 4: What are the implications of any findings for general practitioners, general practice, and the healthcare system in Australia?

3.3 Mixed methods: An overview

While ‘mixed methods research’ has varying definitions,[732] this thesis favours the following one:

> [R]esearch in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry.[733(p4)]

As a methodology, mixed methods has gathered momentum since the 1980s when scholars from diverse fields began to debate the philosophical and procedural issues associated with combining qualitative and quantitative methods and data in the one study.[734] Before this, researchers had worked within either a quantitative or qualitative tradition, both of which differed in their assumptions about the nature of reality (ontology), the nature and limits of human knowledge (epistemology), and the role of values (axiology).[735] Those working purely within one tradition might, therefore, consider these new systematic efforts to mix paradigms as problematic.[736] Some of the differences between the qualitative and quantitative research approaches are shown in Table 3.1.

Table 3.1 Selected differences between the quantitative and qualitative research approaches

Criteria	Quantitative tradition	Qualitative tradition
Research paradigm	Postpositivist	Constructionist
Purpose	Tests theory through observation and deductive experimentation,[737] and is oriented to cause and effect.[738]	Develops theory or generates hypotheses through induction,[737] and is oriented to profound discovery and exploration.[738]
Ontology (the nature of reality)	A singular objective reality exists independently of consciousness but may not be discoverable.[739]	Relativist. Multiple realities exist which are fluid and changing and experienced differently by different people.[740]
Epistemology (the relationship between the knower and the knowledge)	Objective. Knowledge is fallible and shaped by contextual influences, but the researcher can get closer to it by being distant and neutral.[740]	Subjective. Meaning is not discovered but constructed through social interaction between the interpreter and the interpreted as situated in place and time.[741]
Axiology (the role of values)	Bias in research is unavoidable, but researchers should make efforts to control it. Respect, privacy, informed consent, and beneficence are to be respected.[742]	Values language, social interaction, and context. In research, it values dependability, authenticity, credibility, confirmability, reflexivity, and transferability.[743]

Today the mixed methods approach has entered the mainstream of many disciplines[744] and stands alongside qualitative and quantitative research as the third research paradigm.[745] Its methodology might be conceptualised as:

> [B]ringing together the strengths of qualitative research procedures and the strength of quantitative research procedures to achieve something more, or a new whole greater than if you had used either approach alone.[746(p2)]

3.4 The pragmatic paradigm and mixed methods research

A paradigm, as introduced by Kuhn,[747] is a shared belief system or 'worldview' amongst a community of researchers that influences the kinds of questions they seek to answer and the methods they choose to answer them.[748] Paradigms may serve a researcher by providing a framework for approaching the research problem and guiding decision-making during the inquiry process.[749] Furthermore, if made explicit, a paradigm can communicate the researcher's values and beliefs about the world to others.[749]

Pragmatism is the paradigm most often associated with mixed methods.[750] It evolved out of the work of 19th century American philosophers Charles Pierce, William James, and John Dewey.[751] At its broadest, pragmatism is 'knowing the world as inseparable from agency within it'.[751] In research terms, Grbich describes it as 'a mix of postpositivism and social constructivism, a leaning towards postmodernism, and an emphasis on empirical knowledge, action, triangulation and the changing interaction between the organism and its environments.'[740(p9)] Pragmatism is primarily concerned with the actions needed to reach a satisfactory outcome for a problem in a specific time and context.[752] Its starting point is translating a practical problem into a research question, and its endpoint is a resolution of that problem, if only temporarily.[753] Ontologically, pragmatism does not pursue an idea of what is *true* as it assumes the existence of singular and multiple versions of reality.[734] Instead, researchers seek what it befits (or 'warrants') them to believe given their practical ends.[748] Furthermore, researchers may require iterative and pluralistic methods to meet these practical ends,[746, 754] freeing them to draw on whatever tools they deem most capable of answering the question posed by the problem.[754]

The purpose of this study was to explore the experiences of Australian general practitioners in providing care to people with multimorbidity. The inquiry was not a means unto itself but undertaken as a preliminary to recommending any actions needed to resolve issues that general practitioners identified as problematic. This pragmatic orientation prioritised the research question, underpinned the choice of the mixed methods methodology, and determined the methods the researcher considered best able to provide an answer.

3.5 The applicability of mixed methods to this research

The researcher considered mixed methods the most appropriate methodology for answering the overall research question of this study for reasons in addition to its alignment with pragmatism. Firstly, the methodology has proven valuable within health sciences research for studying multifaceted phenomena involving individualistic human attitudes and behaviours alongside complex and dynamic social, political, economic, and organisational factors.[737] It also provides a flexible approach to conducting research projects that span years by allowing the researcher to use multiple smaller questions to answer a larger overarching one.[734] Secondly, the methodology enables the researcher to collect and analyse both qualitative and quantitative data, with each form providing a different perspective on the same phenomenon of interest ('data triangulation').[734] It also provides a means to *integrate* diverse forms of data within a single program of research.[733] Integration might occur across different phases of a project, with the findings of one approach being used to inform the design of the next phase.[755] Integration might also mean bringing together findings based on different methods to illuminate contradictory viewpoints or confer strength to confirmatory ones. Either way, integrating findings can provide more robust inferences at a project's conclusion than any single approach findings on their own.[754] Most appealingly, exploring the same research question using different methods ('methodological triangulation') capitalises on each method's respective strengths while compensating for their weaknesses.[748] In this way, mixed methods might give 'heightened knowledge and validity' to a phenomenon.[755]

3.6 The exploratory sequential mixed methods design

This thesis will address the research question through an exploratory sequential mixed methods design. This design type, part of a set of typologies in mixed methods research, determines the respective timings of the different approaches to be combined and the relative emphasis placed on them.[734, 756] The exploratory sequential design progresses in a series of interdependent phases, beginning with a qualitative phase that allows the researcher to identify relevant themes and concepts inductively. The following phase, often a quantitative study, depends on the 'evidence' from the first phase for its questions or design.[734]

3.6.1 Phase one

Phase one in this research program explored concepts and generated the researcher's questions for general practitioners. It started by determining if there was problem to be investigated and then sought to understand the nature of that problem. Phase one included two independent exploratory studies. Study one was a comprehensive systematic review and thematic synthesis of the extant qualitative research studies exploring general practitioner perspectives on the management of multimorbidity. For data, it relied on the verbatim quotes of general practitioners detailing their first-hand experiences and perspectives. Study two in this phase was an in-depth content analysis of Australian clinical practice guidelines for life-limiting chronic conditions. This research focused on the quality and quantity of the evidence provided to general practitioners concerning the management of comorbidities. It also examined the messages given to general practitioners on their role in providing care at the end of life and whether the palliative care content would likely support their skills and confidence in this area.

3.6.2 Phase two

The research moved to phase two with new knowledge gained from phase one. Phase two focused the research further by qualitatively exploring Australian general practitioner perspectives. It used the synthesised findings from phase one studies as an objective basis for developing a semi-structured interview schedule. In this way, studies across the two phases were interdependent and sequential. Phase two included one study, which used the interview schedule derived from phase one findings to collect data from a sample of Australian general practitioners. It asked open questions with prompts, when needed, to explore the issue of multimorbidity from the general practitioner’s perspective. The interviewer first asked general practitioners to consider multimorbidity care generally before the questions moved to their experiences once care goals had shifted from chronic disease management to end-of-life care. The researcher used thematic analysis to analyse the data.[757]

3.6.3 Phase three

Phase three applied the key combined findings provided by the first two phases to design a survey instrument contextually tailored to Australian general practitioners. A new and broader sample of general practitioners was recruited from across Australia to complete this cross-sectional survey, which explored the topic of multimorbidity management using Likert-type, multiple-choice, and open-ended questions. The analysis of survey responses relied on quantitative descriptive and inferential statistical methods to test hypotheses based on the earlier findings of the systematic review and qualitative interviews. Table 3.2 shows the alignment of each study with its phase, research question and the method used to find an answer to that question.

Table 3.2 Relationships between phase, question, and method of inquiry in the exploratory sequential design

Phase	Research question	Method of inquiry
Phase 1: Exploring the existence of a problem and its nature	If general practitioners experience challenges, what are they, and what strategies do they employ to circumvent them?	Study 1. A systematic review of qualitative studies and thematic analysis of their data.
	Do Australian clinical guidelines and evidence summaries for life-limiting chronic conditions support Australian general practitioners to provide care to people with multimorbidity in both the chronic and end-of-life phases?	Study 2. Content analysis of Australian clinical practice guidelines for life-limiting chronic conditions
Phase 2: Collecting rich qualitative data, analysing and interpreting results	What is the Australian general practitioner experience of managing patients with multimorbidity across the adult life course, including the palliative and end-of-life stages?	Study 3. In-depth qualitative interviews with Australian general practitioners
Phase 3: Collecting data, analysing, and interpreting results to test the generalisability of the qualitative findings		Study 4. Cross-sectional interviews with Australian general practitioners

3.7 Integrating and interpreting the results

How and when the collected data across studies are integrated is a critical consideration in mixed methods research.[758] This exploratory sequential design employed two integration strategies: building and comparing.[746] Building took place when the qualitative themes and quotes obtained from in-depth interviews were built into the questions and items of the survey instrument.[746] Comparing occurred when data and findings from across all studies were brought together in the Discussion chapter (Chapter 8) for comparison using joint displays.[758, 759] Joint displays are a visual method for establishing how the data fit together.[737] They aid interpretation by helping the researcher 'draw out new insights beyond the information gained from the separate quantitative and qualitative results.'[759(p2143)] This research used joint displays based on the two main concepts of the conceptual framework—evidence and patient-centred approaches to managing patients with multimorbidity. For each concept, the display matrix is divided into domains which represent the themes to come out of the data across studies. Within each domain, each study and its findings are presented on a different row. Side-by-side comparison establishes how well the qualitative and quantitative data fit together. The fit can be described using the terms ‘complementary’, ‘convergent’, or ‘divergent.’[737, 746] Complementary findings are those which offer different but not conflicting interpretations. In contrast, convergent findings lead to the same conclusion. Divergence occurs when the qualitative and quantitative data describing the same domain contradict each other substantially.[759]

Once fit was established for each case, the researcher considered the two types of data together to reach an overall interpretation, or *meta-inference*,[760] for each case.[746] Figure 3.1 illustrates this three-phase design. Here the relative weighting of individual parts of the research plan is shown using a notation system based on capitalisation and symbols.[761] Capitalised ‘QUAL’ and lowercase ‘quan’ across phases two and three indicate that the research prioritises the qualitative data in the overall methodology.

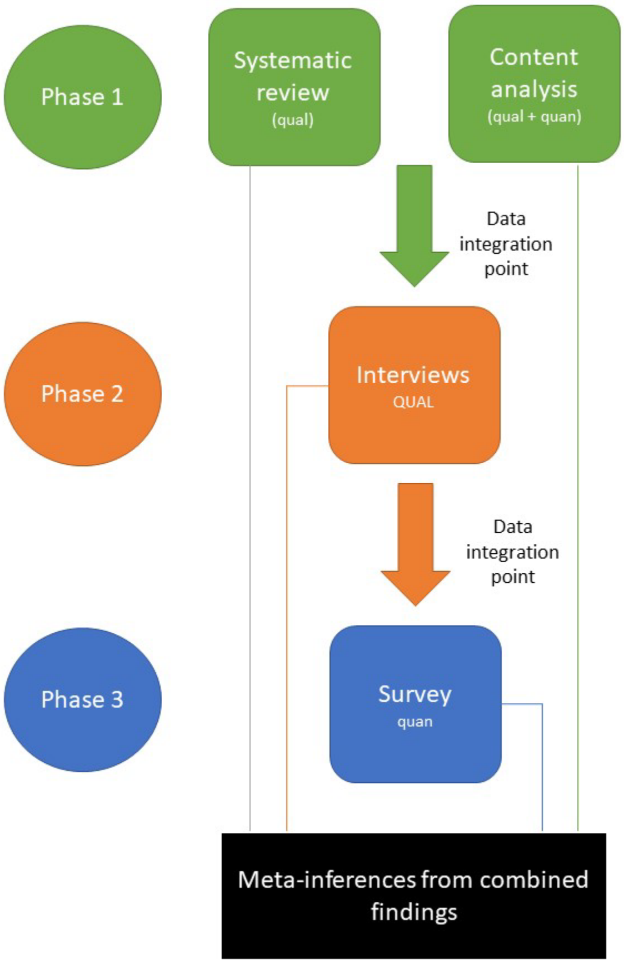

Figure 3.1 The exploratory sequential mixed methods research design with mixed methods notation

The exploratory sequential design conferred several benefits to this research. First, it supported exploring concepts in the absence of an existing theory of relevance to the research topic.[734] It also provided an objective, informed basis for developing both the interview schedule and the survey instrument. Third, it facilitated generality by allowing the more broadly administered survey study to test hypotheses derived from the context-specific findings of a small qualitative interview study.[738] Using the design presented one drawback. The three phases of the research programme had to be conducted consecutively, as the results of one study informed the design of the next. Each study's analysis phase, therefore, had to be finalised before the next study could begin, making it challenging to estimate timelines for each study.

3.8 Conclusion

This chapter has outlined and justified the research methodology used to answer the overarching research question: *What is the Australian general practitioner's experience of negotiating evidence-based and patient-centred approaches in managing patients with multimorbidity across the adult life course?* It has described how the researcher will integrate study findings throughout the development of the research and at its conclusion to provide a more complete understanding of the research problem than any of the four studies could do on their own.

The next chapter (Chapter 4) reports the specific methods and findings of a systematic review and thematic synthesis of the international qualitative literature. This review sought to find evidence supporting or refuting the perception that general practitioners find the management of multimorbidity to be challenging. It also clarified the nature of reported difficulties and the strategies used by general practitioners to circumvent them.

CHAPTER 4 GENERAL PRACTITIONER PERSPECTIVES ON MANAGING PATIENTS WITH MULTIMORBIDITY: A SYSTEMATIC REVIEW AND THEMATIC SYNTHESIS OF QUALITATIVE RESEARCH

4.1 Chapter preface

The previous chapter provided an overview of the methodology of this research project and its worldview (pragmatism). It also described the rationale for its choice of mixed methods and the exploratory sequential design.

Chapter 4 reports on a systematic review of extant qualitative studies where general practitioner participants describe their experiences managing patients with multimorbidity. This first study in the programme of research addresses the following research question: If general practitioners experience challenges in managing patients with multimorbidity, particularly when a life-limiting condition is involved, what are the challenges, and what strategies do they use to circumvent them?

4.2 Publication of this study

A paper describing this study was published in the peer-reviewed, open-access journal *BMC Family Practice* in 2020. (Q1, impact factor: 2.469.) This chapter is a modified version of that paper which the researcher has provided as Appendix A1.1

> Damarell RA, Morgan DD, Tieman JJ. General practitioner strategies for managing patients with multimorbidity: A systematic review and thematic synthesis of qualitative research. BMC Fam Pract. 2020;21(1):131.

The researcher was responsible for 95% of the work involved in this study. This included: conceiving the study; designing and conducting the literature searches; screening citations and full text against eligibility criteria; conducting the quality appraisal; and coding, extracting, and synthesising the data. The researcher also wrote up the study for this chapter and for journal publication. The researcher’s two supervisors (JT and DM) supervised the coding process and assisted in the development of the themes, which constituted a 5% unique contribution. Another researcher (CL) assisted with screening for relevant studies, which was done in parallel with the candidate.

Since publication, the following journal articles and book have cited this study:

1. Aggarwal P, Woolford SJ, Patel HP. Multi-morbidity and polypharmacy in older people: Challenges and opportunities for clinical practice. Geriatrics (Basel). 2020;5(4):85. doi: 10.3390/geriatrics5040085.
2. Aveyard H, Payne S, Preston N. A postgraduate's guide to doing a literature review in health and social care. 2nd ed. London: Open University Press/McGraw Hill Education; 2021.
3. Bjørk E, Thompson W, Ryg J, Gaardboe O, Jørgensen TL, Lundby C. Patient preferences for discussing life expectancy: A systematic review. J Gen Intern Med. 2021. Online ahead of print. doi: 10.1007/s11606-021-06973-5.
4. Corry DAS, Carter G, Doyle F, Fahey T, Gillespie P, McGlade K, et al. Successful implementation of a trans-jurisdictional, primary care, anticipatory care planning intervention for older adults at risk of functional decline: Interviews with key health professionals. BMC Health Serv Res. 2021;21(1):871. doi: 10.1186/s12913-021-06896-1.
5. Damarell RA, Morgan DD, Tieman JJ, Healey DF. Multimorbidity through the lens of life-limiting illness: How helpful are Australian clinical practice guidelines to its management in primary care? Aust J Prim Health. 2021;27(2):122-129. doi: 10.1071/PY20164.
6. Kuipers SJ, Nieboer AP, Cramm JM. Easier said than done: Healthcare professionals' barriers to the provision of patient-centered primary care to patients with multimorbidity. Int J Environ Res Public Health. 2021;18(11):6057. doi: 10.3390/ijerph18116057.
7. Kuluski K, Reid RJ, Baker GR. Applying the principles of adaptive leadership to person-centred care for people with complex care needs: Considerations for care providers, patients, caregivers and organizations. Health Expect. 2021;24(2):175-181. doi: 10.1111/hex.13174.
8. Leiva-Fernández F, González-Hevilla A, Prados-Torres JD, Casas-Galán F, García-Domingo E, Ortiz-Suárez P, et al. Identification of the multimorbidity training needs of primary care professionals: Protocol of a survey. J Multimorb Comorb. 2021;11:26335565211024791. doi: 10.1177/26335565211024791.
9. Madsen K, Wibe T, Bye A, Debesay J, Bergland A. Top 10 research priorities to improve the everyday life of older patients with multimorbidity: A James Lind Alliance (JLA) inspired Priority Setting Partnership (PSP). Tidsskrift for omsorgsforskning. 2021;7. doi: 10.18261/issn.2387-5984-2021-02-05.

10. Pati DS, Sinha R, Mahapatra P. Health communication and inter-professional care in context of multimorbidity management: Assessment of health professional curricular focus in India. Front Commun (Lausanne). 2021;6:123.
11. Ricci-Cabello I, Yañez-Juan AM, Fiol-deRoque MA, Leiva A, Llobera Canaves J, Parmentier FB, Valderas JM. Assessing the impact of multi-morbidity and related constructs on patient reported safety in primary care: Generalized structural equation modelling of observational data. J Clin Med. 2021;10(8):1782. doi: 10.3390/jcm10081782.
12. Steinman M, Reeve E. Deprescribing. In: Schmader K, Givens, J, editors. UpToDate. [Internet]. Waltham, MA.: UpToDate; 2021. [updated 2021 Apr 22; cited 2021 Jul 8]. Available from: https://www.uptodate.com/contents/deprescribing

4.3 Context for this systematic review

General practitioners are at the frontline of healthcare provision for people with multimorbidity in countries where they act as gatekeepers to the rest of the healthcare system.[89, 147] It is commonly accepted that at least half of their consultations now involve a patient with two or more chronic conditions.[65, 89] Even with the more complex conceptualisation of multimorbidity as chronic conditions affecting at least three different body systems, the prevalence in general practice is still high at 27.4%.[19] It is difficult to conceive that this demographic shift in disease burden does not impact general practitioner workload, decision-making, and ability to provide quality care and care coordination for patients. According to Starfield,[369] the strength of a country's primary care system can indicate the overall health of that country. If true, understanding general practitioner challenges should be a prerequisite to efforts to reshape primary care and improve overall system performance ahead of a predicted 'grey tsunami'.[71]

Therefore, the first phase of this research programme required an examination of available evidence attesting to the scale and nature of the problem. This investigation took the form of a systematic review of international qualitative studies that privilege the voices of general practitioners. This review is not the first to examine the perspectives of general practitioners on the issue of multimorbidity. A 2013 systematic review by Sinnott et al. synthesised the very first studies to appear on the topic (2010-2012) and revealed several challenges to multimorbidity care provision.[107] These included the inadequacy of the evidence base for decision-making in the presence of multiple chronic conditions and the challenges in delivering patient-centred care in this context.[107] Since this review, awareness of multimorbidity and its impact on patients and healthcare systems. The Academy of Medical Sciences recently labelled multimorbidity 'a priority for global health research'.[49(p3)] New primary care models for managing multimorbidity are being discussed and trialled, such as the patient-centred 3D study in the United Kingdom,[762] and the Australian Government's Health Care Homes pilot.[16] Furthermore, the National Institute for Health and Care Excellence (NICE) and the American Geriatrics Society (AGS) recently produced multimorbidity guidelines in the form of general guiding principles of care.[715, 720] It cannot be assumed, therefore, that the findings of this 8-year-old review hold today.

Rather than create a new, more recent systematic review to complement the first, this review integrates those studies from the earlier synthesis to produce a more convenient single set of findings. This ‘knock the house down and rebuild it’ approach[763] to synthesis gave an opportunity to use a different search strategy, broader inclusion criteria, and a different method of synthesis to the original review. A table highlighting the differences between the original Sinnott review and this one in terms of methods and findings has been provided in the Appendices (A1.5).

4.4 Aim

This systematic review aims to understand if and how multimorbidity affects the work of general practitioners by analysing the collective first-hand data within existing qualitative primary studies. It also looks to identify general practitioner strategies for dealing with challenges to ensure quality care provision. The review questions are therefore:

1. Which aspects of patient care are considered challenging for general practitioners in the therapeutic management of patients with multimorbidity?
2. What strategies do general practitioners engage to circumvent these challenges in providing satisfactory patient care?

4.5 Methods

Qualitative studies are best suited to answering the review questions as their methods provide 'an approach for exploring and understanding the meaning individuals and groups ascribe to a social or human problem.’[758(p4)] The thematic synthesis methodology of Thomas and Harden was used to synthesise this qualitative research data.[764] This was chosen for several reasons. Firstly, it is considered better suited to synthesising large numbers of studies than other methods.[765, 766] Secondly, this approach does not integrate data merely to quantify the prevalence of certain concepts. The integrated data undergo interpretation which can lead to new, novel insights on an issue.[767]

Thirdly, thematic synthesis provides a systematic and transparent approach to conducting and reporting the review through its three delineated stages. These stages are line-by-line inductive coding of findings within the primary studies, organising any related 'codes' into descriptive 'themes', and creating more abstract 'analytic themes'.[764] The systematic review was conducted per the standards of the ENTREQ statement for ensuring transparency in the reporting of qualitative research syntheses.[765]

4.5.1 Search strategy

The researcher employed a diverse range of search strategies in the interests of comprehensive retrieval for 'conceptual saturation' and 'maximal variability in findings'.[764] Broad searching was also essential to counter known challenges in identifying qualitative research using electronic databases.[768, 769] A database search strategy was first developed and tested in the Ovid Medline database. This strategy included a combination of database subject headings and free text terms for three distinct concepts: 'multimorbidity' AND 'general practitioners/general practice' AND 'qualitative research'. Once finalised, the researcher translated the Medline search for additional databases: PubMed, Embase (Ovid), PsycINFO (Ovid), Ageline (EBSCOhost), CINAHL (EBSCOhost), Scopus, Web of Science, and the health and medicine subset of ProQuest. The researcher conducted all database searches on 17 September 2018. The Medline version is available in Appendix A1.2.

A general web search was also conducted using Google and Google Scholar to identify unpublished literature and organisational websites relevant to primary care and multimorbidity. These searches were limited to retrieving the first 50 websites returned per search variant. Theses were identified using the following resources: ProQuest Dissertations & Theses Global, Networked Digital Library of Theses and Dissertations, Theses Canada, British Library's Electronic Thesis Online Service, TROVE (National Library of Australia), and NZResearch.org. Other sources of grey literature searched include CORE (an open-access research aggregator), Grey Literature Report, OpenDOAR, and OpenGrey. As final measures, the researcher scanned the online contents pages of the *Journal of Co-morbidity* (2011-2018) and the reference lists of included studies.

4.5.2 Eligibility criteria

An eligibility checklist was developed and iteratively tested using a small sample of retrieved citations.

4.5.2.1 Types of participants

To be included in the synthesis, studies had to describe the perspectives of general practitioners. For this review, 'general practitioner' is defined according to The European Definition of General Practice/Family Medicine by WONCA Europe:

> General practitioners/family doctors are specialist physicians trained in the principles of the discipline. They are personal doctors, primarily responsible for the provision of comprehensive and continuing care to every individual seeking medical care irrespective of age, sex and illness. They care for individuals in the context of their family, their community, and their culture, always respecting the autonomy of their patients. They recognise they will also have a professional responsibility to their community. In negotiating management plans with their patients, they integrate physical, psychological, social, cultural and existential factors, utilising the knowledge and trust engendered by repeated contacts. General practitioners/family physicians exercise their professional role by promoting health, preventing disease and providing cure, care, or palliation and promoting patient empowerment and self-management …[14(p9)]

Studies investigating experiences of general practitioners as part of a broader group of health professionals were included if the researcher was able to extract the first-person contributions of general practitioners.

4.5.2.2 Phenomena of Interest

The phenomena of interest were general practitioners' perspectives, views, attitudes, or beliefs on their therapeutic management of patients with multimorbidity. Therapeutic management might be pharmacological or non-pharmacological or involve interventions such as referral, screening, prevention, diagnostic testing, or follow-up.[770]

Patients had to be adults, 18 years and over, with any combination of chronic conditions providing their general practitioner considered them a 'patient with multimorbidity'. Studies focused on an index condition with comorbidities were eligible if their investigators explicitly explored multimorbidity as a subject of interview questions or a theme within the study results.

4.5.2.3 Context

General or family practices operate differently across countries regarding practitioner training requirements, funding models, speciality recognition, and the degree to which they authorise access to specialty and hospital care. General practitioners working across significantly different models of general practice will have divergent challenges and experiences which may be difficult to compare.

Therefore, the researcher made the pragmatic decision to limit this review to countries with somewhat similar general practice models. This list included, but was not limited to, Australia, New Zealand, United Kingdom, Ireland, Canada, Netherlands, the Nordic countries, Poland, Portugal, Slovenia, and Spain.[771, 772] The United States was a significant omission. However, its uniquely complex healthcare system rendered it difficult to draw comparisons with the systems of other high-income countries.[773] All settings of general practitioner work were eligible, including primary care centres, private practices, and residential aged care.

4.5.2.4 Types of studies

This review considered any study design providing the study reported the verbatim quotes from general practitioners conveying their views, opinions, beliefs, attitudes, and perspectives on the impact of multimorbidity on their clinical practice. Studies were limited to those in the English language. No date restrictions were applied.

4.5.3 Study selection

Citations were imported into an EndNote X8 library where duplicate citations were removed. Using the piloted eligibility checklist, the researcher screened all titles and abstracts for relevance, moving each to one of three groups created within the library titled 'relevant', 'irrelevant', and 'uncertain'. A second reviewer (CL) then screened 20% of the 'irrelevant' group citations to check the researcher’s decision-making consistency. Full-text articles were obtained for each citation in the 'relevant' and 'uncertain' groups. The researcher and CL then independently reviewed each full-text report to determine its relevance. They also discussed any disagreements until they reached a consensus.

4.5.4 Quality appraisal

The appropriateness of including or excluding qualitative studies in a synthesis based on an appraisal of their quality remains contentious.[767, 774] The researcher appraised all included papers for quality to gain a richer understanding of the methodological choices reported. However, studies of lower quality were not excluded, for they still contributed unique themes to the synthesis.[767] Quality was appraised using a 10-question qualitative checklist developed by the Critical Appraisal Skills Programme (CASP).[775] This tool is provided within Appendix A1.3.

4.5.5 Thematic synthesis

PDF versions of all included articles were imported into QSR International's NVivo 12 qualitative data analysis software. The thematic synthesis then proceeded according to the three stages described below.

Stage 1. Free coding of study data and findings

The researcher performed detailed coding of participants' verbatim quotes (herein 'data') and author 'findings' which were in each study's Results and Discussion sections. Coding involved reading the relevant sections line-by-line and assigning a unique descriptive label ('code') to every salient concept within the text on its first appearance. Subsequent occurrences of a concept within the text were then tagged with the existing code. This 'initial coding' method created tentative and provisional codes which the researcher further refined in stage two.[776] In keeping with the review's inductive intentions, decisions on the names of codes and the number of codes created were driven by the quotes and findings themselves rather than any predetermined framework.

Stage 2. Developing descriptive themes

Once all data and findings were coded, the researcher examined the list of codes for duplicate, overlapping, or redundant codes. Next, each code's assigned text was reread to check for consistency in coding across the full range of articles. From this process, additional codes were created, and nondescript code names were replaced with more descriptive labels ('axial coding').[776] The resultant list of codes was then sorted by highest to the lowest frequency of text assignment to see which codes were predominant and recurrent across the complete set of articles. From here, all codes were then iteratively and hierarchically arranged to form conceptually similar or related groups. For example, 'communication between providers' was grouped with 'conflicting advice to patients' and both were put under the broader code 'Interface of primary care and other sectors'. Resultant codes became the descriptive themes of the review.

Stage 3. Developing analytical themes from descriptive themes

The researcher and her two supervisors (JT and DM) then discussed the descriptive themes and their relationships, testing new ways of organising and labelling them. From this, more abstract 'analytical' themes which 'go beyond the content of the original studies'[777] were developed by discussion and consensus (i.e., triangulation). These analytical themes had to encapsulate and explain the descriptive themes and be richly supported by the data.

4.6 Results

Electronic database and grey literature searches, together with reference list checks, identified 8374 citations. This total was reduced to 4214 citations once duplicates were removed. After scanning titles and abstracts against the inclusion criteria, 127 citations remained for further review. More detailed full-text analysis reduced the set to 33 articles for the final synthesis. Of these, four pairs of studies shared the same data but were retained because they reported on distinct aspects of it. A PRISMA flow diagram (Figure 4.1) summarises the selection process.[778]

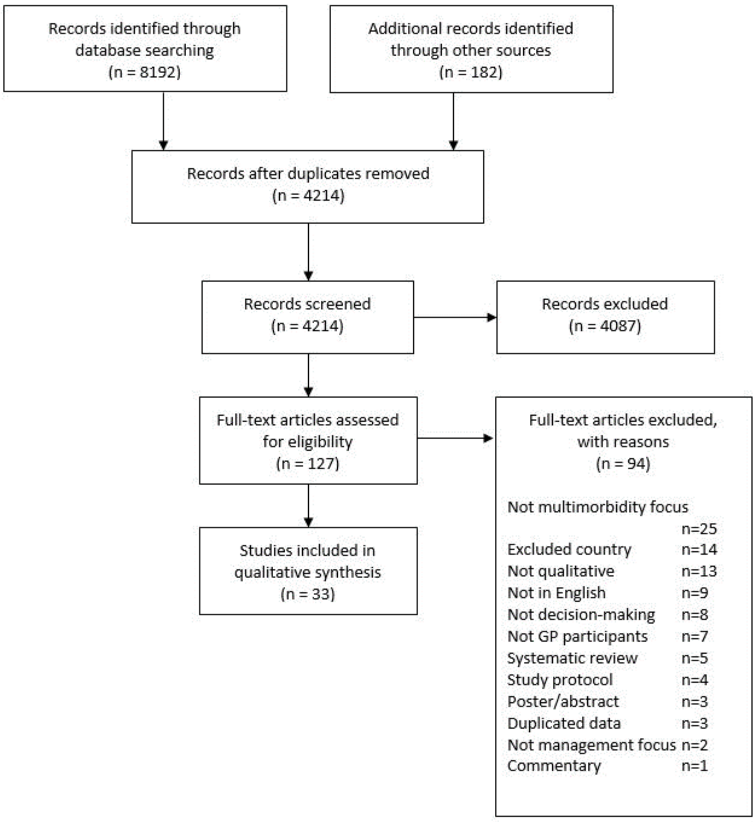

Figure 4.1 PRISMA flow diagram of article selection decisions

4.6.1 Characteristics of included studies

Table 4.1 provides details of the characteristics of each included study.

Table 4.1 Individual study characteristics

Author (Year) and country	No. of GP participants and their characteristics	Patient population and topic focus	Multimorbidity content	Method of data collection	Theoretical framework and form of analysis
Ailabouni (2016a)[779] New Zealand	10 GPs No. of years' experience prescribing in residential care: 2–32 years	A hypothetical patient with multimorbidity Deprescribing	Focus. Uses a hypothetical patient with multimorbidity to stimulate discussion of multimorbidity	Semi-structured interviews	Theoretical Domain Framework Content analysis
Ailabouni (2016b)[780] New Zealand	10 GPs No. of years' experience prescribing in residential care: 2–32 years. Gender: 7 males; 3 females	Older patients in residential aged care Deprescribing	Derived theme	Semi-structured interviews	Theoretical Domain Framework Content analysis
Anderson (2017)[781] Australia	32 GPs Mean age: 47 years (range: 28-70 years). Mean time in practice: 18 years (range: 1-50 years). 63.3% full-time. Gender: 18 males; 14 females	Older patients with multimorbidity in primary care Deprescribing	Focus. Uses a hypothetical patient with multimorbidity to stimulate discussion of multimorbidity	Focus groups	Not stated Thematic analysis using Framework Method
Austad (2016)[686] Norway	25 GPs Not stated	Patients with multimorbidity in general practice Clinical practice guidelines	Focus	Focus groups	Phenomenological approach Systematic text condensation
Blakeman (2012)[782] England, UK	11 GPs Median age: 45 years (range: 30–62 years).	Patients with early-stage chronic kidney disease in primary care	Focus. Contained a section on multimorbidity in the	Semi-structured interviews	Normalisation Process Theory Deductive analysis using

	Gender: 6 males; 5 females	Patient management	interview guide		framework
Bower (2011)[783] England, UK	15 GPs 'A mix of males and females'; 'significant variation in age and experience among participants'	Patients with multimorbidity in general practice Service organisation; Decision-making	Focus	Semi-structured interviews	Not stated Framework analysis
Clyne (2016)[784] Ireland	17 GPs 14 GPs in practice > 10 years. Gender: 13 males; 4 females	Older patients in primary care Potentially inappropriate prescribing	Derived theme	Semi-structured interviews	Not stated Thematic analysis
Jones (2018)[785] Australia	14 GPs Mean time in practice: 21 years	Remote Australian Aboriginal patients with complex health problems Clinical practice guidelines	Focus	Semi-structured interviews	Critical theory and a realist paradigm Thematic analysis
Kenning (2013)[786] England, UK	16 GPs Mean time in practice: 17 years. Gender: 7 males; 9 females	Patients with multimorbidity in general practice Working with patients; self-care	Focus	Semi-structured interviews	Not stated Thematic analysis
Kristensen (2017)[787] Denmark	12 GPs Median time in practice: 16 years (range: 1-41 years). Gender: 6 males, 6	Patients with multimorbidity living in rural, socioeconomically deprived regions Self-care	Focus	Semi-structured interviews	Not stated Systematic text condensation

	females				
Kristensen (2018)[788] Denmark	See Kristensen (2017) as duplicate data	Patients with multimorbidity and lowered self-care ability Disease management programs	Focus	Semi-structured interviews	Not stated Systematic text condensation
Kuluski (2013)[789] Canada	4 Family Physicians Time in practice: 3 GPs > 10 years; 1 = 1 year	Older patients with multimorbidity in primary care Care goals	Focus	Semi-structured interviews	Not stated Thematic analysis
Laue (2016)[790] International but only data and findings for Norway, Wales, and the Netherlands were extracted	23 GPs (Norway: n=7; Netherlands: n=6; Wales: n=10) Norway. Time in practice: 2 months-20 years. Netherlands. Time in practice: 3-30 years. Wales. Time in practice: 4-28 years	Patients with COPD and exacerbations Decision-making	Derived theme	Focus groups	Grounded theory Thematic analysis
Laursen (2018)[791] Denmark	14 GPs Mean time in practice: 15 years. Gender: 7 males; 7 females	Poly-medicated patients with multimorbidity Medication review	Focus	Semi-structured interviews	Phenomenological, hermeneutic orientation Content analysis
Luijks (2012)[792] Netherlands	25 GPs Mean age = 50 years. Mean time in practice: 20	Patients with multimorbidity in general practice Patient management	Focus	Focus groups	Realism paradigm Constant comparative analysis

	years (range: 2-36 years). Gender: 18 males; 7 females				
Luijks (2015)[793] Netherlands	See Luijks (2012) as duplicate data	Patients with multimorbidity in general practice Clinical practice guidelines	Focus	Focus groups	Not stated Constant comparative analysis
McNamara (2017)[794] Australia	5 GPs (26 healthcare professionals in total) Not stated	Patients with multimorbidity in general practice Patient management	Focus	Semi-structured interviews	American Geriatrics Society Guiding Principles used as a framework for analysis Constant comparative analysis
O'Brien (2011)[795] Scotland, UK	15 GPs Gender: 8 males; 7 females	Socioeconomically deprived patients with multimorbidity in general practice Patient management	Focus	Semi-structured interviews	Modified grounded theory approach Constant comparative analysis
Ploeg (2017)[796] Canada	4 Family Physicians Not stated	Older, community-dwelling patients with multimorbidity Patient management	Focus	Semi-structured interviews	Thorne's interpretative description approach Constant comparative analysis
Prazeres (2016)[797] Portugal	74 GPs Mean time in practice: 16 years (range 1-37 years). Gender: 23 males; 51	Patients with multimorbidity in general practice Patient management	Focus	Online survey	Not stated Thematic content analysis

	females				
Risor (2013)[798] International but only data and findings for Norway, Wales, and the Netherlands were extracted	See Laue (2016) as duplicate data	Patients with COPD and exacerbations Decision-making	Derived theme	Focus groups	Grounded theory Not stated but 'line-by-line coding' used
Sandelowsky (2016)[799] Sweden	59 Primary Care Practitioners Mean age: 46 years (range 28-68 years). Mean time in practice: 14 years (range 1-39 years). Gender: 30 males; 29 females	Patients with COPD Patient management	Focus	Semi-structured interviews and focus groups	'Inspired by the grounded theory method' Constant comparative analysis
Schuling (2012)[800] Netherlands	29 GPs Mean age: 54 years (range 39-65 years). Gender: 27 males; 2 females	Older patients with multimorbidity in primary care Deprescribing	Focus	Focus groups	Not stated Thematic analysis
Sinnige (2016)[801] Netherlands	12 GPs Mean age: 56 years (range 46-63 years). Mean time in practice: 25 years (range 10-35 years)	Older people with polypharmacy in general practice Medication management; Polypharmacy	Focus of clinical vignettes	Focus groups	Not stated Framework approach

Sinnott (2015)[706] Ireland	20 GPs Length of time qualified: 6 GPs < 10 years; 14 GPs > 10 years	Patients with multimorbidity in general practice Prescribing decisions	Focus	Semi-structured interviews and chart-stimulated recall	Grounded theory approach Constant comparative analysis
Smith (2010)[802] Ireland	13 GPs Not stated	Patients with multimorbidity in general practice Patient management	Focus	Focus group	Not stated Framework analysis
Solomon (2012)[803] England, UK	8 GPs Not stated	Patients prescribed a statin or a proton pump inhibitor in primary care Clinical practice guidelines; Patient-GP partnership	Derived theme	Semi-structured interviews	Not stated Framework analysis
Sondergaard (2015)[804] Nordic countries: Denmark, Finland, Iceland, Norway, Sweden	62 GPs Not stated	Patients with multimorbidity in general practice Patient management	Focus	Plenary session and short open-ended questionnaires	Not stated Framework analysis
Stanners (2012)[805] Australia	8 GPs Time in practice (range): 20-40 years. Gender: 7 males; 1 female	Patients with multimorbidity and depression in general practice Patient management	Focus	Semi-structured interviews	Grounded theory Constant comparative analysis
Stokes (2017)[806]	12 GPs	Patients with multimorbidity in	Focus	Semi-structured interviews	Not stated

New Zealand	Not stated	general practice Patient management			Thematic analysis
Tonkin-Crine (2015)[807] England, UK	19 GPs Mean age: 46 years (range: 31-60 years). Mean time in practice: 16 years (range: 3-32 years). Gender: 12 males; 7 females	Patients with advanced chronic kidney disease in primary care Patient management	Derived theme	Semi-structured interviews	Not stated Thematic analysis
van de Pol (2015)[808] Netherlands	20 GPs Mean age: 48 years (range: 32-60 years). Gender: 11 males; 9 females	Older patients in residential aged care Patient management	Derived theme	Focus groups	Not stated Constant comparative analysis
Vermunt (2018)[727] Netherlands	15 GPs Mean age: 51 years. Mean time in practice: 16 years. Gender: 6 males; 9 females	Older patients with multimorbidity in general practice Patient management	Focus	Semi-structured interviews	Not stated Thematic analysis

As Table 4.1 shows, 14 individual countries were represented across the 33 included studies. These were (in order of frequency): Netherlands,[727, 792, 793, 798, 800, 801, 808] England,[782, 783, 786, 803, 807] Australia,[781, 785, 794, 805] Denmark,[787, 788, 791, 804] Norway,[790, 798, 804, 809] Ireland,[706, 784, 802] New Zealand,[779, 780, 806] Canada,[789, 796] Wales,[790, 798] Sweden,[799, 804] Finland,[804] Iceland,[804] Portugal,[797] and Scotland.[795] Together these studies included a total of 593 unique general practitioner participants (range: 4-74 general practitioners). The median date across all studies was 2016 (range: 2010-2018).

Studies focused on multimorbidity were usually oriented towards an aspect of care. Some used the broad lens of patient management,[782, 792, 795-797, 799, 802, 804, 805, 807, 808] while others focused on medication management[706, 779-781, 784, 791, 794, 800, 801] (including deprescribing and potentially inappropriate prescribing); clinical practice guidelines;[785, 793, 803, 809] general practitioner decision-making;[790, 798, 806] care goals;[727, 789] patient self-care;[786, 787] disease management programs;[788] and health service orientation.[783]

The quality of each of the 33 included studies was high as judged using the CASP Qualitative Checklist. Only two areas were inconsistently reported: consideration of the nature of the researcher/participant relationship and ethical issues. It is not possible to know if these elements were considered by researchers and not reported or not considered at all. Therefore, they were marked with a 'Cannot Tell' (CT) rather than a 'No' response. The results of the appraisal are provided as Appendix A1.4.

4.6.2 Synthesis of results

The thematic analysis of general practitioner experiences of multimorbidity focused on two broad areas in line with the review questions: (1) patient management challenges; and (2) strategies for dealing with challenges. In looking at inherent challenges, the researcher identified three predominant analytical themes: *Practicing at the bounds of evidence; Confronting patient complexity* and*; Intersectoral failures and problematic policy.*

Two themes emerged from the data to help our understanding of how general practitioners manage these challenges. These were: *Prioritising a patient-centred approach to care* and *Strategies for managing the consultation*. These themes and their subthemes are shown in Table 4.2.

Table 4.2 Themes and subthemes of the qualitative thematic synthesis

Challenges	
Theme	**Subthemes**
Practicing at the bounds of evidence	*Evidence—insufficient, non-generalisable and potentially unsafe* *Protocol-driven medicine versus clinical judgement* *Clinical uncertainty and risk perception*
Confronting patient complexity	
Intersectoral failures and problematic policy	*The primary-secondary divide* *Primary and community care* *Struggling with time and workload*
Strategies	
Theme	**Subthemes**
Prioritising a patient-centred approach to care	*Building and safeguarding a continuous patient-GP relationship* *Working with patient and caregiver values, goals, and priorities* *Tailoring care to each patient*
Strategies for managing the consultation	

4.6.2.1 Challenge theme 1: Practising at the bounds of evidence

General practitioners questioned the applicability of existing therapeutic research to patients with multiple chronic conditions. Furthermore, their awareness of evidential limitations in this context induced a tension between practising according to guideline recommendations—which might be mandatory within a specific national or regional primary care system—or deviating towards a more patient-centred and less evidence-based approach.

Evidence—insufficient, non-generalisable and potentially unsafe

General practitioners viewed clinical practice guidelines as oriented around managing single conditions—an approach aligned with secondary rather than primary care.[780, 786, 788, 793, 794, 800, 802, 804, 806, 809] This could render guidelines 'reductionist'[786, 809] and an inadequate foundation on which to base clinical decisions.[706, 784, 793, 798, 802-804] They also described guidelines as silent on the cumulative effects of prescribing different medications for concurrent conditions. This omission left them in the difficult position of having to balance the potential benefits and risks of each patient's unique therapeutic cocktail. General practitioners were therefore operating in the knowledge that treating one problem risked exacerbating or creating new problems for other conditions.[780, 781, 786, 788, 790, 793, 796, 797, 800, 802, 804, 809]

> The problem is that you are trying to weigh up unmeasurable harm quite often against unmeasurable benefit. We are trying to do that in our minds and trying to work it out—Is it more likely to be doing benefit or more likely to harm? The truth is that, in many cases, I don't know.[781(p1939)]

When faced with problematic polypharmacy, general practitioners found available guidance on deprescribing medications similarly inadequate.[779-781, 794, 802, 809] One general practitioner described this as 'a riskier, less certain, and more cognitively and socially demanding process, with minimal decision support.'[781(p1945)] Knowing when and how to deprescribe *preventative* medicines for older patients or those with a poor prognosis was considered particularly important, but often challenging as it meant reconciling statistical concepts such as absolute/relative risk reduction, number needed to treat, and time-to-benefit with questions of life expectancy and quality of life.[779, 780, 793, 794, 800, 802]

> With a 40-something year old, the treatment aim is clear ... to reduce risk over a long-term period. But for an 80-something-year-old, it becomes less clear cut [...] What can the patient get out of it, and also, what are the possible side-effects?[793(Suppl p[2])]

Existing clinical tools for therapeutic decision-making, such as alerts in electronic medical record systems, were often disregarded as lacking user-friendliness in their current form[706, 794] or not necessarily addressing the main challenges in multimorbidity care. Without the benefit of evidence-based statistical guidance in the form of risk reduction ratios and numbers needed to treat, general practitioners tended to rely on considerations such as time-to-benefit, life expectancy, quality of life, and frailty in decision-making.[706, 779, 780, 792-794, 801, 802, 807]

> You know what, when you are 85 years old you don't have to perform anymore and at the same time there is this 'time to effect', that means, it takes more than 10 years before a patient at 85 is getting a marginal effect, marginal![791(p4)]

Even when available for single conditions, these numbers, derived from population-based studies, might offer little help:

> If something estimates a risk of death in five years of 20% or 40 … it doesn't really help me [to decide if I should] prescribe a statin or not. If someone's risk of death is 80% within a year, I wouldn't prescribe that person a statin.[794(p294)]

Some considered guidelines too simplistic to encompass the complexities involved in managing multimorbidity:

> There are no guidelines yet which can encompass 'complexity-based medicine'. To grasp how to work with the complexity we confront as GPs requires a massive, theoretical quantum leap. Perhaps in 10–15 years we will realize that all of today's reductionist guidelines within the natural sciences were wrong and had led us astray.[809(p3)]

In many instances, the need to apply recommendations across multiple guidelines created more complexity, with general practitioners concerned that this might jeopardise patient safety by driving polypharmacy, overdiagnosis and overtreatment. 'It's also very overwhelming to them. They're on 15 different medications because everybody has been giving them all, but taken altogether, it's just too much.'[796(p8)]

Patient management according to multiple guidelines was also seen to impose a high burden of treatment on patients, thereby putting patient adherence at risk.[788] These concerns were particularly apparent in countries where clinical indicators derived from research evidence or expert consensus are linked with quality improvement incentives such as pay-for-performance schemes.[782, 783, 793, 803] General practitioners from these countries described being unwilling to 'medicalise' people when guidelines stipulated lowering clinical target thresholds or when condition definitions widened.[782, 809] This was evident when the English Quality and Outcomes Framework (QOF) extended the definition of what constitutes problematic chronic kidney disease (CKD) while linking documented cases of CKD diagnosis and treatment to remuneration:

> So the first thing was really to validate our register of CKD ... And we had a huge jump of patients on the register, because we inhouse had actually [previously] decided that all patients over the age of 80 would not be on the register. That this was a progressive natural deterioration, physiological deterioration in kidney function … To get your points of course, you had to do the necessary test that linked in with QOF.[782(p235)]

General practitioners attributed the lack of generalisable multimorbidity guidance to the hegemony of the controlled clinical trial methodology with its preferential focus on internal rather than external validity.[793, 800, 809] They were aware that guideline recommendations were often based on trials that tested therapies using much younger and less complicated patients than those they regularly encountered in their practices.[780, 793, 796]

> For example, such a guideline for diabetes or hypertension is based on, I don't know, research on 40-60 year olds ... with mono-morbidity, probably. I don't know if this is like this in all cases. But in general, that's what happens. And what's that worth for an 80-year-old patient with multimorbidity? Nothing, in my opinion.[793(Suppl p[3])]

Protocol-driven medicine versus clinical judgement

Despite these concerns around the generalisability of research evidence to older patients and those with more than one morbidity, general practitioners within and across studies frequently differed in their views on adhering to the tenets of Evidence-Based Medicine. Some questioned if it was feasible or even desirable in the context of multimorbidity. For some general practitioners, awareness of the limitations of existing evidence appears to justify a preference for relying on their professional autonomy and clinical judgement: '[Multimorbidity] gives you a lot of freedom to use your experience and own ideas as a doctor to help the patient's problem.'[793(Suppl p[4])] When this approach did not result in adverse outcomes, this could boost the general practitioner's self-confidence:

> I think, as you get older, you realize that is not really true because you have done it so many times and they have not had a stroke the next week.[781(p1943)]

Other general practitioners valued guidelines while viewing consistent adherence to them as an impediment[793] or 'a kind of hindrance'[800(p5)] to patient-centred care: 'Guidelines can only say so much about the disease and nothing about the whole patient.'[791(p3)] Some general practitioners regarded strict adherence to guidelines as a way to 'protect their back' against any professional or legal challenges to their decision-making.[809] 'We could always go back to CARPA and say, "Look, this is how we're doing it and that's what's in the book. So leave us alone."'[785(p7)] This kind of defensive medicine was also played out when general practitioners felt it necessary to deviate from guidelines:

> When I deviate from the guidelines, I am careful to write my reasons down in the patient record. For instance, if I take a patient off acetylic acid because he developed a stomach ulcer, I write that I am aware of the increased risk of a blood clot. Good record-keeping helps protect me.[809(p4)]

A further group of general practitioners said they generally disregarded guidelines due to the overwhelming volume of evidence coming at them, combined with a lack of time or willingness to consult it.[780, 781, 799] This attitude, primarily evident in studies from Australia and New Zealand, contrasted with those of general practitioners in countries where policy mandated guideline adherence even though 'the map and the terrain simply [do] not match.'[809(p3)] A Norwegian general practitioner, for example, described the pressure to conform to all guidelines as '[t]he insecurity that a guideline hell brings.'[809(p3)] Similarly, a general practitioner from The Netherlands stated, 'I have difficulty not following the guidelines if I don't have good reasons to do so.'[800(p5)]

Clinical uncertainty and risk perception

In the absence of adequate evidence, general practitioners had a strong sense of the risks associated with their decision-making,[706, 727, 780, 781, 786, 790-792, 794, 797, 798, 800-802, 804, 805, 807-809] a situation described as 'doing it without the really significant evidence-based security.'[781(p1940)] This could lead general practitioners to feel nervous, anxious, or fearful of making mistakes and creating unfavourable consequences for their patients.[706, 779-781, 786, 790, 794, 802, 809] As a result, general practitioners might adopt one of two mindsets: what Anderson[781(p1941)] describes as a 'risk to be reconciled' or a 'risk to be avoided' frame. Positive or negative past experiences could reinforce these orientations.

> Since I've started to look at that more globally, the number of medicines I'm prescribing on average for patients in rest homes is about 50% of what I was prescribing a year ago and they aren't falling off their perch in greater numbers.[780(p7)]

In avoiding risk, general practitioners might maintain the status quo or demonstrate 'clinical inertia' in decision-making,[706, 781, 784, 794] especially in the context of deprescribing.

> Struggling yeah, it's just not feeling that confident, not feeling that confident about managing one condition, but realising it has an impact on the other one, affecting it adversely. I'm not sure what balance to strike.[786(p4)]

This uncertainty might manifest as a reluctance to 'stir things up'[802(p187)] or a focus on removing just the 'low-hanging fruit.'[781(p1939)] The general practitioner might also wait for a clear trigger event, such as a patient falling, to know when to reduce or cease a therapy.[781] The opposite reaction to a sense of risk was to provide, rather than withhold, treatment to patients.[790, 791, 809]

General practitioners might base a prescribing decision on their perception that healthcare systems rarely criticised them for overtreating patients but could take a hard line against those who undertreated.

> We never get criticized for doing too much. You don't get in trouble for having initiated unnecessary examinations, even if they lead to complications. But you can be sure you'll get in trouble if you haven't done enough! We're much more vulnerable to the entire health care system's expectation that things must be done. There's an intense 'action imperative' to do more.[809(p4)]

4.6.2.2 Challenge theme 2: Confronting patient complexity

General practitioners reserved the term ‘complex’ for a subset of patients whose morbidity burden interacted with advanced age, frailty, or non-medical factors such as social, cultural, or economic context.[784, 786, 802, 808] They also viewed any difficulties impairing the patient's ability to comprehend problems, participate in decision-making, or self-manage as adding to the complexity. Problems could include memory loss, cognitive impairment,[780, 783, 789, 792, 794] low literacy,[785, 795] and patient passivity, lack of motivation or initiative,[706, 784, 787, 788, 798, 803] A low expectation of a patient's ability to self-manage might escalate into general practitioner feelings of hopelessness,[787, 792, 798, 799, 804] or the perception of a patient as ‘difficult.’[798(p6)]

> There are a couple of things we encounter such as most patients are 'dead horses'. This does not sound respectful but there are a lot of patients who want to be left alone. We cannot make them understand what we expect from them. Be active, quit smoking, more exercise, loyal to therapy, take their own initiatives.[798(p6)]

This perception was particularly evident around COPD, which some general practitioners described as a self-inflicted disease with low status and low expectations of adherence.[798, 799, 804] ‘You really don’t expect adherence to treatment from someone who has smoked himself to COPD. That’s probably why you don’t refer or treat them.’[799(p61)]

4.6.2.3 Challenge theme 3: Intersectoral failures and problematic policy

General practitioners described a range of problems in their attempts to share care of patients with multimorbidity with health professionals outside of primary care, chief among them insufficient or incomplete communication. This confounded efforts to optimise patient experiences of the health and social care systems and could threaten patient safety. They described a sense of professional isolation (the ‘lonely game’[784(p4)]), even demoralisation when trying to create coordinated, holistic care for patients in the face of a fragmented system.

They were often unsupported in this by policies dictating consultation times and remuneration.

The primary-secondary divide

General practitioners reported a critical disconnect between primary and secondary care prescribers which often resulted in a reluctance to deprescribe or modify therapies initiated by specialists, even when uncertain of the initial indication.[779-781, 784, 791, 794]

> Yeah, look the big doctor in the white coat in the big house on the hill always knows more than the GP especially the house surgeon who might have a brief amount of experience and does what they're told and one of the issues with this process is, experienced GPs still think that the doctor up the road knows more.[780(p12)]

Patients may also be unwilling to consider reducing or stopping medications when general practitioner advice went against the perceived higher authority of the specialist: 'Doctor X said I must never, ever stop that.'[781(p1941)] Furthermore, general practitioners described the information coming to them from specialists as frequently 'delayed, lost or vague'.[794(p296)]

The transition point between the hospital and the community setting was considered particularly dangerous for conveying information on patients with multiple conditions. Hospital staff may not explain to the general practitioner why certain drugs had been added or removed from the patient's list, nor whether this change should be considered permanent or temporary.[791] Across several studies, general practitioners reported wishing to 'share the onus of responsibility' of multimorbidity care with specialists, 'rather than flying solo on it.'[706(p188)] However, endeavours to contact specialists for guidance could be frequently frustrated. According to one general practitioner, this lack of communication had led to '[a] collusion of anonymity, which is, you know, this is not my patient, not my patient ...'[802(p288)] Not all general practitioners described a poorly established general practitioner-specialist relationship. General practitioners in one study regularly contacted renal specialists for advice about chronic kidney disease and felt buoyed by their availability in the case of a deterioration.[807]

Some general practitioners perceived specialists as operating in silos with a single disease mindset. This approach could significantly impact their own workload: 'If we could stop hospital physicians prescribing single issue medicines for compromised older people, we'd reduce our problems by 50% overnight.'[780(p17)] Specialist prescribing practices might even interfere with the general practitioner's professional accountability or prescribing autonomy. According to one general practitioner:

> I see how patients go into the hospital and have new medications added because the hospital has followed the guidelines. We often have to take responsibility later for having the patients discontinue some meds and we thereby 'break the rules.' That's no easy job! But we have to try to see the whole patient.[809(p4)]

As a result, patient care might become disjointed, with little flow of information and continuity of care between settings.[788, 806] Poorly defined individual roles across sectors led many general practitioners to assert professional responsibility for counteracting this fragmented, piecemeal approach by providing holistic, coordinated care. When workload pressures often made this hard to achieve in practice, this could lead to 'general inaction on multimorbidity' altogether.[794(p298)]

Primary and community care

General practitioners raised several areas of difficulty in providing care to patients with multimorbidity living in the community. They viewed residential aged care settings as especially challenging with their different computer systems and operational policies and procedures, which could be inconsistent or unclear. They used terms such as 'disorganised', 'chaotic', 'ad hoc', and 'deficient in coordination'[780, 808] to describe the environment. In the absence of a shared electronic patient record, data continuity was also problematic between the nursing home and their clinic.

> You try and find the notes, hard to find. You can't find the medicine chart; it could be on the rounds somewhere. It's not computerised, it doesn't link with our technical notes at the medical practice, so quality just goes down. It shouldn't be, but at the practice we've got the computer, we've got light, we don't have a darkened room in a rest home, and we can actually see what's going on.[780(p16)]

General practitioners specifically mentioned difficulties in dealing with the anonymity, unavailability, and low skill level of nurses in nursing homes: 'Your first challenge is; you go to the rest home. You try and find a nurse. You can never find one.'[780(p16)] The substantial number of people involved in providing care in this environment was also seen as problematic as it could lead to 'confusion and miscommunication between the staff.'[808(p503)] Overall, general practitioners found the extra workload, stress and inconvenience in working in nursing home visits around their clinic work as a 'juggling act' for which they felt inadequately compensated.[780]

Many general practitioners spoke positively about working with other primary care health professionals to provide team-based care. Some regarded pharmacists as vital for enabling medication reviews.

However, a few general practitioners did not believe pharmacists had sufficient clinical expertise to work independently managing patients with multimorbidity: 'I am not sure that the pharmacist per se is going to be able to make those decisions. I mean they are probably more clinical decisions.'[802(p289)] This view also extended to practice nurses: '[T]hat's what we spend years doing, is training to make clinical decisions, you know, so you can't expect nurses to do that, except in a limited way.'[802(p289)]

General practitioners working in areas of social deprivation reported a separate set of local challenges. The social problems they encountered daily had broadened their definition of multimorbidity beyond medical considerations to take in unemployment, poor housing, problems with relationships, and poverty.[795] These general practitioners spoke of feeling powerless to help when they found difficulties in engaging services beyond the clinic in the community to meet their patients' complex needs.[797]

Local clinical systems designed to help general practitioners with care coordination might also impinge on the management of patients with multimorbidity. General practitioners working with Aboriginal populations in remote Northern Australia described an inflexible electronic data entry template unable to cater for patient complexity, poorly organised patient data in the electronic health record, and burdensome and inadequately coordinated patient recalls.[785] As one general practitioner said: 'If I had the time and took the time, I would usually take about an hour [to piece together the story] for people who had chronic health conditions.'[785(p5)]

Struggling with time and workload

General practitioners reported struggling with the interrelated concerns of inadequate consultation time, insufficient financial remuneration, and increased workload where multimorbidity was concerned.[706, 780, 781, 783, 788, 792, 794, 795, 797, 799, 801-806, 808] Some of these issues appear to stem from existing national or regional healthcare policies that still view primary care as oriented towards single, rather than multiple, disease management.

The challenge most consistently raised by general practitioners across studies and countries was the lack of consultation time afforded by healthcare systems for them to provide adequate care for patients with multimorbidity.

The fluctuating nature of multimorbidity required general practitioners to monitor patients for adverse biophysiological interactions, changes in psychosocial circumstances or preferences for care, and any communication difficulties. It was also important that someone monitor care continuity as the patient moved between different healthcare sectors. This level of vigilance requires more time than the standard consultation time allows.

> [H]ow on earth can you really, in a busy practice, deal with someone with multimorbidity, multi-polypharmacy in a 10-minute consultation? And to be fair to patients you can't, so you spend longer and therefore your day is longer, and you know, that's the nature of the job, but it does contribute to an increased workload.[802(p288)]

Competing demands in multimorbidity care often left general practitioners just enough time to focus on acute concerns.[706] They might, therefore, put off tackling more time and resource-intensive processes such as medication reviews or deprescribing.[794] Under time pressures, they might also deprioritise discussing non-pharmaceutical or behavioural approaches to prevention such as weight loss or exercise.[780, 781, 801] ‘When you see the obese person limping in with a sore throat [you ask]: “Do you have a sore throat?” [and ignore the limp].’[802(p290)]

Dealing with the most pressing medical priorities in the course of a standard appointment also limited the general practitioner's ability to focus on the patient's concerns.[804] ‘To be honest, you often get that sense [of opening Pandora’s box], and you don’t say anything, because you know you’re at the beginning of the afternoon or whatever.’[802(p290)] This might include their current treatment preferences[794] as well as their longer-term priorities and goals of care.[806] Some general practitioners believed that this constant ‘rationing out time’[795(p51)] had a detrimental effect on their performance,[802, 804] perhaps even putting patient safety at risk. This concern was evident regardless of general practitioner length of time in practice and clinic location.

General practitioners also described payment systems that did not adequately compensate them for the level of care required by their patients.[780, 781, 794, 804, 806] This issue appears to hold sway regardless of whether the primary care model of remuneration was fee-for-service, pay-for-performance, capitation, or a mixed model. Any incentives provided were not proportionate to the extra time required for consultation, follow up, and medication review.

Some participants used emotive language in describing the effect of this workload on their resilience, confidence, and motivation, especially when patients seemed to make few health gains.

> Not worn down, that's not the right word, but they are difficult to manage because they don't seem to get any better and then obviously that has a psychological impact probably on the doctor and on the patient.[786(p5)]

Others used terms such as 'burn-out',[797(p9)] 'exhausting',[795(p52)] 'demoralising',[795(p52)] 'draining',[796(p7)] 'overwhelming'[796(p8)] and 'soul destroying',[795(p52)] or described feeling like a 'wrung out rag'.[795(p52)] Conversely, a few general practitioners working in more deprived areas felt 'energised rather than de-energised' and emphasized 'the privilege and rewards' of supporting complex multimorbidity patients.[795(p52)] One general practitioner described the need to try and find something positive in the work for the sake of 'sanity', or else it meant accepting that 'there's a group of people whose lives you can't change, so don't try.'[795(p52)]

4.6.2.4 Strategy theme 1: Prioritising a patient-centred approach to care

Across all 33 studies, general practitioners described the importance of having and maintaining a good relationship or 'partnership' with their patients. Many prioritised this relationship above all other aspects of care. They believed an excellent relationship produced better communication during the consultation and improved patient outcomes over the long term. It also provided a solid foundation for garnering knowledge of patients and their specific life circumstances. This enhanced knowledge might then translate into individually tailored care for each patient based on a richer understanding of patient difficulties, treatment preferences, life goals and personal values.

Building and safeguarding a continuous patient-general practitioner relationship

General practitioners prioritised building and maintaining a long-term, continuous therapeutic relationship with their patients with multimorbidity, viewing this relationship as a prime facilitating resource for patient care.[706, 781-783, 787, 788, 791, 792, 795, 797, 798, 800, 802, 803, 805, 806] It enabled general practitioners to see the patient beyond the level of a presenting illness. It could also provide insights into aspects of the patient's social circumstances and individual psychology that threatened therapeutic acceptance and success. A long-term partnership was also a counter against the short consultation times within which general practitioners had to operate. Seeing a patient over a long time allows general practitioners to work at a slower pace, 'chipping away' at providing better follow up, monitoring the safety of any medication changes, and gradually introducing self-management skills.[783]

> So it does make it easier when you do build up that relationship with patients, that you do see the same ones for these conditions, because then you realise, partly you don't have to deal with it all in one go, these are chronic conditions and you are going to be seeing this patient regularly, they build up that trust with you that they can come out with things that are bothering them, and that very, very frequently happens.[783(p582)]

A general practitioner's knowledge about a particular patient could serve as a frame of reference, adding a sense of security and confidence to assessment and decisions.[790]

> I think, if it is somebody who I know, I know their background, what the plan is and where we are heading, I am involved in the care relationship with them, that gives me confidence.[781(p1942)]

This knowledge could also provide a dependable 'baseline of well-being'[805(p1060)] with any deviations from this baseline sending up 'contextual red flags'.[790(p3115)] General practitioners might call this their 'intuition'[788(p6)] or 'gut feelings'.[781(p1944)] General practitioners also valued the trust that often came with relational continuity:

> I think that you need to gain the trust of the patient, and that trust can be gained, I think, by showing interest, by talking with them about the social context.[792(p506)]

This trust could extend both ways with general practitioners trusting the knowledge patients were able to contribute to the decision-making process: '" Which drugs do you think are responsible?" Patients are mostly right.'[800(p4)]

Preserving the relationship was often deemed so crucial in the management of multimorbidity that general practitioners prioritised its safeguarding above communicating bad news or changing a suboptimal course of therapy.[706, 791, 800, 803] This could lead to trying to please the patient by 'going down the path of least resistance'[791(p5)] or avoiding discussing poor prognosis for fear of affecting the relationship.[800] Conversations around discontinuing preventative medicines were considered particularly risky as general practitioners worried that patients might perceive them as giving up on the relationship[706, 800] or 'writing them off'.[780(p11)]

The therapeutic relationship appeared particularly intense in socially deprived areas, with one participant likening the role to that of a 'priest' or a 'friend'.[795(p51)] However, other general practitioners working in deprived areas discouraged this level of familiarity, particularly with patients perceived as having 'chaotic lives',[795(p50)] and 'entrenched social problems'.[795(p51)] They spoke of the need for boundaries or limits between care of the medical and the social aspects of a patient's life.

These general practitioners felt long term interaction might risk patients becoming too dependent on the relationship,[795, 798] consuming the general practitioner's time with little expectation of improvement in the situation.[798]

Working with patient and caregiver values, goals, and priorities

General practitioners appeared to understand the highly individual nature of patient goals and values, accounting for them in the management plan:[706, 727, 779, 780, 787, 789, 790, 792, 793, 803, 805, 807]

> I [need to] get a better complete idea about the background, that is, what’s the priority of this old lady, what’s the priority of this man…. [If] I get a better idea [of the background] this will solve many problems.[804(p124)]

Eliciting patient goals and preferences could often be an intuitive, rather than systematic, process that once again rested on the foundation of a general practitioner-patient relationship.[788] General practitioners were particularly attentive to the goals and preferences of older patients and those with significant multimorbidity, understanding that goals could change quickly with fluctuating conditions and as the end of life approached.[727] Optimising quality of life then became the leading medical goal.

Some general practitioners described decision-making as a somewhat shared process with the general practitioner in the role of an advisor: 'You have to go “this is your life, your decision” and then give them my advice but they have to make the decision for themselves.’[706(p188)] However, not all general practitioners across the studies expressed the importance of eliciting and prioritising patient goals.[794, 800, 807] Some remained focused on clinical issues—often prevention efforts—stating what they viewed as necessary without reference to patient preferences. The extent to which general practitioners involved the patient or family in discussion and decision-making was also variable: 'If it is an important decision, then I'll involve the family. But with some decisions, the family don't need to know everything.'[780(p7)] Several general practitioners believed that some patients preferred to be excluded from decision-making processes: 'I just worry about it myself … rather than imparting a huge amount of knowledge.'[706(p188)]

Tailoring care to each patient

General practitioners described using their knowledge of a patient's unique circumstances to individualise care, even if that meant deviating from the straightforward application of a guideline recommendation.[785] Having this ‘whole picture’ at their disposal allowed general practitioners to be more pragmatic in their approach to management and especially self-care as they weighed up a patient’s capacity to meet the financial, emotional, and physical burden imposed by any care strategy:

> When you have known people for so many years then you really do not need to ask very much about self-care, because you know their work situation, who they are married to, their children and all these things.[787(p4)]

The understanding that comes with relational continuity led many general practitioners to express empathy for their patients in their illness experience: ‘I worry that what we increasingly ask people to do is something we have got no experience of ourselves ... We’re telling them to do some impressively horrible things.’[795(p49)]

4.6.2.5 Strategy theme 2: Managing the consultation

Some general practitioners described strategies for the consultation that ensured action, rather than passivity, and came with built-in insurance against risk for both patient and general practitioner.[706, 781, 783, 790, 801, 805, 806] One strategy was to offset some of the uncertainty by ‘broadening the loop’ to include other healthcare professionals in the care of a complex patient.[706]

> [T]o bounce [ideas] off your colleagues just helps, even if it is just something like ‘what in the name of God am I going to do about this’, it’s really important.[788(p188)]

Another common approach across studies was first to prioritise patient problems within a consultation, then manage them sequentially until the consultation time ran out. The general practitioner then deferred the patient's remaining problems for a subsequent consultation.[706, 781, 783, 806] Bower et al.[783] call this priority-based, sequential method for dealing with the multiple issues thrown up by multimorbidity ‘the additive-sequential’ approach.

> If they've got several conditions and several conditions need addressing, then you're limited in what you can do in one consultation slot. You get to know them and maybe next time you might say something like, 'can you make a double appointment next time?' So it gives them that little bit longer. Or ask if they can come back; you do what you can within your time, usually go over time and then get them to come back for the rest if they haven’t managed to achieve everything.[783(p582)]

For general practitioners, this process could generate a sense of ‘having time’, alleviating some of the stress associated with inadequate consultation length for complex problems.[805] It could also buy more time to deal with diagnostic or therapeutic uncertainties as the general practitioner has a more extended period to observe patients for adverse reactions or therapeutic benefits.

Chiefly, however, it could aid to build greater relational continuity and the trust that can come with it.[806] These benefits were regarded as especially useful for the diagnosis of depression in patients with multimorbidity[805] and when educating patients about self-management, as all information need not be imparted in one go.[805]

General practitioners might also use 'safety netting' as a risk mitigation strategy within the consultation when uncertain of the best course of action but concerned for patient safety. Here, general practitioners prioritised their own agenda for the consultation over that of the patient,[806] advising the patient on symptoms to watch for and building contingency plans if the patient's condition worsened between consultations. General practitioners also employed 'satisficing' in decision-making under conditions of uncertainty.[706, 781, 806] Sinnott et al.[706(p186)] define this as ‘settling for chronic disease management that was satisfactory and sufficient, given the particular circumstances of that patient.’ This approach was evident whenever general practitioners discussed relaxing targets or deviating from guideline recommendations (the ‘ideal’) to base care on patient goals and preferences. 'I think, not perfectly managed, but managed well enough within that person's individual parameters.'[806(p4)] Satisficing might allow general practitioners to factor in patient self-care ability, as well as life expectancy:

> I’m not aiming for very tight control — I’m happy if his sugars are running a little higher than normal. I mean he has got cardiac failure as well, his life expectancy isn’t brilliant — so long term I think, I don’t think it’s his type 2 diabetes that’s going to kill him.[706(p186)]

A further strategy described by general practitioners was to look for synergies between patient conditions and focus the management plan on treating a common causal pathway. This plan could then be sold to the patient as a solution to more than one of the patient’s problems.[803, 806]

4.7 Discussion

This review demonstrates that general practitioners find inadequate guidelines and fragmented healthcare systems built around single disease states challenging. While it confirms findings from an earlier review,[107] importantly, it identifies additional themes around general practitioners’ pragmatic strategies for circumventing or managing these challenges. The findings make clear that general practitioner views are framed by their specific national or regional policy levers which affect them at the level of their practice. For example, such levers might dictate if, and how, general practitioners refer patients to services such as Disease Management Programs in Denmark[788] or nephrologists in the United Kingdom.[782] They might stipulate how the care provided to nursing home patients will be reimbursed[780] while regulating the evaluation of care quality by linking it to clinician performance incentives.[783, 809] Yet even though there are local and national differences in these examples, this synthesis shows the common experience for general practitioners in terms of problems faced and approaches for dealing with them.

Overall, general practitioners associated multimorbidity with complexity and uncertainty. While uncertainty in the face of undifferentiated clinical and psychosocial problems is not uncommon to the general practitioner,[401] manifold knowledge gaps around multimorbidity persist in general practice,[49] which can produce a sense of emotional strain and ‘heart sink’.[786(p7)] General practitioners perceived the existing evidence as insufficient or inappropriate for answering their clinical questions for patients with multimorbidity. They also revealed a cautiousness in strictly adhering to guideline recommendations for these patients through awareness of the potential for iatrogenic harm, overtreatment with little tangible benefit, and increased patient burden of care.[235] Their use of terms such as ‘risk’, ‘insecurity’, ‘anxiety’, and ‘fear’ to describe their decision-making experiences shows insecurity in both prescribing decisions and questions of when to cease unnecessary or harmful therapies. The research literature confirms general practitioners' perception of a lack of safe deprescribing guidance.[810]

Although general practitioners may be aware of the limitations of the evidence, some expressed a preference for adhering to guidelines as they represented security, viewing decisions based on one's clinical judgement as a riskier enterprise. This tension was particularly notable in places where regulatory bodies have linked payment or professional accreditation to reaching a range of evidence-based quality indicators. It has been widely suggested that these indicators may be less appropriate for patients with multiple conditions as they do not capture the complexity and dynamism of the multimorbidity experience.[213] Furthermore, the outcomes captured by the indicators may not reflect the priorities of patients themselves.[811] For these reasons, alternative evidence-based quality assessment frameworks for complex patients have been proposed or are being developed. These might measure and incentivise continuity of care,[812] patient preferences and values,[213] or use patient-reported indicators to capture the patient’s primary care experience and outcomes.[813]

The review shows that gaps or delays in communication from specialists to general practitioners and specialist inaccessibility to general practitioners are critical system failures that persist despite technological advances such as the shared Electronic Health Record. These inter-professional communication failures provide the general practitioner with an added but avertible source of uncertainty as the specialist's intentions for a patient must be interpreted to minimise treatment conflicts.[814, 815] This problem is not only felt by general practitioners. It can also impact negatively on patients' self-reported perceptions of their care.[212, 816-818]

Policies shaping the organisation of care delivery can have a disruptive impact on the patient consultation by creating a care context 'structured and incentivized to support short clinical interactions and disease focused care.'[819(p1)] This approach is at odds with the principles of patient-centred care endorsed by health systems. It is also discordant with the everyday reality of clinical practice where increased patient complexity requires more, not less, time and interaction with the general practitioner. The additive-sequential model described by Bower[783] could, therefore, be considered a deferment tactic indicative of a workload problem rather than an effective approach to patient care. Currently, general practitioners in the United Kingdom face increasing workloads[820] and the strain of trying to meet the higher volume and intensity of work is said to portend a crisis of general practitioner retention.[821] General practitioners have attributed their widespread low morale and exhaustion to limited time and resources for dealing with increased patient complexity, together with non-commensurate financial rewards.[822] Lack of time to deal with the problems faced in general practice and high rates of general practitioner psychological stress were recently highlighted as concerns in Australia as well.[413, 823]

Despite the strong association of multimorbidity with aging populations, only two studies focused on general practitioner care provision for residential aged care patients with multimorbidity.[780, 808] Here again, general practitioners conveyed a sense of hopelessness in achieving a reasonable standard of care for their patients due to time pressures, poor communication between care providers, inefficient local systems and policies, and perception of multimorbidity care as being beyond the skill level of some nurses. Primary care models and their associated financial incentives also appear to impact general practitioner satisfaction with their residential aged care duties.

Similarly, few general practitioners described any challenges to multimorbidity care when older patients approached or reached the end of their life. For some, a consideration of advanced age enabled them to factor life expectancy and time to benefit into deprescribing decisions. Expressions of concern for the older person’s quality of life were also present in the data, most notably in respect to patients with chronic kidney failure.[807] Here, the presence of comorbidities or advanced age could influence a general practitioner’s decision to not recommend patients to nephrology or renal replacement therapy out of regard for their quality of life.

Despite the many challenges they confronted, general practitioners saw themselves as having an essential role in managing patients with multimorbidity. The views conveyed within the data strongly support the general practice ethos of providing whole person care with its emphasis on the biopsychosocial context and the importance of family and community. General practitioners expressed concerns for patient safety and well-being that align well with the concept of the patient-centred consultation as operationalised by Stewart.[92] General practitioners strove to understand the patient’s illness experience; see the whole person in context; find common ground; and enhance the doctor-patient relationship through, for example, compassion and the gaining of trust.[581] The approach described by many general practitioners in the study also resonates with the Sage Consultation Model of the 'expert generalist', which takes an inductive, data-driven approach to decision-making by combining information from research, patient, and professional to 'co-create an individualised account of illness'.[824(p207)]

Most strikingly, general practitioners' attitudes aligned firmly with the WONCA statement that general practitioners work by 'utilising the knowledge and trust engendered by repeated contacts'.[14(p9)] This was clear from the importance general practitioner participants placed on relational continuity, appearing to safeguard it in the face of protocolised targets and guidelines. General practitioners might value the longitudinal interpersonal relationship with a patient for quite pragmatic reasons, including its usefulness as a simple and powerful tool for addressing multimorbidity.[825] It could be relied on as an essential source of accumulated knowledge of the patient—one existing beyond the limitations of an inflexible or sparsely populated electronic patient record.[826] This knowledge might impart perceived security to difficult diagnostic decisions by giving context to any signs of change or deterioration. As Sturmberg[827(p884)] states: ‘The ongoing doctor-patient relationship is a necessary a priori to the creation of shared memories, stored as tacit knowledge …’ for this knowledge grants the general practitioner the ability to ‘discriminate between information and noise’ in a patient’s narrative. In addition to this accumulative knowledge benefit, the research evidence supports the importance of interpersonal continuity of care for downstream effects such as decreased mortality,[383, 828] reduced emergency visits,[829] and hospitalisations,[381] and a greater sense of patient satisfaction with care provision.[377, 830]

4.7.1 Study strengths and limitations

This synthesis was conducted according to a rigorous methodology to minimise the potential for bias. The breadth and credibility of the findings were enhanced by including the first-hand accounts of 593 general practitioners representing 14 countries. Furthermore, the synthesis employed a broad search strategy and inclusion criteria to ensure that perspectives on multimorbidity came from as many vantage points as possible without veering away from the research question. Studies, therefore, reflected diverse concerns such as prescribing, deprescribing, use of guidelines, self-care, patient management, and decision-making. When collated and synthesised in the one review, the variety of voices and foci have arguably created a stronger and more multidimensional representation of the issue under investigation than any individual study could. Supervisor input when developing analytical themes was also important for the review's credibility as it reduced bias associated with single investigator interpretation and introduced interdisciplinary triangulation.

Restricting the results to countries with similar models of general practice may be both a strength and limitation. While it made it easier to compare studies meaningfully, a future study might involve a cross-country comparison using the included versus the excluded country studies. Furthermore, the primary data on which these findings are based have already been selected and interpreted by other researchers. Without access to the complete data originally obtained from participants, it is unknown if other quotes exist that better support these findings or ably refute them.[831] That said, the richer the data provided in the original papers and the stronger the methodology used, the more likely the researcher's findings, also analysed in the synthesis, represent the totality of the data. The quality appraisal process found most of the studies in this review strong on both these attributes. Furthermore, the general practitioner quotes only represent what general practitioners say they think and do. Some reflections may describe aspirational beliefs, values, or actions rather than actual ones. The close focus on the topic of multimorbidity may have also led general practitioners to overestimate the problems or underestimate their handling of them.

4.8 Conclusion

This study used a qualitative design to explore general practitioner perceptions of the challenges they confront in providing frontline care for patients with multimorbidity. General practitioners expressed a need for greater support in providing the generalist, patient-centred care required. This support should include better communication and collaboration from other specialists and appropriate evidence to guide decision-making. General practitioners also highlighted the valuable role relational continuity plays in making sound and safe therapeutic decisions that accord with each patient's circumstances and preferences. Therefore, there should be a widespread acknowledgement that, at times, general practitioners need to prefer clinical judgment over clinical guideline adherence when they consider the evidence to be not in the individual's best interests.

Four of the thirty-three studies included in this synthesis involved Australian general practitioners. However, these explored the issue of multimorbidity from a range of divergent perspectives. These were patient management, depression, guideline use in remote Australia, and deprescribing. It is difficult to draw general conclusions on the Australian general practitioner experience based solely on these primary studies. Therefore, findings across all studies will inform the development of an interview schedule for interviewing Australian general practitioners (Chapter 6). This will then determine if the experiences described here by general practitioners working in countries with similar primary care systems can be generalised to the Australian context. It will also seek any disconfirming findings suggestive of issues peculiar to either the overseas or Australian experience.

This chapter has reported the findings of a systematic review of qualitative studies examining the experiences of general practitioners from multiple countries in managing the care of people with multimorbidity. Moreover, it has also described the strategies they employ when faced with difficulties. The next chapter investigates the degree to which Australian clinical practice guidelines acknowledge comorbidity (or multimorbidity) in providing recommendations to general practitioners on the management of life-limiting chronic conditions. It also explores the support provided by these guidelines for general practitioner palliative and end-of-life care considerations.

CHAPTER 5 MULTIMORBIDITY THROUGH THE LENS OF LIFE-LIMITING ILLNESS: HOW HELPFUL ARE AUSTRALIAN CLINICAL PRACTICE GUIDELINES TO ITS MANAGEMENT IN GENERAL PRACTICE?

5.1 Chapter preface

The preceding chapter reported the findings of a systematic review and qualitative synthesis of general practitioner perspectives on the management of patients with multimorbidity. This included the finding that general practitioners operating across similar primary care systems worldwide view clinical practice guidelines as difficult to apply to patients with multimorbidity. A lack of generalisable evidence could induce uncertainty and a sense of insecurity as general practitioners worried about the cumulative impact of recommendations on patient safety and coping.

This current chapter focuses the research on the Australian context. It reports a content analysis of Australian clinical practice guidelines for life-limiting chronic conditions to quantify their acknowledgement of comorbidity and examine the messages they convey regarding its significance for management decisions. It also reports an evaluation of the palliative care content of each guideline. This sought to determine how guidelines might support the work of generalists administering care to people with multimorbidity during the last phases of a condition's trajectory.

5.2 Publication of this study

Modified versions of this chapter formed the basis of two published journal articles which are both provided as Appendix A2.1. These are:

1. Damarell RA, Morgan DD, Tieman JJ, Healey DF. Multimorbidity through the lens of life-limiting illness: How helpful are Australian clinical practice guidelines to its management in primary care? Aust J Prim Health. 2021 Jan 19;27(2):122-9. doi: 10.1071/PY20164
2. Damarell RA, Morgan DD, Tieman JJ, Healey D. Bolstering general practitioner palliative care: a critical review of support provided by Australian guidelines for life-limiting chronic conditions. Healthcare. 2020 Dec;8(4):553. doi: 10.3390/healthcare8040553.

The researcher (RD) contributed to 100% of the work of this study, being involved in all phases of its execution. However, she was assisted in dual reviewing guideline content by DH (10%) and guideline quality by DM (10%). Both her supervisors also advised on the methodology and provided feedback on the final draft of the chapter.

The second article has been cited by: Tieman J, Lewis V. Benefits of structured engagement with target audiences of a health website: study design for a multi-case study. Healthcare. 2021 May;9(5):600. doi: 10.3390/healthcare9050600.

5.3 Context for this content analysis

Multimorbidity is heterogeneous in that a chronic index condition might be accompanied by any number of unrelated (or ‘dissonant’) conditions or conditions with an overlapping pathophysiologic risk profile (‘concordant’).[832] It is therefore unrealistic to expect clinical practice guidelines to address every chronic disease combination and permutation. However, guidelines for conditions prevalent in older people and expected to lead directly to death are uniquely positioned to frame their therapeutic recommendations in terms of limited life expectancy and the ageing physiology. This framing might serve to anchor clinician decision-making, shifting the perspective away from an imperative to add more potentially beneficial care towards the possibility of removing care no longer likely to be of benefit. Guidelines for life-limiting conditions might also emphasise the importance of providing patient-centred care to people as they near the end of life. This means prioritising concerns for treatment burden, quality of life, and the exploration of patient and family goals and preferences for care. At a minimum, these guidelines could address potential interactions between medications for conditions that commonly cluster together, for example chronic kidney disease and diabetes.

Guidelines for life-limiting conditions might also help normalise and demystify palliative and end-of-life care for Australian general practitioners. While there is an expectation that general practitioners will provide non-specialist palliative care in the community as part of their role,[9] a considerable proportion of Australian general practitioners (25% to 37%) report not doing so.[465, 833] Reasons given for this include role uncertainty when other specialists are involved in care,[456, 465, 834, 835] time pressures,[287, 836, 837] and lack of confidence or skills.[466, 838, 839] Likewise, many general practitioners find it difficult to identify the point at which active disease management should transition to end-of-life care[834] and view the task of communicating prognosis and uncertainty to patients as challenging.[287] Non-malignant conditions such as heart failure, dementia and COPD appear to be particularly problematic as their less predictable trajectories can generate prognostic uncertainty for general practitioners.[287, 290, 840]

Here guidelines might help general practitioners by, for example, informing them of established decision aids, tools, strategies, and prompts such as the Supportive and Palliative Care Indicators Tool (SPICT) for early detection of palliative care needs.[841] They might also provide guidance on how to consider and manage comorbid conditions during the end-of-life phase.

Clinical practice guidelines could therefore be an opportunistic source of support for general practitioners faced with decisions made more challenging by multimorbidity. However, the extent to which Australian guidelines currently provide such support across the active and end-of-life management phases is unknown. This remains a significant issue given the population is not only ageing but dying older with more complexity arising from accumulating morbidities.

5.4 Aims

This study aimed to determine if and how Australian clinical practice guidelines acknowledge or address the management of multimorbidity in the context of life-limiting illness and general practice. It also assessed the scope of support provided for general palliative care provision.

5.5 Methods

5.5.1 Ethics approval

As a content analysis, this study did not require ethics approval.

5.5.2 Guideline eligibility criteria

Guidelines and evidence summaries were eligible for analysis if they met the definitions and production and content criteria described below.

5.5.2.1 Production criteria

Eligible guidelines and evidence summaries are those produced for a national Australian audience during or since 2012 and providing an explicit report of their methodology. Guidelines are defined as:

> [S]tatements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options.[6(p4)]

Unlike guidelines, which often address care for a condition across its full trajectory, an evidence summary is a short ‘overview of the available evidence addressing a research question or set of questions related to a single topic …’[842(p2)]

For this analysis, guidelines and evidence summaries must state the basis on which practice recommendations were formed. This might be 'expert consensus' where there is little or no evidence available, or 'evidence-based recommendation' where evidence has been weighed for its quality and strength. This criterion ensures that all included resources are comparable in meeting a minimum standard of reporting quality for gauging trustworthiness. It also aligns with the expectations of critical appraisal tools such as AGREE-II and national agencies responsible for endorsing guidelines, for example the National Health and Medical Research Council (NHMRC).

5.5.2.2 Content criteria

Resources had to be explicitly relevant to general practitioners and not targeted solely at a different specialist audience. They also needed to focus on the therapeutic management of a chronic, life-limiting condition in adults. A *life-limiting illness* is one where death is expected to be direct consequence of a specified illness.[253] This might include cancer, forms of organ failure, and neurodegenerative conditions. Guidelines for the care of frail elderly or palliative populations where a high prevalence of multimorbidity might be expected were also eligible. Acute stroke and chronic conditions such as diabetes, which may contribute to mortality without being the direct cause, were not included.

5.5.3 Search for guidelines

A comprehensive search for published and unpublished guidelines and evidence summaries was undertaken. The search strategy was originally developed and tested within Ovid Medline and then translated for Embase (Ovid), Joanna Briggs Institute EBP Database (Ovid), PubMed, Scopus, and Web of Science. A variety of simple keyword searches were conducted within online guideline repositories, organisational websites, and Google which do not support complex search construction. Database citations were downloaded into EndNote X8 for screening while items found via internet searches were entered into an Excel spreadsheet. The Ovid Medline search strategy and a list of websites targeted by the search are provided as Appendices A2.2 and A2.3.

5.5.4 Guideline selection

Screening of guidelines and evidence summaries proceeded in three stages: (1) The researcher screened titles and abstracts to determine broad relevance; (2) the researcher then assessed retained items against the *production criteria* described above; before (3) a general practitioner (DH) was invited to review the short list of full text documents against the *content criteria*.

5.5.5 Content analysis of guideline content

Guideline data were analysed using the content analysis method. This method allows the researcher to systematically code and categorise the content of documents using a qualitative or quantitative approach[740] but without the need to transform categories into higher level conceptual constructs.[843] Content analysis also supports inductive and deductive coding and categorisation[844] and the application of different coding frames to the same text to highlight different aspects of it.[740]

This study coded data deductively against two different coding frames: one for assessing comorbidity acknowledgement and another for categorising palliative care content. Prior to this, the full text PDFs of included resources were imported into NVivo 12 Pro (QSR International). The researcher read guideline content in its entirety, line-by-line, and where appropriate coded text against the relevant coding frame.

5.5.5.1 Assessment of comorbidity acknowledgement

The comorbidity coding frame was an existing 17-item checklist originally developed by Boyd[100] and later extended by Fortin[101] (hereon 'the checklist'). This checklist focuses on a broad range of concerns with relevance to multimorbidity care. It is organised into six domains. Four of the six reflect evidence-based practice concerns, asking if (1) comorbidity is acknowledged somewhere in the guideline; (2) the quality of comorbidity evidence is discussed; (3) acknowledgement occurs within a guideline recommendation; and (4) advice is provided on potential adverse effects of medications. This study defined a 'recommendation' as a directive statement upon which clinicians can act. Recommendations may be based on evidence, consensus or exist as opinion-based 'practice points.' The remaining two of the six domains ask if the guideline addresses patient-centred concerns such as burden of treatment and cost to the patient, the importance of patient preferences, and consideration of patient quality of life.

The researcher and a general practitioner content expert individually applied the checklist against the extracted, coded content, with each checklist 'yes' answer scoring a point, up to a maximum total of 17 points per guideline. Scoring differences were discussed until reviewers reached consensus.

5.5.5.2 Assessment of palliative care content

In addition to coding against the checklist items, the researcher coded guideline content against two broad data nodes: 'palliative/end-of-life care' and 'communication'. The communication node provided a place to capture more generic communication advice which may have non-exclusive relevance for palliative care. An example might be the importance of providing information to culturally and linguistically diverse patient groups in their own language.

The candidate then mapped all palliative/end-of-life care and communication data against the domains of the PEPSI-COLA palliative care framework.[845] (See Table 5.1.) This aide memoire was developed out of the Gold Standards Framework,[846] which is a practical and systematic approach for delivering end-of-life care within the community and now widely implemented across the United Kingdom's primary care sector.[847] Although the PEPSI-COLA framework is not a validated tool, it was designed to help general practitioners remember the key aspects of comprehensive and whole-person palliative care and aligns well with WHO's definition of palliative care.[22] Guideline palliative care content that did not fit into the PEPSI-COLA framework was analysed inductively and listed separately.

Table 5.1 PEPSI-COLA aide memoire for palliative care patient assessment

Domain of need	Considerations
Physical	Physical needs, including symptom control and prevention and/or relief from medication side effects.
Emotional	Emotional needs, including psychological assessment, understanding patient wishes for information, mood, anxiety, coping, fears.
Personal	Personal needs, including cultural, language, religious, or spiritual needs. Also includes concepts of quality of life, values, beliefs, and dignity.
Social support	Social care needs of patient and carer(s). Includes practical concerns such as managing at home and at work, financial concerns, family and close relationships, social life and recreation, and concern for dependents.
Information & communication	Information and communication needs within the health care team: between clinicians, to and from patient, and to and from carers.
Control & autonomy	This includes assessing mental capacity to make decisions around choice, determining the person's preferences for treatment options, and advance care

	planning.
Out of hours & emergency	Identifying and establishing contacts for ensuring continuity of care after-hours. This includes informing patient and family of arrangements, letting after-hours general practitioners/locum services know of patient's needs, and ensuring patients and carers have access to medications and equipment for when required.
Late care	Care considerations at the very end of life. This might include stopping non-urgent medications, communicating stage of condition to patient and family, alerting them to what might happen (e.g., rattle, agitation), providing comfort measures, and death pronouncement.
After care	Bereavement needs including bereavement risk assessment and follow up with the family.

5.5.6 Quality appraisal

To strengthen the credibility of this study, two independent assessors—the researcher and her supervisor (DM)—appraised the quality of each full guideline using the validated Appraisal of Guidelines Research and Evaluation (AGREE II) critical appraisal instrument.[848] When scores on one of the tool's domains varied more than three points, appraisers discussed their decision with the goal of reducing the gap in scores. Final domain scores were calculated according to the tool's instructions. Evidence summaries were not appraised as these were not expected to be produced or reported to the same level of detail as full clinical practice guidelines. The AGREE-II guideline critical appraisal tool is provided as Appendix A2.4.

5.6 Results

Database and web resource searches were conducted 15-22 August 2018. These together identified 1201 unique resources. After title and abstract screening, 116 documents remained to be checked for eligibility based on their full text. Full text screening reduced the set to 11 documents. The full selection process is shown as a PRISMA flow diagram (Figure 5.1).[849]

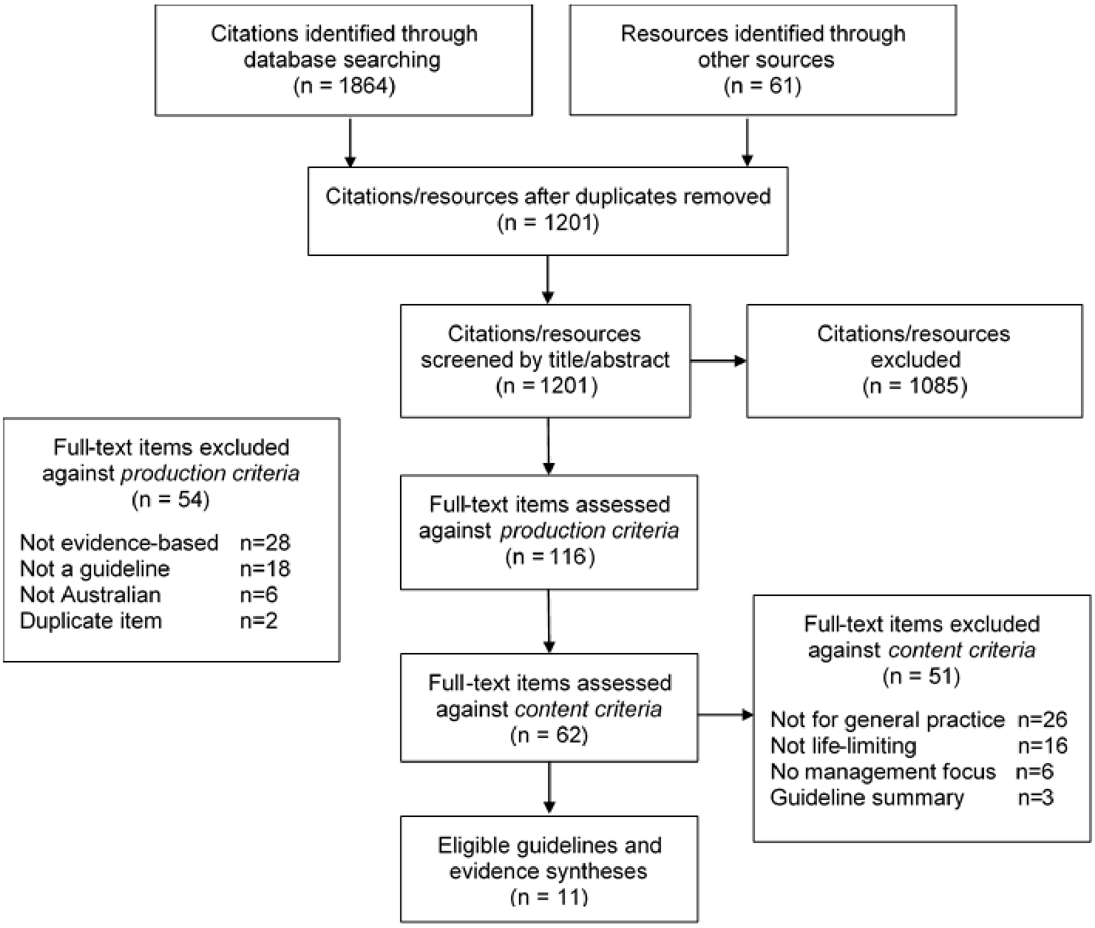

Figure 5.1 PRISMA flow diagram of screening process for guideline inclusion

5.6.1 Characteristics of included guidelines and evidence summaries

The eleven documents for analysis included six full guidelines,[850-855] a guideline summary for general practitioners,[856] and four evidence summaries.[857-860] These covered the management of heart failure,[850, 859] chronic obstructive pulmonary disease,[854-856] dementia,[852, 853] cancer,[851, 857, 860] and palliative care in aged care.[858] All resources were freely available online in PDF or HTML format with the exception of *Cancer survivor: Exercise and physical activity* which sits behind a database paywall. The length of the full guidelines (PDF) varied considerably, ranging from 20 to 210 pages. General practitioner involvement in guideline development was noted for most resources apart from cancer pain,[851] pulmonary rehabilitation,[855] and cancer survivor exercise and physical activity.[857] Included resources and their characteristics are shown in Table 5.2.

Table 5.2 General characteristics and checklist scores of included resources

Title (date)	Development organisation	Description	Length in pages	No. of checklist criteria satisfied
Guidelines for the prevention, detection, and management of heart failure in Australia (2018)[850]	National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand	Full guideline (update)	86	14/17
Cancer pain management in adults (2013)[851]	Australian Adult Cancer Pain Management Guideline Working Party and Cancer Council Australia	Full guideline (adapted)	NA (Online, HTML)	6/17
Clinical practice guidelines and principles of care for people with dementia[B] (2016)[852]	Cognitive Decline Partnership Centre. Guideline Adaptation Committee	Full guideline (adapted)	136	12/17
Evidence-based clinical practice guideline for deprescribing cholinesterase inhibitors and memantine in people with dementia[B] (2018)[853]	University of Sydney, Cognitive Decline Partnership Centre, and Bruyère Research Institute	Full guideline (new)	132	12/17
The COPD-X Plan: Australian and New Zealand guidelines for the management of chronic obstructive pulmonary disease (2018)[854]	Lung Foundation Australia and the Thoracic Society of Australia and New Zealand	Full guideline (update)	210	15/17
Australian and New Zealand pulmonary rehabilitation guidelines (2017)[855]	Lung Foundation Australia and the Thoracic Society of Australia and New Zealand	Full guideline (new)	20	3/14[A]

COPD-X concise guide for primary care (2017)[856]	Lung Foundation Australia, the Thoracic Society of Australia and New Zealand, and Royal Australian College of General Practitioners	Guideline summary	40	9/17
Cancer survivor: Exercise and physical activity (2017)[857]	Joanna Briggs Institute (JBI)	Evidence summary	3	5/14[A]
PalliAGED: Palliative care aged care evidence. Evidence summaries (2017)[858]	PalliAGED Evidence Advisory Group	Evidence summary	NA (Online, HTML)	12/17
Exercise based rehabilitation: Heart failure (2016)[859]	RACGP Handbook of Non-Drug Interventions (HANDI)	Evidence summary	5	6/14[A]
Exercise: Cancer fatigue (2016)[860]	RACGP Handbook of Non-Drug Interventions (HANDI)	Evidence summary	2	1/14[A]

[A] Non-pharmacological management resources excluded from medications scoring (i.e., maximum possible score is 14, not 17)
[B] Guidelines endorsed by the National Health and Medical Research Council (NHMRC)

5.6.1.1 Comorbidity acknowledgement across guidelines

Table 5.3 shows the total number of guidelines and evidence summaries meeting each of the 17 Boyd/Fortin checklist criteria. The completed Boyd/Fortin checklist criteria are provided as Appendix 2.5.

Acknowledgement of comorbidity

Most resources (9/11) acknowledged comorbidity as an issue for treatment somewhere in their text, generally (‘comorbidities are common in people with …’) or as part of practical management advice. Fewer (6/11) resources raised ‘older age’ as a potential treatment modifying factor on its own and only three explicitly acknowledged the association between comorbidity and ageing.

Most resources (8/11) provided at least one recommendation addressing the management of a single comorbidity in addition to the index condition. Only the full COPD guideline addressed the management of two additional conditions.[854] No resource discussed the implications of managing more than two comorbidities simultaneously.

Patient/carer preferences and burden of treatment

Over half of the resources (6/11) acknowledged the potential burden of treatment for the patient while fewer (5/11) addressed time needed to treat to benefit in the context of life expectancy, despite all conditions being of a life-limiting nature. The potential for patient out-of-pocket costs was noted by most (7/11). All resources referred to patient quality of life, with most highlighting factors that might jeopardise or improve it. Most resources (10/11) also stated the importance of incorporating patient preferences into decision-making.

Advice on medications

Four resources focussed solely on non-pharmacological management of an index condition.[855, 857, 859, 860] The medication section of the checklist was therefore not applicable to them. Of the seven remaining resources, three addressed potential adverse interactions between medications in the context of comorbidity.[850, 853, 854] Two specifically referred to ‘polypharmacy’ as an issue of concern.[853, 854]

Table 5.3 Number of resources addressing checklist criteria

Issues addressed		No. of guidelines addressing criteria
	Guideline addressed treatment for older patients	6/11
	Guideline addressed treatment for patients with multiple comorbid conditions	9/11
	Guideline addressed treatment for older patients with multiple comorbid conditions	3/11
Quality of evidence		
	Quality of evidence discussed for older patients	5/11
	Quality of evidence discussed for patients with multiple comorbid conditions	7/11
	Quality of evidence discussed for older patients with multiple comorbid conditions	2/11
Recommendations		
	Specific recommendations for patients with one comorbid condition	8/11
	Specific recommendations for patients with two comorbid conditions	1/11
	Specific recommendations for patients with more than two comorbid conditions	0/11
Burden of treatment		
	Time needed to treat to benefit from treatment in the context of life expectancy discussed	5/11
	Guideline discussed burden of comprehensive treatment on patients or caregivers	6/11
	Guideline discussed patients’ financial burden	7/11
	Guideline discussed patients’ quality of life	11/11
Patient preferences		
	Guideline discussed patient preferences	10/11
Medications[A]		
	Guideline discussed medications’ side effects	6/7
	Guideline is adapted to possible medications’ side effects	6/7
	Guideline discussed possible medications’ interactions related to comorbidities	3/7

[A] This section excludes n=4 resources focused solely on non-pharmacological management.

5.6.1.2 Comorbidity acknowledgement within individual resources

The final column of Table 5.2 provides the individual Boyd/Fortin checklist scores for each resource.

Acknowledgement of comorbidity

Individual resource scores ranged from 1/14 to 15/17. The full COPD guideline met most checklist criteria (15/17) followed by the heart failure guideline (14/17). While references to comorbidity were often diffuse throughout resources, the heart failure and COPD guidelines provided separate sections addressing specific comorbidities.

Strength and quality of the guidance

Most resources (8/11) provided at least one recommendation which might guide clinician decision-making when managing a single comorbidity. Of these resources, 7 provided recommendations directly accompanied by a grading or ranking of the evidence. The heart failure guidelines provided the most graded recommendations (n=11), followed by COPD (full) (n=10), cancer survivor exercise and physical activity (n=7), dementia (n=3), exercise-based rehabilitation for heart failure (n=2), and COPD (concise) (n=2). Rather than appraise the strength and quality of evidence accompanying specific recommendations, the PalliAGED resource provided a summary ('weak' or 'strong') of the studies informing its evidence synthesis on comorbidity.

Graded recommendations varied in their specificity and directiveness. The COPD guideline, for example, provided several general, non-directive graded recommendations such as 'Comorbid conditions are common in patients with COPD [evidence level III-2, strong recommendation]'[854(p66)] and 'The combination of COPD and obstructive sleep apnoea (OSA) is known as the "overlap syndrome" … [evidence level III-2].'[854(p75)] Heart failure guideline recommendations were more directive, for example: 'Thiazolidinediones (glitazones) are not recommended in patients with heart failure due to the risk that they will lead to worsening of heart failure (Weak recommendation AGAINST; moderate quality of evidence.)[850(p1176)]

While the COPD guideline discussed heart failure as a common comorbidity and vice versa, there was little overlap in the advice given for managing people with both conditions. For example, the heart failure guideline gave practice advice discouraging theophylline, oral corticosteroid, and beta-2-agonist use in patients with heart failure and COPD. However, this advice was not reciprocated within the COPD guideline which focused exclusively on the safety of beta blockers in the same population. Appendix 2.6 provides further examples of graded recommendations from relevant guidelines.

Patient/carer preferences and burden of treatment

Four resources met all criteria across the patient-centred domains.[852-854, 858] The two dementia guidelines were especially strong in their consideration of carers, frequently urging clinicians to consider the social and health care needs of the patient-carer dyad.[852, 853] Appendix 2.7 provides a selection of illustrative statements on burden of treatment, quality of life, and patient and carer preferences.

5.6.1.3 Palliative care content mapped to PEPSI-COLA domains

The PalliAGED evidence summary covered all domains of the PEPSI-COLA framework. It was also the only resource to advocate WHO's comprehensive needs assessment for ascertaining unmet physical, social, and occupational, psychological, and spiritual needs in the person with a life-limiting illness.[858] Mapping of resource content against palliative care domains is summarised in Table 5.4 with fuller details provided in Appendix 2.8.

Most comprehensively covered palliative care domains

The domains *information and communication needs*, *control and autonomy*, and *physical needs* were best covered across all guidelines although each resource took a different perspective to these issues. Firstly, the COPD (full), dementia, and PalliAGED guidelines provided detailed practical advice for managing specific symptoms while the heart failure guidelines did not address specific symptoms but prompted clinicians to refer patients with late-stage problematic symptoms to palliative care. All resources addressed the need to acknowledge and meet patients' information and communication needs, with most suggesting revisiting goals of care with the patient and family as the end of life approached and endorsing advance care planning. Few resources, however, discussed the appropriate timing of goals of care conversations. The importance of good communication between clinicians, patients, and families was a strong theme, although few guidelines addressed the value of clear and timely communication between health professionals for ensuring care continuity. This includes the importance of shared information between a person's general practitioner and other members of their care team.

Less comprehensively covered palliative care domains

Out of hours/emergency care and after care were more sparsely covered across the guidelines. The COPD (concise) and PalliAGED guidelines addressed the importance of ensuring continuity of care for patients outside of office hours. The COPD (full), dementia, and PalliAGED guidelines recommended families be followed into the bereavement period and assessed for needs. The importance of recognising patient emotional needs was mentioned in the COPD (full), cancer pain, and PalliAGED guidelines. The latter, however, provided an extensive coverage of the various interventions available for managing various psychosocial issues such as depression and anxiety.

Nature, strength, and quality of palliative care guidance

Two of the seven resources provided graded recommendations for palliative care content with the heart failure and full COPD guidelines recommending referral to palliative care for symptom control and improved quality of life early in the course of advanced disease.

> Referral to palliative care should be considered in patients with advanced heart failure to alleviate end-stage symptoms, improve quality of life, and decrease rehospitalisation. Involvement of palliative care should be considered early in the trajectory towards end-stage heart failure. (Strong recommendation FOR; high quality of evidence.)[850(p1185)]

The heart failure guideline rated this recommendation as strong and the evidence as high quality using the GRADE rating system while the same recommendation in the COPD guideline was designated ‘level II weak evidence’ using the NHMRC grading system. The dementia guidelines provided four expert opinion practice points for managing people living with dementia at the end of life. All other information about palliative care across the guidelines was provided within a literature review format.

Table 5.4 Mapping of guideline palliative care content against PEPSI-COLA framework

	Guidelines						
Domain of need	**Heart failure**	**COPD (full)**	**COPD (concise)**	**Dementia**	**Deprescribing in dementia**	**Cancer pain management**	**PalliAGED**
Physical							
Recognition of physical needs	✓	✓	✓	✓			✓
Expected symptoms described		✓	✓	✓		✓	✓
Symptom control approaches specified		✓	✓	✓		✓	✓
Referral for physical needs	✓	✓		✓			✓
Medication management					✓	✓	✓
Emotional							
Recognition of emotional needs		✓				✓	✓
Psychological concerns described		✓					✓
Approaches to addressing needs							✓
Referral for emotional care		✓					✓
Personal							
Recognition of personal needs	✓	✓					✓

Spiritual/religious/cultural needs				✓		✓	✓
Quality of life	✓	✓					✓
Preferences etc. at end of life				✓	✓	✓	
Referral for personal needs	✓	✓					
Social support							
Recognises social support needs	✓	✓		✓		✓	✓
Practical support				✓			✓
Financial support				✓			✓
Support groups		✓	✓	✓			✓
Information & communication							
Patient/family/clinician(s)	✓	✓	✓	✓	✓	✓	✓
Between clinicians in care team	✓	✓			✓		✓
Discussing revised care goals	✓	✓	✓	✓	✓		✓
Timing of discussion		✓			✓		✓
How/what to communicate		✓		✓	✓	✓	✓
Control							
Advance care planning/directives	✓	✓	✓	✓		✓	✓
Out of hours & emergency							
Continuity planned for			✓				✓

Late care							
Types of terminal care support	✓		✓	✓	✓		✓
Preparing family				✓			✓
Referral for late care		✓					
After care							
Bereavement care for family		✓		✓			✓

5.6.1.4 Palliative care considerations beyond PEPSI-COLA domains

Inductive analysis of guideline content identified several areas not accommodated by the PEPSI-COLA framework but of potential relevance to general palliative care. The first concerned prognostic indicators for identifying when a person's end-of-life care needs are starting to take priority over chronic disease management goals. The full COPD guideline provided comprehensive advice on clinical indicators that might be used to initiate a review of the goals of care. It also conceded the challenging nature of prognosticating for COPD, suggesting that palliative care initiation should not, therefore, be delayed pending an accurate prognosis. The COPD primary care concise version was equally descriptive but added in the well-known 'surprise question' for general practitioner consideration. The heart failure guidelines provided statistics and some general guidance on what clinicians might look for as suggestive of a change in the disease trajectory. PalliAGED provided a section for general practitioners on 'recognising change' which included links to tools such as SPICT and an app (PalliAGEDgp) incorporating the surprise question amongst other tools for managing care needs at the end of life.

The second additional topic was the role of the general practitioner in providing palliative or end-of-life care. This was addressed variably by several guidelines. The COPD (full) guideline allocated general practitioners a management and coordination role within a multidisciplinary team. The COPD (concise) guidelines for primary care were most specific, suggesting that general practitioners develop a GP Management Plan under the Australian Medicare Benefits Scheme for each patient and arrange pharmacists to do Home Medicine Reviews. The heart failure guideline stated that general practitioners have a 'vital role' in patient management. The PalliAGED resource provided a separate section for general practitioners on managing palliative care needs with an acknowledgement that '[f]or some clinicians, individuals requiring palliative care can be few and far between.' As PalliAGED is focused on the aged care setting, the general practitioner's role was contextualised as part of a community-based primary care team and not in relation to secondary care specialists. Additional palliative care content contained in the guidelines but not captured by the PEPSI-COLA domains is provided as Appendix A2.9.

5.6.2 Guideline quality assessment

All six guidelines were assessed for quality using the AGREE-II tool. The results of this assessment are shown in Table 5.5. The two guidelines relating to dementia management—both endorsed by Australia's NHMRC—achieved near perfect quality scores (95.7% and 96.5%). The pulmonary rehabilitation guideline also scored highly (87.2%), while the remaining three guidelines scored between 70–78%.[850, 851, 854] The domain best covered across guidelines was clarity and presentation (95.8%). The applicability domain was the least well covered (64.4%).

Table 5.5 AGREE II scores per domain for individual guidelines

Guideline	Scope and purpose (%)	Stakeholder involvement (%)	Rigour of development (%)	Clarity and presentation (%)	Applicability (%)	Editorial independence (%)	Average score (%)
Heart failure							
Full guideline	86.1	47.2	72.9	100	68.8	50.0	**70.8**
Chronic Obstructive Pulmonary Disease (COPD)							
Full guideline	80.6	88.9	69.8	88.9	37.5	100	**77.6**
Pulmonary rehabilitation	94.4	83.3	93.8	97.2	75.0	79.2	**87.2**
Dementia							
Full guideline	100.0	100.0	100.0	100.0	79.2	100.0	**96.5**
Deprescribing cholinesterase inhibitors and memantine	97.2	100.0	96.9	91.7	88.3	100.0	**95.7**
Cancer							
Cancer pain management in adults	75.0	75.0	78.0	97.0	37.5	61.9	**70.7**
Average standardised domain score	**88.9**	**82.4**	**85.2**	**95.8**	**64.4**	**81.9**	**83.1**

5.7 Discussion

Most of the Australian guidelines and evidence summaries included in this analysis acknowledged the likelihood of one comorbid condition in addition to the life-limiting condition of interest. None, however, addressed the possibility of cumulative and complex comorbidity, especially in older people, despite this being the everyday reality of general practice. Furthermore, almost half missed the opportunity to highlight the potential burden of treatment cumulative comorbidity poses for patients and their families. The narrow topic focus of the evidence summaries understandably precludes this level of detail. Within the more comprehensive guidelines, however, some discussion of the more common concordant disease clusters may have been of value to general practitioners, if only to prompt awareness of the potential for additional but related comorbidities to emerge in the future.

There are clear challenges for guideline developers in accommodating multimorbidity guidance in single condition guidelines, especially beyond a count of two conditions. Firstly, there is still a paucity of multimorbidity intervention evidence[49] which makes strong recommendations unlikely. However, general practitioners may find support for their decision-making in knowing where evidence is weak or non-existent and where patient preferences and shared decision-making become of paramount priority. Likewise, areas of clinical uncertainty associated with patient safety risks merit some discussion in guidelines. Few guidelines in this analysis included statements on adverse drug–drug interactions. While patient heterogeneity and the myriad other confounding factors associated with multimorbidity make conclusive recommendations improbable, general practitioners might still be alerted to the potential for drug-drug interactions, as well as factors like advanced age, that could impact on medication-related outcomes. Practical advice grounded in the Australian context might also prove useful. For example, problematic polypharmacy might be linked to a recommendation promoting the benefits of Medicare-subsidised pharmacist Home Medication Reviews or of deprescribing preventative drugs with a long time horizon to benefit.

An exemplar of a more inclusive approach to multimorbidity awareness is the current Australian general practice guideline for management of type 2 diabetes.[861] This guideline references multimorbidity throughout, hyperlinking readers where necessary to its own separate chapter titled 'Managing multimorbidity in people with type 2 diabetes'. This section details important investigations with timelines for monitoring potential or actual comorbidities, common type 2 diabetes comorbidity clusters, and guidance on avoiding drug interactions, polypharmacy, and inadequate continuity of care. Furthermore, this section acknowledges the inadequacy of the multimorbidity evidence before directing practitioners to alternative 'guiding principles' of care.

It was not evident from the guidelines analysed if comorbidities present a challenge for generalist palliative and end-of-life care provision. Comorbidities were not referred to beyond the active management sections of the guidelines, neither was there any suggestion that comorbidities may have a potential impact on the index condition in the final phases of its trajectory. The exception was PalliAGED, which suggested prognostication remains poorly understood in older adults with multimorbidity.[858]

The palliative care content provided did reveal, however, considerable heterogeneity in the domains covered across guidelines, the relative emphasis given to each domain, and the depth of content provided to clinicians in support of decision-making during the end-of-life phase of care. Some differences in depth and scope of coverage may be an appropriate reflection of condition-specific challenges such as the relatively fuller emphasis given to clinician-patient communication within the dementia guideline. Pronounced variation in approaches to symptom management across palliative care content, however, may warrant attention. Whereas some guidelines provided full advice for managing symptoms such as breathlessness,[854] fever,[852] and dysphagia[858] during the palliative phase of care, the heart failure guideline did not identify specific end-of-life symptoms, nor advise on management of physical conditions within its palliative care section. Its coverage focused on integration of palliative care with the multidisciplinary team. Furthermore, none of the guideline recommendations on end-of-life symptom management were accompanied by an evidence strength and quality grading. While this may reflect a developing palliative care evidence base not yet sufficiently robust for synthesis, general practitioners may benefit from an overall precis of the state of the evidence to help them know where greater emphasis on patient-centred outcomes and the exercising of their own clinical judgement may be warranted.

Clinical practice guidelines have an important educative role and potential to build capacity and raise the quality of care.[862] Therefore, future guidelines for life-limiting conditions might consider widening their scope to cover topics known to hinder general practitioner palliative care provision. This includes determining when the end-of-life care approach might be introduced and how best to communicate this transition to patients and their families. While most of the guidelines analysed noted the importance of communicating changing goals of care to patients, few advised on timing or acknowledged the challenges in trying to prognosticate. Furthermore, few mentioned the availability of well-established tools for identifying palliative care needs such as the 'surprise question' or SPICT. Guidelines might also provide more clarity regarding the general practitioner's role within the multidisciplinary team and how an effective continuum of palliative care might be achieved within the Australian healthcare system.

5.7.1 Study strengths and limitations

This analysis relied on a comprehensive search to identify guidelines and evidence summaries and employed non-clinician/clinician combinations to screen and appraise the data, providing for diverse viewpoints. Furthermore, comorbidity data were analysed using validated tools and both qualitative and quantitative methods. However, there are some potential limitations in this study. The term 'life-limiting condition' is not precisely defined, and there may be different views on which conditions should have been included. Furthermore, many topic-relevant resources were excluded for not being *evidence-based,* meaning they did not document their development processes and the decisional basis of their recommendations. The rationale for this eligibility criteria was to ensure these findings were based only on resources whose quality could be determined. We acknowledge that this may have led to the exclusion of guidelines commonly used and valued by general practitioners. A key example is the chronic kidney disease (CKD) Management in Primary Care handbook[863, 864] which did not grade the evidence it provided, nor outline its development process. However, its highly practical and easy-to-use format ensures that it is 'used widely out in the field.'[864] Another important exclusion was Australia's important *Therapeutic Guidelines* resource. This was also excluded on the grounds that the evidence underpinning recommendations was not traceable.

Furthermore, AGREE-II scores, no matter how objectively calculated, cannot account for how general practitioners interact with guidelines in clinical practice (or if they do) and their own real-world views on issues of format, accessibility, and applicability. A future study might triangulate perceptions of guideline quality versus utility from the viewpoint of developers and clinician end-users.

5.8 Conclusions

Australian clinical guidelines and evidence summaries for life-limiting chronic conditions provide some acknowledgement of comorbid conditions during the active management phase only and are strong on person-centred considerations such as patient preferences and quality of life. However, there is scope for the inclusion of more general advice within guidelines on the potential for drug–drug interactions and the cumulative effects of multimorbidity. Guidelines might also suggest where treatments should be modified based on limited life expectancy or advanced age. Addressing comorbidity/multimorbidity issues within a separate chapter and providing ‘guiding principles’ in the absence of evidence on treatment may offer a better approach for general practitioners working to manage multiple conditions. If more general palliative care is to take place in the future as the population ages, general practitioners will require more guidance on managing end-of-life symptoms, prognostication, and their role within the multidisciplinary team, at a minimum. Despite the biopsychosocial ethos of general practice, general practitioners may also benefit from better guidance on the emotional, social, and spiritual care of people approaching the end of life.

This chapter has reported the results of a content analysis of Australian clinical practice guidelines for life-limiting conditions and interpreted findings from the perspective of general practitioners looking for guidance on comorbidity management before and at the end-of-life phase of care. The next chapter describes a qualitative study of Australian general practitioner perspectives on managing patients with multimorbidity across these same two phases of care.

CHAPTER 6 AUSTRALIAN GENERAL PRACTITIONER PERSPECTIVES OF MULTIMORBIDITY AND ITS MANAGEMENT ACROSS PHASES OF CARE: A QUALITATIVE STUDY

6.1 Chapter preface

Chapter 5 reported the findings of a content analysis of Australian clinical practice guidelines for life-limiting conditions, examining their level of acknowledgement of multimorbidity concerns across both the active and end-of-life phases of care. The analysis found little practical advice on multimorbidity generally or the concurrent management of more than two diseases. Furthermore, there were scant recommendations on the potential for drugs for different conditions, even common ones, to interact and variable types of advice to general practitioners on providing palliative care.

This chapter describes a qualitative study with Australian general practitioners which employed an interview schedule informed by the themes and findings of the previous two studies (Chapters 4 and 5). This study sought to answer the research question: What is the Australian general practitioner experience of managing patients with multimorbidity across the adult life course, including the palliative and end-of-life stages?

6.2 Context for this study

General practitioner experiences of multimorbidity in Australia warrant attention. In a country where most people (almost 90%) visit a general practitioner within the year,[411] 52% of all consultations involve a person with two or more conditions,[89] and 27% include conditions affecting three or more body systems ('complex multimorbidity').[19] Furthermore, as Australian general practice serves as a gateway to specialist care, general practitioners often take on the responsibility for coordinating the total healthcare needs of their patients with multimorbidity. Despite growing evidence internationally that multimorbidity care poses myriad challenges to general practice,[783, 795, 802] how Australian general practitioners manage this demand within the existing parameters of the Australian primary care system remains largely unknown.

Life-limiting chronic conditions with comorbidities may pose additional challenges to general practitioners as care inevitably shifts from stabilising existing conditions and preventing new ones to providing palliative and eventually end-of-life care to patients and their families.

Research on the palliative and end-of-life care needs of people with multimorbidity remains limited.[254] However, existing studies reveal a heavy symptom burden and clinical challenges in determining the aetiology of symptoms when they may belong to more than one condition.[865] There has not yet been a formal recognition of multimorbidity as a condition of dying by specialist palliative care services.[866] However, the high symptom burden associated with multimorbidity is likely to increase demand for more complex palliative care in the future as more people age with chronic conditions.[449] If some of this demand is to be absorbed by general practitioners, it is crucial to understand their current experiences of providing end-of-life care in the presence of multimorbidity.

Several studies have examined first-hand experiences of Australian general practitioners in managing specific aspects of multimorbidity such as polypharmacy,[794] deprescribing,[781] and comorbid depression.[805] However, this study is the first to explore Australian general practitioner perspectives on the care of patients with multimorbidity more generally, including what supports their management of multimorbidity, impediments to achieving desired standards of care, and challenges from comorbidities when a life-limiting condition reaches the end-of-life phase.

6.3 Aim

This study aimed to elicit, analyse, and interpret the perceptions and experiences of Australian general practitioners in managing multimorbidity, to understand the impact it has on their practice.

6.4 Method

A qualitative methodology was employed to explore the issue of multimorbidity as this allowed a flexible and inductive approach to examining a ‘small number of naturally occurring cases in detail …’[867(p12)] This study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ).[868] (See Appendix A3.1)

6.4.1 Context

The study recruited registered general practitioners working in the Australian general practice setting with no restriction on location.

6.4.2 Ethics

The Flinders University Social and Behavioural Ethics Group granted ethical approval to this study on 22 January 2020 (Project number 8546). Participants indicated their informed consent by signing a consent form or providing verbal consent (recorded) after reading full details of the study, its purpose, what the study expected of them and how they might terminate involvement. The ethics approval and interview recruitment materials are provided in Appendix A3.2.

6.4.3 Sampling and recruitment

The study first used purposive sampling with the aim of recruiting general practitioners from across Australia who could describe the experience of providing care for people with multimorbidity. Purposive sampling is the deliberate selection of individuals most likely to be able to provide important, appropriate, and useful information for answering a research question.[869] Using 'information rich' cases of this kind can provide 'insights and in-depth understanding instead of empirical generalisations.'[870(p264)] It is also an efficient use of research resources.[870]

Recruitment involved several strategies, including personalised and non-personalised, digital, and print approaches, as multiple strategies have demonstrated improved general practitioner response rates in other studies.[871, 872] General practitioners were offered a monetary incentive in the form of an electronic gift card which reimbursed them for their time over and above the Medicare remuneration fee of a consultation lasting more than 20 minutes. This was funded from the researcher's postgraduate research maintenance budget. The initial target sample size was 12 general practitioners. However, the researcher reserved the option to continue recruiting if, during analysis of the data, it was clear new, divergent insights were still forthcoming in the latter interviews. If the latter interviews produced little or no additional information of importance to the study aims, the researcher would conclude that the point of thematic saturation had been reached.[873]

In February 2020, a notice inviting general practitioners to participate in a 15-30-minute interview was included in the e-newsletters of 13 Australian Primary Health Networks and the Western Australian branch of the Royal Australian College of General Practitioners. A copy of the notice was also disseminated from the Twitter accounts of several palliative care organisations. It was not possible to know how many general practitioners saw the newsletter notice; however, it resulted in five responses.

The researcher supplemented the digital approach with a personalised mailed invitation sent to twenty-five general practitioners, two of whom were known to her. The others were chosen randomly using Health Engine, an online health service directory. This approach led to four general practitioners making contact to express interest in participating in the study.

Two general practitioners withdrew from the study at the start of the COVID-19 pandemic in mid-March, citing pressure to implement telehealth capability in their workplace. At this stage, no further participants were forthcoming and only four general practitioners had been interviewed, with three of these representing Aboriginal Community Controlled Health Organisations. It then became necessary to build the sample via snowball sampling. Snowball sampling is an opportunistic approach to recruitment which relies on asking participants to recommend people amongst their contacts who would be a good source to interview.[874] Two general practitioners offered to contact colleagues with information about the study, which yielded five additional study participants.

6.4.4 Data collection

Semi-structured interviews took place between March and July 2020. The piloted interview guide used questions based on the findings and themes of the systematic review described in Chapter 4 (see Table 6.1). It employed demographic questions, broad, open questions, and more focused prompts to explore general practitioner experiences in managing patients with multimorbidity.[875] The postcode of each general practitioner’s leading clinical practice was converted to a quintile score (1-5) using the 2016 Index of Relative Socio-Economic Disadvantage from the Australian Bureau of Statistics.[876]

The researcher conducted all interviews, either by phone or Zoom, depending on the general practitioner’s preference. All interviews were digitally recorded with the interviewee’s permission. A professional transcriber transcribed the first three interviews. The researcher then took over to become better familiarised with the data. All interviews were transcribed verbatim.

Table 6.1 Interview schedule for Australian general practitioners

Demographic questions

- What is the postcode of your principal place of work?
- Do you work part-time or full-time?
- How many general practitioners (including residents) work at the same practice?
- Do you work in any other settings, for example, aged care?
- Approximately how many years is it since you gained your first medical qualification?

Multimorbidity in general

If multimorbidity is the presence of two or more chronic conditions within one person, what proportion of your patients would you describe as having multimorbidity?

1. Tell me about your experiences of managing people with multimorbidity

   Prompts: Are there challenges? What are some of the challenges? Are there positive aspects too?

2. What role do evidence-based resources such as guidelines play in supporting your management decision-making for patients with multimorbidity?

   Prompts: How do you apply recommendations across multiple conditions? How does the presence of multiple conditions influence your medication decisions? Under what circumstances might you deviate from guideline or protocol recommendations?

3. What are your thoughts on the way the current health care system works for patients with multimorbidity?

4. How well do you think the current systems and policies support you in providing care for patients with multimorbidity?

   Prompts: Are there government incentives or programs of which you take advantage? How useful do you find them?

5. What changes do you think could make a positive difference to how you manage patients with multimorbidity?

Multimorbidity with a life-limiting illness

I'd now like us to focus on people with multimorbidity approaching the end of life, say within their last 12 months. They may be older, frail, or have a life-limiting, progressive illness such as noncurative cancer, COPD, heart failure, Parkinson's, or dementia. I'd like you to think about this patient or a hypothetical patient fitting this scenario for the next few questions:

6. How do you approach the care of a patient with multiple conditions when it becomes clear that the person has a poor prognosis?

Prompts: Does the presence of multimorbidity provide any additional challenges to palliative or end-of-life care for you? What about medications?

7. If general practitioners were to have a more prominent role in providing end-of-life care in the future, in your opinion, what might optimal **general practice end of life care** look like for people with multimorbidity?

   Prompts: Where is end-of-life care likely to take place? What will be the role of the general practitioner? Who might be involved?

8. Is there anything else you would like to add about multimorbidity management?

   Prompt: Is there anything about the topic that you think we should have covered but didn't?

6.4.5 Data analysis

The data set was analysed inductively using thematic analysis.[877] Thematic analysis requires searching across a data set to identify and code repeated patterns that may indicate common or shared meanings.[757] Codes were derived directly from the data and themes were constructed from these codes, rather than imposed on the study via a pre-existing conceptual or theoretical framework.[870] The thematic analysis method is a good fit for the pragmatic approach as it flexible enough to accommodate different degrees of data interpretation, from the more descriptive to the highly interpretative and transformative.[878]

Data analysis was informed by the six steps suggested by Braun and Clarke.[757] Firstly, each interview transcript was imported into NVivo 12[879] and read several times to gain familiarity with the data and an orientation to the overall data set. Second, the researcher created codes for each new concept as it arose in the data or assigned data describing recurring concepts to their existing codes. Codes were subsequently collapsed into others, renamed, or iteratively placed in a hierarchical relationship. A codebook was developed using NVivo software and the researcher generated paper versions at several points during the data analysis process. The codebook was used to allocate definitions to codes for consistency and transparency and to begin the process of charting the relationships between each code. An excerpt of this codebook is provided as Appendix 3.3.

The third step involved examining the codes to construct potential themes which might provide broader meanings. A visual thematic map facilitated analysis during its early phase (Appendix A3.4) by showing potential interconnections between themes and subthemes. At step four, the candidate's two supervisors (DM, JT) reviewed the themes and provided suggestions for refinement. Once this process was exhausted, the higher-order themes and their subthemes were named and linked to supporting illustrative quotes (step 5). Finally, during step 6, themes and accompanying data were set in a unifying narrative and critically reviewed by a general practitioner (TS).

6.4.6 Strategies to enhance rigour

The researcher employed several strategies to enhance the rigour of the methodology to enable the reader to judge the trustworthiness of the findings. These strategies are discussed using the quality criteria established by Lincoln and Guba, namely credibility, transferability, dependability, and confirmability.[880]

Credibility

Credibility in qualitative research equates to internal validity in quantitative research.[881] It establishes the confidence that can be placed in the research findings based on the degree of fit between what the participants say and how the researcher represents their viewpoints.[881, 882] Firstly, the researcher ensured credibility through prolonged engagement with the data during the transcription and analysis phase with extensive reading and rereading and iterative development of a hierarchical coding frame to arrive at themes. Second, theme development was overseen and cross-checked at multiple points prior to interpretation by the researcher's two doctoral supervisors, one of whom has extensive qualitative research experience. This 'investigator triangulation'[883] added richness and credibility to the theme development with different researchers lending their varied expertise and perspectives to the process.

Member checking was a further strategy for ensuring the credibility of the findings. Member checking is feeding back data, or researcher interpretations of it, to participants for them to comment on its accuracy.[874] The researcher invited each participant to review the transcript of their interview. Six interviewees accepted this offer, returning their transcript with corrections or requests for details to be removed to not jeopardise confidentiality.

Participants were also given the opportunity to review preliminary themes and interpretations. No participants took up this offer, but several said they would welcome a final report summarising findings. Instead, the general practitioner member of the research team reviewed the themes, complete with interpretative narrative and data, and provided feedback on the fit between the data and the researcher's interpretation of it.

Transferability

Qualitative research transferability, an analogue to external validity, refers to the likelihood that the findings will be applicable to other individuals, contexts, settings, or to a larger population.[882] To help others judge the transferability to other contexts, the researcher has provided detailed information (or 'thick description') on the participants' characteristics and contexts in the results section. The purposive and snowball sampling processes have also ensured that those recruited to the study were able to offer insights into the phenomenon of interest (the management of multimorbidity). The transferability of the study findings will be tested in the next chapter when translated into survey questions and applied to a larger population of general practitioners.

Another important facet of credibility in qualitative research is reflexivity, which is an acknowledgement that the researcher is not a detached and objective observer, but rather a participant by virtue of having experiences, beliefs, and personal history that might influence the interpretative process.[884] At the time of this study, the researcher had 20 years of experience as an academic medical librarian, teaching the principles and practice of Evidence-Based Medicine to medical students, including critical appraisal of research. She also worked concurrently for 10 years as a researcher and research librarian within the discipline of palliative and supportive care. She therefore came to this study as a strong advocate of both evidence-based approaches to care and every individual's human right to be provided with high-quality palliative care at the end of life. Furthermore, although she did not have a clinical care background to claim a shared understanding of clinical issues, she was not completely unfamiliar with medical concepts, having been enrolled in three years of a six-year undergraduate medical degree.

Dependability

Dependability, which corresponds to quantitative research's reliability, describes the extent to which the researcher can ensure others that the research process was rational, traceable, and transparently documented.[880] This requires clearly describing all the research steps from start to finish in the form of an 'audit trail'.[882] In using NVivo software, the researcher was able to save progressive versions of the coding using different file names and generate codebooks at different points to maintain a documentation trail of the coding process. This record should provide enough detail for another researcher to understand the methodological choices made. Other forms of documentation contributing to evidence of a logical process include the COREQ reporting checklist and the visual thematic map—both presented in the Appendix of the thesis.

Confirmability

Confirmability is the degree to which the findings of the study might be confirmed by other researchers and that 'interpretations of the findings are not figments of the inquirer's imagination, but clearly derived from the data.'[882(p121)] The researcher has interwoven interpretations of the data with many richly illustrative, verbatim quotes to help others judge confirmability. Furthermore, on reading the results section, the general practitioner recognised the participants' experiences from their words and the researcher's interpretation of those experiences.

6.5 Results

Twelve general practitioners were recruited to the study and interviewed for a mean duration of 55 minutes (range: 27-90 minutes). Three worked exclusively with First Nations Australians as part of a multidisciplinary team serving an Aboriginal Community Controlled Health Organisation (ACCHO). Unlike the other participants, the ACCHO general practitioners were salaried rather than working under the fee-for-service model. Furthermore, two worked in geographically remote parts of Australia which required them to cover wide distances to provide medical care to sparse and often socioeconomically disadvantaged populations. The third ACCHO general practitioner worked in an outer suburb of a capital city.

Overall, the participant group was highly experienced, with a mean of 26.7 years since obtaining a primary medical qualification (range: 8-52 years). Several of them were charged with supervising registrars. Most were female, working part-time, and employed in a metropolitan clinic with an average of 9.8 general practitioners (range: 2-18). Relative geographic disadvantage scores were equally represented across the sample. In addition to their clinical work, 6 participants had part-time academic work within a university in a teaching or research capacity. This high proportion of academic participants can be attributed to snowball sampling as existing academics promoted the research to their academic colleagues. Only two participants consulted within residential aged care, although a larger proportion reported having previously done so.

Participants perceived that they regularly consulted with people with multimorbidity, irrespective of their clinic location. Their estimates of multimorbidity prevalence ranged from 15%–95%. Tables 6.2 and 6.3 summarise general participant characteristics.

Table 6.2 Characteristics of individual general practitioner interview participants

Code	Gender	No. of years since first medical qualification	Work fraction	No. of GPs in practice	Geographic designation[885, #]	IRSD score[876,$]	Additional GP-related roles	Estimated proportion of patients with multimorbidity*
GP1	F	10	PT	17	Metro	4	NA	40%
GP2	F	8	PT	9	Remote AMS	2	NA	Two-thirds
GP3	F	9	PT	4	Metro AMS	2	Academic	80%
GP4	M	20	FT	2	Remote AMS	2	NA	15-60%
GP5	M	40	FT	10	Regional	1	NA	'They're probably more the norm than not'
GP6	M	30	FT	16	Metro	1	Aged care	50-60%
GP7	M	34	PT	4	Metro	3	Academic	80% plus
GP8	F	36	PT	16	Metro	5	Academic	60-65%
GP9	F	34	PT	10	Metro	3	Academic, Aged care	95%
GP10	F	52	PT	8	Metro	4	Academic	'Sometimes, I'd like a cough and a cold to walk through the door.'
GP11	F	32	PT	18	Metro	5	NA	75%
GP12	F	15	PT	3	Metro	3	Academic	20% (works with younger patients)

Notes: AMS: Aboriginal Medical Service. NA: Not applicable. [#]Based on data cube for Correspondence, 2017 Postcode to 2016 Remoteness Area. [$]IRSD: Index of Relative Socio-Economic Disadvantage. Postcodes of clinics converted to a quintile (1-5) score based on the 2016 Census summary of an area's disadvantage relative to other areas. (1=Most disadvantaged, 5=Least disadvantaged). [*]Based on World Health Organization definition provided: 'the presence of two or more long-term chronic conditions in the one person.'[78]

Table 6.3 Summary of GP interviewee characteristics (n=12)

Attribute	Participants, n
Gender	
Female	8
Male	4
No. of full years since first medical qualification, *years*	
5-15	4
16-30	2
31-45	5
46+	1
Work fraction	
Part-time	9
Full-time	3
No. of general practitioners in practice	
1-4	4
5-9	2
10-14	2
15+	4
Clinic location	
Metropolitan area	9
Remote	2
Regional	1
IRSD quintile	
1 (most disadvantaged)	2
2	3
3	3
4	2
5 (least disadvantaged)	2
Additional roles	
Aged care	1
Part-time academic	6

Four main themes were constructed from the data, each with at least two subthemes (Table 6.4). These main themes were: (1) *Multimorbidity as an encounter with complexity and contingency;* (2) *Evidence constraints in multimorbidity care;* (3) *General practitioner concerns for patient safety;* and (4) *Multimorbidity management at the end of life.* Themes will be described below with additional data supporting these themes provided in Appendix A3.5.

Table 6.4 Summary of the themes and subthemes descriptive of Australian GP experiences managing patients with multimorbidity

Main theme	Subthemes
Multimorbidity as an encounter with complexity and contingency	*Patient heterogeneity and complexity* *It's the full biopsychosocial model in managing them* *Converging system and practice challenges* *Contingency problem solving and conflicting agendas*
Evidence constraints in multimorbidity care	*General practitioner perspectives on guidelines* *You're treating this person in front of you, not a population* *It's thinking based on years of knowledge of them and their bodies*
Concerns for patient safety	*Dangerous lack of communication with specialists* *Concern for patient access to allied health and home services*
Multimorbidity management at the end of life	*It's all symptom control* *Determining and communicating prognosis* *The general practitioner role at the end of life*

Theme 1. Multimorbidity as an encounter with complexity and contingency

All participants described multimorbidity as a confrontation with complexity. They considered this complexity stemmed from the heterogeneity of patient problems and was often compounded by inflexible healthcare system processes and policies.

Patient heterogeneity and complexity

General practitioners routinely encountered people afflicted by myriad combinations of conditions and diverse symptom presentations who tested their problem-solving skills.

> I saw a lady today, and she has gastric problems, she's osteopenic, she’s hypertensive, she’s got hypercholesterolaemia, she’s got COPD. And she’s also got some fibromyalgia, but now she’s got low iron … And it’s like, ‘where do I really start?’ (GP1)

There might also be a paradox between the number of conditions burdening a person and the manifestation of physical or psychosocial ill health. For example, an ‘overwhelmingly sad’ patient profile might belie a person functioning well, while someone with less morbidity might appear ‘very compromised and frail’ (GP5). The potential for drugs taken for different conditions to interact was particularly worrisome for general practitioners, even very experienced ones: *‘It’s really hard. I find it difficult. Everyone finds it difficult’* (GP6). Some participants worried how their younger colleagues might be managing the challenges of multimorbidity:

> The complexity of the conditions requires a lot of time to deal with them. This is the challenge. For me, that said, being very experienced, it’s not so difficult, but it's still difficult. But for junior … young doctors, especially our registrars, it's really challenging because they’ve got three or four different conditions and each of the conditions interacts with the other conditions in some way. (GP6)

Furthermore, participants were aware that some patients experienced their illness burden as an aggregation that was more than the sum of its parts. Cumulative multimorbidity could be dynamic and unpredictable, throwing up unexpected symptoms. To manage these appropriately, general practitioners needed to first deduce their causes carefully.

> [T]here are multiple things often going on at once, and you have to tease them out, and that takes time. And sometimes, there's something new that you haven't picked before, bogged down in the four or five different chronic diseases that you know about. (GP8)

More clinically experienced participants reported seeing increasing numbers of complex patients over their time in practice. However, they considered this partly due to an ageing population, but predominantly a positive consequence of having maintained long-term relationships with their patients over years, ageing in tandem alongside them. One general practitioner stressed the importance of not portraying general practice as unvaryingly complex to younger colleagues.

> I think you have to allow doctors to grow into it rather than say, ‘oh, this is what you're doing, this is all you're doing. This is what life's going to be like’, you know, because it isn’t. There are still people coming with musculoskeletal problems and you need people who are interested in musculoskeletal problems. (GP9)

It’s the full biopsychosocial model in managing them (GP6)

Most participants described confounding, interwoven psychological, socioeconomic, and cultural issues that could interfere with a person’s ability to self-manage or adhere to treatment recommendations. These considerations also needed to be explored and incorporated into any management plan for it to be successful. This took time which was not always readily available to the general practitioner.

> It actually takes time to get to know them, as a person, know their medical conditions and know their social environment, their support, … what their home environment is like. It’s just the sheer complexity of everything that impacts on their lives and their medical conditions that are really hard to grapple with on that intellectual, scientific basis. (GP6)

Participants working for an Aboriginal Medical Service (AMS) in a remote region of Australia described a range of socioeconomic circumstances that influenced their communities' health and the clinician’s ability to provide optimum care. These might include overcrowding, insecure housing, long public housing waitlists, and inadequate access to transport and nutritional food.

> So, you know, if somebody's got insecure housing and their diabetes is very poorly controlled such that you would like to start them on insulin, but they're not sure they’re going to be able to access refrigeration and where they’re going to sleep is an issue. (GP2)

General practitioner insight into the contribution made by non-medical factors to complexity led some to question the prominent two-condition definition of multimorbidity, which they viewed as simplistic. They argued instead for a definition that weighted problems for their impact on people’s lives.

Disease- and age-centric interpretations of multimorbidity were also contested, with several participants describing complex younger patients:

> You've got the autistic child who's also non-verbal … non-acting, but they also have asthma. And their asthma is poorly controlled. But then you can't manage the asthma because you can't even give them an inhaler. So it's 'Argh. What do we do here?' (GP1)

Multimorbidity associated with childhood trauma was also considered particularly difficult to manage. Several Aboriginal Medical Service participants emphasised the urgent need to focus on addressing upstream social determinants of chronic ill health. Without this, remote health was like '*a kind of balloon that's got a weakness in it that bulges out, and you push that bulge back in and then another one comes out'* (GP4).

Converging system and practice challenges: Time's the biggest enemy of us all (GP6)

Participants described a constant tension between the care they wanted to provide and system factors that restricted what they could do for patients. All agreed that they needed more time with complex patients yet were under pressure to curb the number of longer appointments they provided. They attributed this conflict to Australia's small business, fee-for-service model of general practice which incentivises moving patients through as quickly as possible. The stress between the obligation to the clinic to produce income—keeping it *'financially viable'* (GP3) or *'sustainable'* (GP5)—and patient care led some to prioritise patient needs over income. As one participant explained:

> You don't earn as much money when you have long appointments, but I can afford to book double appointments and just spend the time that's necessary so that I feel I'm doing a reasonable job. (GP8)

While some participants routinely scheduled long appointments for complex patients, others relied on the relationship they had built with the patient to find a balance*:*

> When you have some good relationships with your patients who understand the pressures you can say "Look. I know that's important to you. I will deal with it. I'll get back to it. Let's sort this thing out first." (GP6)

By breaking down their schedules into short blocks of consultation time, general practitioners might jeopardise therapeutic relationships. According to one participant (GP8), it reduced opportunities for her to hear and validate a person's illness experience or pick up on seemingly inconsequential disclosures holding clues to the person's mental and physical health.

> And people want to tell you about how anxious they are or, you know, the next-door neighbour's dog, or something. Or … they had to go down to the vet with the cat and how much the vet cost. And it's relevant, it's relevant to their, to their mental and physical health. And it's relevant to the relationship between us as, as a health professional with a patient. So, it's important to listen and that takes time as well. (GP8)

Participants viewed patients sharing in management decisions as important yet communicating complex information about relative risks and benefits across multiple conditions was challenging, especially when patients struggled to comprehend issues at hand, or the information provided to them. *'I don't tell my patients what to do so it takes a lot more time'* (GP12). Participants were also concerned with the adequacy of the Government's chronic care initiatives, labelling the GP Management Plan *'not worth the paper it's written on'* (GP6), *'really not sufficient'* (GP11), and *'a complete debacle'* (GP9). They generally appreciated Medicare rebates for preparing plans, but time remained an issue in completing them to their own standards.

> [The care plan is] so inadequate, and then people will rely on it, and there will be things that aren't there or are wrong. And there's been no attempt, again, to fund GPs for the extra time it would take to do it properly. (GP9)

Several participants also deemed it too time-consuming to try to arrange real-time multidisciplinary case conferences between themselves and other specialists under the Team Care Arrangement. They were already spending large amounts of time undertaking unpaid administrative work to ensure care continuity for complex patients. This work often included chasing up information not forthcoming from other health professionals involved in an individual's care.

A few participants expressed regret for parts of their role they could not proactively undertake due to time pressures. They considered preventative work a major area of neglect: important for patients and the sustainability of healthcare, but too complex and time-consuming to address within the current system. (*'The system does not allow for us to do good preventative work'* (GP3)). Practice nurses often picked up this role within a practice, and this was valued and appreciated by general practitioners. Some participants even viewed nurse practitioner work as vital to the sustainability of general practice:

> If I had the budget and could make the policy, I would be directing funding to nursing positions in general practices. And I would ensure that they were upskilled in understandings of public health and in chronic care as well. And the government could then utilize that to implement really important public health measures. (GP9)

However, participants were also aware that nurse remuneration via Medicare's practice nurse item number was often inadequate, being 'not enough to cover the time spent with the patient' (GP3). According to one study participant whose weekly nurse-led diabetes management clinic was seeing positive outcomes, the funding gap left by the rebate meant sessions had to be funded 'partially through the goodness of our hearts and interests' (GP6).

Consequently, some participants predicted a future when there would be *'a limit to the number of patients with complex multimorbidity that a practice can carry'* (GP5). Some saw a salaried model, like that of the Aboriginal Medical Service, as a potential solution to the time-remuneration issue. This was also put forward as a potential means to encourage more general practitioners to work within the residential aged care setting. Based on their own experiences, most of participants were deeply pessimistic about the future of general practitioner work in residential aged care. They described a setting with underqualified staff and poor communication systems and expressed frustration at being underpaid for the frustration and level of inconvenience involved for providing care.

> It's not well remunerated, that's true, because there's a lot of trying to find the patient. 'Are they in the toilet?' 'No, they're not in the toilet. I think they're down at the recreation room. I'll just go and see'. Ten minutes later they come back and go 'I'm sorry. I had to see someone on the way … I don't know where they are. I think they may be in the hairdressers. Do you just want to just pop down there and see if they're there?' Excuse me, I haven't even started being paid yet!

Participants currently providing this care expressed a sense of professional obligation to continue, even as a 'community service', when they saw few colleagues doing so. Here again, general practitioners could see a potential role for practice nurses.

> I think there is potentially a real role in having more outreach nurses, particularly going to nursing homes. There's a huge crisis here with nursing homes, because there are probably patients in nursing homes in this area that don't have a doctor. A couple of practices have pulled out. It's really, really hard to service large numbers. And yet we all feel very uncomfortable about it. (GP5)

Contingency problem solving and conflicting agendas: You got to try something I guess (GP1)

For general practitioners, multimorbidity could heighten the awareness of needing to act without necessarily knowing what to do. Participants described having to think flexibly under pressure as a person's conditions or circumstances changed, or treatments proved ineffective or harmful: *'You have rough ideas, and things are always changing as well. And you go, "Well, what do we do?"'*

(GP1). Two participants independently described the experience of problem solving in multimorbidity as occasionally akin to *'scraping the bottom of the barrel'* when first, second, and even third line treatments failed to work. Furthermore, multimorbidity often required the general practitioner to weigh up multiple competing priorities in determining a feasible management strategy. This might involve determining which problem required the most urgent attention or attending to a patient's conflicting agenda for the consultation.

> [A]s a GP, you can say, 'well, I'm going to concentrate on this particular problem you've got. I think it's really important.' But the person will arrive and bring up something else. And if you're a psychiatrist and they say, 'I've got a cold today,' you can ethically ignore that. But as a GP, you can't ignore something they bring up. So, it's very hard to deal adequately with each problem. (GP9)

General practitioners managed the clinical uncertainty associated with multimorbidity in different ways. Some scheduled patients more frequently to pre-empt problems occurring. Others split consultations or booked patients for longer, less financially profitable consultations to address all agendas. One general practitioner saw longer sessions as important for saving patients the cost and inconvenience of having to return for multiple appointments.

> I know what's important to their health; they know what's important to them. And it is tricky to manage because they want to talk about something totally bloody unimportant when you've got this result back, you know, that they've potentially got a cancer and they're talking about their ingrown toenail which they really want to get fixed up … You end up dealing with both of them. (GP6)

Multimorbidity management required participants to be mindful of a person's ability to adhere to recommendations and to factor this into decisions. Several participants described having to modify management plans to conserve patient self-management capacity. Instead of burdening patients with too much treatment, they opted for what one participant (GP9) called 'minimally disruptive medicine', rationalising referrals and actively seeking ways to reduce patient out-of-pocket costs: *'So it does make things just a bit more difficult because it's not just the practice of medicine but also moving into including other aspects of patient care'* (GP12). Participants also worried about the psychosocial impact of the multimorbidity care experience, particularly on older, more vulnerable people. Several described situations where they weighed a course of action against inevitable repercussions for patient independence and autonomy.

> So isolated elderly patients with multimorbidity who are dependent on driving vehicles to go to the town ... You know, I've got a couple who I think, 'do I really need to have that discussion with them and say you can't drive anymore? And what am I risking?' Because I know as soon as I do that, they can't come and see me. Their whole life changes. (GP5)

Theme 2. Evidence constraints in multimorbidity care

Most participants questioned the applicability of single condition guidelines to patients with multimorbidity. They also expressed awareness of the potential risks associated with strictly applying recommendations across multiple guidelines to the one patient. A minority of those interviewed, nevertheless, described a preference to align decisions to guideline evidence for this group of patients. Others could describe a range of alternative sources of information and knowledge which had more influence on their clinical thinking and decision-making than the research evidence in the context of multimorbidity.

General practitioner perspectives on guidelines

Participants' views on the role of guidelines in their decision-making ranged from *'I love guidelines because … guidelines are evidenced-based'* (GP11) to *'ultimately, they're often not terribly helpful'* (GP4). Yet even participants who spoke positively about guideline evidence for this population were cognisant that the underlying research was possibly drawn from non-representative populations: *So, the guidelines aren't necessarily based on our age group. And usually, they nearly always pick patients who don't have other co-morbidities to develop their guideline* (GP8). One participant expressed doubt as to the quality of guideline recommendations:

> [M]aybe judges make decisions based on whether we follow guidelines or not, but the guidelines, they are generally very, very poor-quality evidence. And often opinion and consensus opinion, and those sorts of things. (GP6)

Despite admitting generalisability challenges, some participants adhered closely to guidelines to have a structured, secure base for making decisions when confronted with clinical uncertainty*:*

> I think because the patients are so complex, and one thing can affect the other so easily, I tend to always look to guidelines. Yeah, I rely on them a lot.' (GP3)

They might also use guidelines to justify decisions to other health professionals. As one explained: '*If they go on to see someone else, [specialists] are not going to necessarily question why you've suddenly tried to reduce that PPI they may not need'* (GP1).

However, others struggled to harmonise evidence across guidelines: *'If somebody's got diabetes, and they've got a bleeding score, and they've got dementia? How do you craft the diabetes guidelines for that person?'* (GP5). Some participants saw scope for improving the current form of guidelines by incorporating more information on conditions that commonly cluster together. The current Australian diabetes guideline was given as an exemplar of this approach:

> I appreciate the ones that openly address the really common combinations. So, you know, I think the diabetes guideline addresses cardiovascular disease and renal disease appropriately, as it should, because heart disease, diabetes and kidney disease—that's a triad, you know. That's very common. (GP2)

You're treating this person in front of you, not a population (GP6)

Most participants described deviating from guideline recommendations when they did not fit the person before them:

> Almost always the multimorbidity modifies what you do ... [W]e just look at a guideline or protocol and just shake our heads sometimes and just go 'we cannot do it with this person.' (GP8)

Several participants emphasised the danger of losing sight of the person in the struggle to reconcile evidence founded on population means and the real-life values and concerns of individuals: '*Guidelines are good but they're good for populations. They don't apply to individuals'* (GP6). A few of the more clinically experienced participants did not conceive their dismissal of guidelines as problematic: *'[My registrars] are constantly reminding me of the guidelines, and I look them up and I constantly don't follow them properly' [Laughs]* (GP7). One justified his greater reliance on clinical judgement as being *'more interested in understanding the situation and what's really going on'* (GP5). Some general practitioners were especially critical of guidelines for being written by specialists and based on hospitalised patients. Several found the single condition, 'protocol-driven' approach taken by some hospital specialists as reflective of a reductionist view of patients and their lives.

> [H]ospital-based clinicians who do guidelines don't know, haven't got a clue about the real world … [A]ll their patients are sitting there politely in bed. They're not going out and drinking unsuitable amounts of alcohol or caffeine or going back to the smokes or sleeping irregular hours or eating stuff that they shouldn't eat. They're kind of in a controlled environment. (GP8)

[I]t’s thinking based on years of knowledge of them and their bodies (GP6)

Participants described relying on alternative forms of information for decision-making when guideline recommendations were deemed inappropriate. In addition to accumulated clinical knowledge, those in practice for a long time drew on familiarity with the patient and an accrued understanding of their circumstances, values, and capabilities:

> It’s that relationship that builds up over time that you both know what the next answer’s going to be and what the next question is going to be. And what is most appropriate for that person. Because you both have that same sort of shared, you know, ‘these are the things that are important to me.’ That sort of shared understanding of the situation. (GP6)

One participant described the idea of investing in relationships with patients for the sense of trust it fostered as taking a ‘*more fluid approach*’ rather than ‘*going through the hoops, ticking the boxes, taking the long way around*’ (GP4). Once trust was established, the nature of patient disclosures to their general practitioner might approach that of the confessional:

> People let you into their lives in a way that nobody else is let in. They tell you things that they don’t tell their life partner … You become the first person they disclose something to. It's an incredible privilege, but it's an incredible responsibility. (GP11)

This form of intelligence gathering was particularly evident in the AMS context, where the gradual approach was essential to a therapeutically beneficial establishment of trust.

> Because Indigenous people, particularly in remote communities, see so many different doctors and programs start and stop and come and go, they do watch you and see what you do at first. And then suddenly, when they think ‘Yeah, okay, this person is genuine,’ then you start to get that relationship. And there's no way you are going to get good results, I think, until you establish that relationship. (GP4)

Aboriginal Medical Service participants spoke positively of their experiences building strong relationships with families within remote communities, which could happen when an individual general practitioner reliably returned to the same community time and time again. One participant described relational continuity built on trust as *‘one of the things you have to your advantage’* (GP2). It served as a two-way flow of understanding which could help both parties negotiate a difficult management decision. It could also trigger recognition of changes to a person’s baseline of health in the absence of diagnostic data—what some general practitioners labelled ‘gut feeling’.

> I mean you've patients who you've known for so long and you see them, you just glance at them in the waiting room and you think, 'Gee there's something going on there.' (GP11)

For one participant, the move to telehealth consultations during the COVID-19 pandemic obfuscated this source of knowledge.

> I can't see how they're walking. I can tell if they're on a bad day when I get them from the waiting room because they sort of walk very slowly down the corridor to my room … So that gives me a wealth of information … [A]nd I could see if they're short of breath, hear if they're wheezing. I don't have any of that happening with the telephone. So that's really challenging. (GP8)

When at the limits of personal knowledge, participants might seek advice from other primary care team members, such as practice nurses, who often had better opportunities for observing peoples' functioning and coping outside the consultation room. Practice nurses also had more time to follow up on patients:

> I frequently get told by our RN, 'this patient's eligible for a bone density' or 'this patient's eligible for this or that' or 'you haven't done this in a long time. Perhaps you could consider that' (GP6).

Medical colleagues were also important sources of information: *'I think general practice is much better in a team environment when you're dealing with multiple morbidity'* (GP7). Those participants supervising registrars and medical students described training them to look for 'the unseen' and the 'taken for granted' being *'the sort of stuff that we go looking for as GPs'* (GP5). Several highlighted the importance of keeping the focus on the patient by emphasising the patient as a source of knowledge.

> All this stuff in the textbooks, walking and talking in front of them. In a story. So often when we finish, I will often turn to a student and say … and I'll say that to the patient, 'Now so and so's got cancer and hypertension and you're going to learn a lot from them.' And a lot of these older people feel that they've really made a contribution. Which is paradoxical, isn't it? (GP5)

General practitioners also sought to learn from specialists. This approach might be successful when specialists could be contacted when needed, sent general practitioners detailed patient letters and made general practitioners feel involved in the care team.

Theme 3. Concerns for patient safety: *Often the right hand doesn't know what the left hand is doing (GP1)*

Most participants expressed concern for the safety of patients with multimorbidity within a healthcare system they perceived as fragmented. They attributed some blame for lack of integration on Australia's split in healthcare funding across a primary and tertiary divide which hindered smooth transitions and information flow between sectors. Australia's public-private hospital divide was another source of complexity, although participants differed on which sector was most problematic for them to deal with. Overall, participants sympathised with the inherent complexities faced by patients dealing with different parts of a fractured system: *'But it is hard to navigate the systems, the different billing systems, private-public, health insurance. Oh, gosh. Yes, I think it's hard for people. Particularly if they're unwell'* (GP12).

Fragmentation also occurred at the level of the individual's body when each condition required the attention of its own set of specialists. This single-condition approach could jar with the general practitioner's holistic approach and lead to poor outcomes for the individual:

> This is why medical specialist management of these people is a disaster. Because they're only focused on one disease and not the whole patient. And they see them for a tiny snapshot in time, which potentially does more harm than good. (GP6)

Dangerous lack of communication with specialists

A consequence of poor integration and coordination between sectors was incomplete or poorly timed information transfer at the interfaces. It seemed the more players involved, the greater the risk of communication failures:

> Now the way we often interact with multimorbidity is we interact with a person and who they're seeing. And a lot of the issues for us as GPs is the communication between all of these people (GP5).

When asked what might make a positive difference to their management of multimorbidity, several participants nominated 'better communication with specialists.' Most spoke at length of frustrations with the information they received from secondary and tertiary care clinicians about their own patients. Potential safety implications were at the forefront of these concerns.

> Lack of communication is the really dangerous aspect in looking after these people. What you don't know often becomes a big issue. 'I don't know what tablets you're on. I don't

> know whether they found cancer. I don't know whether the doctors thought you had leukemia.' (GP5)

Discharge letters, often written by very junior doctors, were considered especially problematic when uninformative, delayed, or not forthcoming. Poor communication impeded care and added to the general practitioner’s workload. It often led to general practitioners actively tracking and soliciting the information they needed. Lack of information sharing also reduced opportunities for general practitioners to learn from specialist colleagues.

> And it’s really bad for our registrars because they see someone with some eye condition, and they didn't know what it is … So, they send them off to the eye clinic. And the correct thing to do is, you see them; you send back a letter to the registrar saying, ‘This is what the condition was.’ The registrar gets educated. The next time they see that thing, they don't have to send it to hospital. But no. There's no feedback whatsoever. It's crap. (GP6)

One general practitioner attributed the difficulties in communication between sectors as to the split in State-Commonwealth government oversight:

> So, because of that, the hospital-based system doesn't properly take into account what GPs do. They don’t. We’re kind of invisible to them because they don't have any jurisdiction over us. We’re paid by the Commonwealth; they don't understand our funding and they can't manage it. (GP8)

Without clear communication between all clinicians involved in a person’s care, participants saw patients as being at risk of inappropriate polypharmacy, medication errors, or opting out of care, unable to keep up with what health professionals were asking of them. General practitioners saw it as their role as generalists to counteract fragmentation by being *'across the range of a person's problems',* and *‘across the many systems’* so that they might *‘pull it all together for people’* (GP8). However, this took time they did not have. They also felt responsible for keeping patients out of the hospital, perceiving that hospitalisation often exacerbated patient problems through inappropriate and confusing medication changes.

Several participants believed that part of the solution lay in strengthening general practice through an increased funding investment. Foremost, this would allow general practitioners to do good preventative work, working with people to help them make small but significant changes to their health over time. This work might then pay back the healthcare system through money saved on prescriptions, patient safety incidents averted, and costly hospitalisations.

> [I]f the care could be augmented, we'd keep a lot of people out of hospital and would save millions of dollars. There's the will and the way to do that, but still, the dollars are not stacking up enough for the average practices to take on more and to want to do more. (GP5)

Concern for patient access to allied health and home services

Participants worried that older people had limited access to services designed to help them remain in the community. Several criticised complex government 'self-service internet-based systems' such as the My Aged Care portal, which many elderly, frail people struggled to navigate.

> It's designed for them to sit down and do it themselves. And that's very problematic because that's sort of like a type of Darwinian selection. So, the most healthy, unhealthy elderly individuals get help and the other ones, they just languish. (GP7)

Australian Government Home Care Packages designed to help older people remain in their homes could also be too late to arrive, with people often dying on the waiting list.

> And then you get into the next layer of the system which is the support systems out there. Which [are] really difficult to navigate. I mean, aged care packages for home care, you know. You wait ages to get approved then you're told there's a two year wait to get your package. (GP6)

Access to district nurses for rudimentary care such as wound dressings was also problematic, driving people back to the general practice clinic for routine care. Furthermore, time and financial considerations restricted many general practitioners from making home visits to their incapacitated patients, although several said they would make an exception for palliative care needs. Several participants also expressed frustration that their patients were limited to five allied health appointments per year under the Government's Team Care Arrangement.

> The problem with it is it doesn't give them access to much; you know. Five visits to a podiatrist per year. It's not terribly exciting to do a whole heap of paperwork for five visits to a podiatrist. You think 'why bother?' (GP6)

Without further government subsidisation, access to allied health was seen as financially out of reach for many patients. In contrast, patient access to nursing and allied healthcare was positively facilitated within Aboriginal Medical Services, providing clinicians could be recruited to remote locations.

> It's all part of the ethos of the Aboriginal Medical Services that the service has taken over, not just the running of the clinic but the whole gamut of social interventions. That includes diabetes educators, physiotherapists, exercise physiologists, nutritionists to work with people. And often, they come out to visit the community, and they're not in the clinic. They're out in the schools, community centres and so on. (GP4)

General practitioners working in an Aboriginal Medical Service setting expressed satisfaction with this integrated, holistic model. It simplified care coordination and fostered an authentic team-based approach firmly contextualised within a community. However, this facilitated access to allied health contrasted with access to medical specialist care. Aboriginal Medical Service remoteness could challenge efforts to get patients seen by specialists in a timely fashion, with one participant describing waiting lists stretching for years. Remotely situated general practitioners also faced a difficult choice when considering sending someone on a long, inconvenient journey away from their community for a diagnostic test, using scarce transportation and human resources in the process. The alternative was to manage the person in the community, risking a severe problem arising.

Theme 4. Multimorbidity management at the end of life: *With great relief I start to reduce their medications* (GP8)

Most participants noted a difference in how they approached multimorbidity management when they determined a person was approaching the end of their life. For some, management became simpler; the priority shifting from controlling conditions to alleviating symptoms and striving for quality of life *'as opposed to prolonging life or trying this new drug'* (GP1). Others found it challenging to identify the appropriate time to initiate a conversation about prognosis conversations or clarify if other specialists had taken responsibility for this. Consequently, some patients could receive information about their impending death very close to this eventuality.

It's all symptom control (GP1)

The shift from active to end-of-life care appeared to free general practitioners to manage the person's illness experience holistically rather than keep in check a range of different conditions of varying significance. As one participant said: '*Palliative care is pretty straightforward. You're dying. My role is to keep you happy, comfortable as much as possible. Doesn't matter what your condition is; that's fine'* (GP7).

Comorbidities appeared to remain important, but only insofar as they impacted the person's quality of life: ‘*So it all blends in. It’s all symptom control*’ (GP1). Preventative medications, or those with a long time to treat to benefit, could now be stopped, along with testing and screening for new diagnoses. Participants might also perceive the need to educate or counsel a patient about lifestyle risks such as obesity and smoking as no longer important. One participant described the freedom to provide adequate pain relief to older patients without fear of being questioned by regulators on her prescribing practices.

> We're always being told to keep people off pain medication. But if you're looking at someone who's … if you certainly would not be surprised if they died in the next 6 to 12 months, and I think they're in pain, I'm not going to tell them to listen to music and walk and meditate and put their pain into their left little finger. I'm going to give them pain relief, you know, because that's the kindest way. (GP8)

However, a subset of participants expressed a more ambivalent attitude towards multimorbidity care at the end of life, considering it to become simultaneously more challenging and yet more straightforward: *‘Okay, so it doesn't make things more complex. Sometimes it makes things simpler. Sometimes it does make things a bit more complex. But you tend to simplify your treatment’* (GP7). Respiratory distress and dyspnoea associated with COPD and heart failure were viewed as ‘very challenging’. So too was the more gradual trajectory of decline related to frailty. One participant labelled witnessing a person stepping down from an active, autonomous life against a ‘miserable background’ of issues such as pneumonia, osteoporosis, and chronic kidney failure with diabetes as *‘the hardest thing in general practice’* (GP5).

Determining and communicating prognosis

Participants acknowledged the importance of having a conversation with the person approaching the end of life to identify or clarify their priorities and care preferences for the time they had remaining. However, timing this conversation based on prognostic indicators could be problematic, especially for non-cancer terminal conditions such as frailty and dementia. The presence of comorbidities in addition to the terminal index condition could further cloud general practitioner ability to accurately predict an end stage of an illness, delaying opportunities for the person and their family to plan for death.

> I tend to do it probably a lot later than you should because, you know, do you think this person will …? Are they three months? 12 months? Would you be surprised if this patient died within the next 12 months? (GP1)

Lack of clarity about who should initiate a conversation on changing care goals might also compromise timing. Role ambiguity was a core concern for participants working with remote Indigenous communities who understood the spiritual and cultural significance of returning home to die 'on country' surrounded by family and community. One Aboriginal Medical Service general practitioner described the potential ramifications of informing patients of their prognosis too late:

> Once he realised what was actually happening, it definitely affected his decision-making. And it was very lucky that we had the opportunity to have that conversation because … it's always an uncertain prognosis, but we had thought he had months based on his general function and whatnot. And he ended up passing away within a week and a half. At least he had the chance to, you know, be on country … spend time with family for them all to understand the implications. (GP2)

In addition to giving patients and families an opportunity to clarify their preferences, open discussions around prognosis gave healthcare providers the information and time needed to put systems in place to facilitate those preferences. For example, when a person expressed a desire to die at home, some participants actively worked towards making this possible by providing home visits (GP1), organising a care system using the person's family and friends (GP10), or staying bedside of someone dying in a nursing home to help staff (GP8). Aboriginal Medical Service general practitioners held family meetings to ensure the family felt equipped to support a person to die 'on country' in remote Australia. They also took care to document care plans for after-hours staff to follow to ensure continuity of care (GP2).

The general practitioner role at the end of life

Participants differed in their level of involvement with palliative care. Some described *'helping people have a good death'* and supporting families as a *'very important role for GPs'*, *'rewarding'*, *'a fantastic thing to do'*, *'an incredible privilege'*. At the same time, it was also *'an incredible responsibility'*, *'challenging'*, and *'exhausting'*. Here again, participants saw the importance of having a relationship with the person, developed over time and based on continuity.

> I think to be able to do palliative care properly as a GP, you need to … know the patient. You need to have built up that rapport well and truly before you start discussing 'Okay. How about I start doing home visits.' (GP2)

Mutual understanding established over years might also mitigate some of the difficulties inherent in end of life discussions.

> I can tell you before they answer whether they'd want to have treatment or whether they'd want palliative care. Whether they'd want to be ventilated or not ventilated. And that's that shared understanding and knowledge about their values but also, they learn about their doctor as well, and his approach [Laughs]. (GP6)

Some participants described the ability of palliative care provision to transfigure an established relationship between general practitioner, patient, and family: *'The relationship is completely different to the one before as well. It develops into something else'* (GP11). The strength of the relationship appears to drive some general practitioners to provide palliative care even when it came at a cost to themselves: *'You're doing it out of love'* (GP10). Many could describe caring for specific patients and their families and relayed the emotional impact this had on them:

> '[T]here's an intimacy that you have with the doctor/patient relationship by looking after someone in their last days or even being with them when they die, and take their ... it's very, it's very intimate' (GP11).

This effect on the practitioner might last years: *'And if I walked down the street, I would immediately recognise them, and it would be an immediate recognition, probably tears, you know, powerful stuff'* (GP5). However, some participants were aware that not all their colleagues felt the same way about providing this type of care. There was a perception that fewer general practitioners were receiving or seeking out training in palliative care, and home visits for end-of-life care were becoming rarer. Again, they attributed this to inadequate remuneration. However, individual general practitioner attitudes also played a part: '*It's probably perceived as being a little bit too hard or "who wants to do that?" For I don't know what reason'* (GP1). Two of the more clinically experienced participants saw palliative care as a specialist undertaking (GP7) or as care increasingly provided by a limited number of general practitioners with special, extended skills and an interest in the area (GP5).

> I think palliative care is a specialist field. I think that general practitioners can do it, but I think ... if you are going to do it, I think you should be locally known as the person who does it and get patients referred by other GPs. And that makes up 20% of your patient load. (GP7)

One participant had other local practices referring people with palliative care needs to her practice (GP11) rather than providing this care themselves. However, rural and remote participants saw palliative care as a necessary part of their job: *'You just do everything because there's just you'* (GP2).

6.6 Discussion

This qualitative study of 12 Australian general practitioners has revealed several important findings about how they experience caring for people with multimorbidity. Firstly, general practitioners perceive multimorbidity as pervasive in their practices with well over half of their consultations involving a person with two or more chronic conditions. Although general practitioner estimates were subjective, they exceed epidemiological findings for general practice in Australia (52%)[89,19] and elsewhere.[65, 75] However, they appear to align with an Australian general practitioner subjective estimate of 85% previously reported in an international survey study on multimorbidity.[815] A gap between objective and subjective estimates may reflect multimorbidity's heavy impact on general practitioner workload and resources. In this study, it is doubtful that the high estimates are due to more liberal conceptions of multimorbidity as several participants criticised the two-condition threshold for being too low and unweighted for complexity. A more likely explanation is that the general practitioners who agreed to participate in the study did so because of their extensive experience with multimorbidity, which may stem from longer time in clinical practice.

Irrespective of their degree of clinical experience or the setting of care, participants experienced their patients with multimorbidity as complex, time-consuming, and perplexing to manage when biomedical problems were accompanied by a range of personal difficulties outside the medical sphere. This finding corroborates first-hand accounts from general practitioners internationally[804] where this confrontation with complexity has been described as 'an endless struggle'[795] and akin to opening 'a Pandora's box'.[802] Older participants expressed concern for their younger colleagues, especially in relation to medication management, as patient complexity induced uncertainty (*'And you go, "Well, what do we do?"'* (GP1)) which, for many, was not assuaged by referring to clinical practice guidelines. Some participants, however, acknowledged single condition guidelines had limited generalisability to patients with multimorbidity but still believed it important to adhere to their recommendations so that '*we can all sing from the same song sheet'* (GP1). This seemingly contradictory attitude has been described in other studies with general practitioners, although there it was explained by system mandates or rewards for guideline adherence.[686, 793] There are only weak incentives for Australian clinicians to adhere to guidelines.[692]

The Royal Australian College of General Practice *Standards* require general practices to merely demonstrate they have access to evidence-based tools, not that they use them.[9] Therefore, adherence despite awareness of patient safety issues is most likely driven by a need to have a sound and systematic basis on which to justify clinical decisions. This approach may warrant further investigation where it has implications for patient care safety and quality.

It was clear from participant responses that most thought deeply about their care decisions and were cognisant of weighing up a range of medical and non-medical considerations in determining a course of action. Like their international counterparts, Australian general practitioners appear to reconcile a tension between evidence-based and patient-centred approaches by pragmatically prioritising their relationship with the patient.[783, 788, 792] Through this relational continuity, they accumulated knowledge of a person's social context and individual priorities, then relied on this knowledge to formulate an appropriate therapeutic strategy and avoid contextual errors.[385, 569] Participant decision-making was often grounded unapologetically in a patient-general practitioner relationship. Many spoke empathetically and in depth of individuals for whom 'best practice' did not serve higher-order goals of maintaining quality of life, reducing treatment burden, and avoiding adverse outcomes. This finding tends to support McWhinney's assertion that, 'General practitioners tend to think in terms of individual patients rather than generalised abstractions'.[374(p433)]

This patient-centred approach was particularly evident in the remote Australian setting where building trust was considered foundational to healthcare success. In fact, most of those interviewed spoke highly of the ACCHO comprehensive service model, even those working outside of it. Several non-remote participants saw benefits in the salaried model of practice which appears to free general practitioners from the tyranny of the short consultation, allowing them to take the time needed to fully provide the care required by more complex patients. As one ACCHO participant said:

> I think if I worked in a private practice … I would be at … really high risk of burnout. Because patients who have chronic conditions or complex comorbidity … they really seek out doctors who actually care ... And so, if you're one of those doctors in a bulk billing practice then you'd definitely be at high risk of burnout and finishing late and running late and all those pressures. (GP3)

This perception illustrates another important tension in Australian general practice. Participants describe a constant and wearying struggle to provide the patient-centred care they wished to provide and system impediments to doing so. Time pressure was a prime issue. While this concern is not unique to Australian general practice,[780, 781, 802, 804] some factors contributing to it were perceived as stemming from the Australian healthcare model. Firstly, patients with private health insurance might see specialists within the private or public hospital sector, or both. Most participants found it time-consuming and challenging trying to communicate with specialists across these different sectors, although communication was vital for providing coordinated and safe patient care. Furthermore, general practitioners had to chase up this information, or make communications themselves during non-billable time which, under the Australian fee-for-service model, penalises them and their clinic financially. It might also serve as a disincentive for pursuing continuity of care for patients. One Australian study has estimated the annual average loss of general practitioner income from non-billable time to be between $10, 526 and $23, 008.[886] Participants' reluctance to provide a service to residential aged care or make home visits also arises out of dual concerns for time and income generation. This was acknowledged in the findings of Australia's recent Royal Commission into aged care quality and safety. The Commission therefore recommended that the Royal Australian College of General Practitioners amend its *Standards* to allow general practices to be accredited to practise exclusively in the residential or community aged care setting.[28]

Dual concerns for time and income generation may also reduce the quality and quantity of information exchanged between doctor and patient in the clinic consultation.[804] Here, the impact is likely to be on the exploration of patient concerns, values, and priorities, as well as on shared decision-making.[887] Over time, this has the potential to erode the general practitioner's store of knowledge of individual patients. Notably, however, not all Australian general practitioners view lack of consultation time as a system issue. In a recent study on goal elicitation, one general practitioner stated: *'Nobody's making GPs spend too little time with patients, they're doing it themselves.'*[888(p6)]

The finding that participants perceived multimorbidity care to become simpler at the end-of-life phase was unexpected considering the substantial proportion of Australian general practitioners who report being unwilling to provide palliative care through lack of confidence.[465, 833, 839, 889, 890] Again, the considerable amount of participant experience contained within this study sample may be associated with this relative sense of ease. These general practitioners spoke confidently of managing symptoms and pain holistically in parallel with a relaxation of concern for managing conditions individually. Unlike participants in other studies, none of the general practitioners interviewed expressed uncertainty over decisions to deprescribe.[780, 891, 892] One general practitioner's relief at finally being able to prescribe opioids for adequate pain management needs to be contextualised against a recent occurrence in Australian general practice whereby regulators contacted around 5000 general practitioners questioning their opioid prescribing behaviour.[893] A concern at the time was that general practitioners might start undertreating pain at the end of life for fear of legal repercussions.[894] This does not appear to be the case as, in a recent study of Australian general practitioner attitudes, many expressed willingness to prescribe 'as liberally as was required to manage pain' when prognosis was poor.[895(p6)]

Australian general practitioners have reported difficulties in providing end-of-life care when uncertain of their role within the multidisciplinary team.[896] As multimorbidity involves a large number of health providers, the general practitioner's role clarity within the end-of-life care team might be expected to be even more unclear. This was not evident within this sample of clinicians as many participants described leading care coordination or picking up this role when they realised specialists were not proactively taking charge. However, some of the most experienced participants viewed palliative care as no longer their role now that Special Interest GPs and specialist palliative care were available. As one participant said: '*There may be an argument that it's been taken away from us. Well, if it has … I think we've allowed that to happen*' (GP5). If more general practitioners with considerable palliative care experience come to share this view, older Australians who value their relationships with their long-term general practitioners may find relational continuity disrupted at the end of their lives. Other general practitioners in the sample, however, described feeling more comfortable in providing end-of-life care, complete with home visits, to people with whom they had an established relationship. This finding, which has been reported elsewhere,[278, 889, 897, 898] suggests a positive association between relational continuity and general practitioner involvement in care at the end of life. If this is so, it argues for incentives that protect, facilitate, and strengthen relational continuity within general practice. As one participant said:

> I would [and] I would think most of my colleagues would look after their patient and keep that continuity of care going, even if it is at a cost to them. Even if it is their only palliative care patient that they would be looking after. They will do that. And even if they don't do home visits, I think they will do the home visits (GP12).

The difficulty of determining and informing a person of a terminal prognosis was acknowledged by participants, as it has been acknowledged in other studies of general practitioners and end-of-life determination.[284, 896, 899] However, while certain comorbidities are known to have a negative impact on the prognosis of an index condition,[341, 900, 901] none of the participants expressed the view that prognosis was more challenging in the presence of comorbidities. Furthermore, most thought prognosis disclosure, although difficult, was vital for a person and their family to come to terms with the information. This finding contrasts with that of another qualitative study of the end-of-life practices of Australian general practitioners.[278] Here many reported withholding prognostic information from their patients, despite forging ahead with an informal, if unarticulated, end-of-life care plan.[278] However, several general practitioners expressed concern that these conversations often occurred close to the terminal phase of care. Timing of conversations within Indigenous communities was especially important, as were advance directives, to ensure people died at home on their traditional lands and not in a hospital.[902, 903] Here again, however, the ACCHO general practitioner had better system support to provide quality end-of-life care than non-ACCHO colleagues.

> I think where I work it's done really well. I have the flexibility to have long home visits and I'm renumerated for when I have to do visits out of hours and things like that. So, in an ideal world, the GP would be renumerated appropriately for it. Because often it, you know, takes you away from home and family out of hours and stuff (GP3).

6.6.1 Strengths and limitations

This study is the first to conduct a broad investigation of Australian general practitioner experiences in managing an increasing number of patients with multimorbidity. It used an interview schedule informed by the findings of a rigorous synthesis of international qualitative studies exploring the general practitioner experience (Chapter 4). The researcher followed processes to ensure the methods used, including the analysis and interpretation of the data, demonstrated a concern for rigour according to the criteria of credibility, transferability, dependability, and confirmability.[880]

The fact that the interviewer was not a general practitioner peer may have influenced the quality of the data obtained in several ways. The interviewer may have elicited richer details from participants through naïve questioning, expressing an interest in knowing more of the topic without it resembling a test of knowledge or competence.[904]

Secondly, general practitioners may have felt freer to speak frankly about challenges to a non-peer without feeling under professional scrutiny.[905] Conversely, interviewees may have been more guarded with their responses, underplaying challenges to protect social trust in the doctor's role or giving simplified, rather than rich answers, assuming a lack of shared understanding.[905]

After only four interviews had been conducted, recruitment was made difficult by the outbreak of the COVID-19 pandemic as this quickly put general practitioners at the forefront of care and under pressure to establish telehealth capability. Snowball sampling for additional participants using existing interviewee recommendations reinvigorated the process. However, it had some unforeseen consequences. Of the five additional participants, three were academic colleagues of one of the participants. Although they had split academic and clinical roles, it is unclear if and how this might have influenced the findings. The final size of the sample did not allow for stratification by length of years in practice, gender or geographic location which may have offered extra insights. However, sample size was deemed sufficient at the point at which no new codes were being created and the researcher assessed from the visual coding map that the existing data was rich enough to amply answer the research question.[906] However, this does not discount the possibility that disconfirming views exist beyond this sample.

The final composition of the sample, while interesting, may be unrepresentative of the overall population of general practitioners in Australia. It was a privilege to interview general practitioners working in communities served by an ACCHO, as well as several more experienced and academic general practitioners; however, their unique experiences and perspectives may not be transferable to general practitioners working in metropolitan areas or those just starting out in the specialty. Furthermore, participant self-selection may have influenced study findings by overstating problems. This might have occurred if only general practitioners with strong feelings on the topic, or negative experiences to report, had volunteered to be interviewed. Alternatively, this may demonstrate a strength of the purposive sampling process as those responding may represent information-rich cases with important experiences of the phenomenon under investigation and the motivation to speak about them. The researcher is also aware that the findings are based only on what participants said they thought or did. They may have felt pressure to provide 'patient-centred' responses which describe aspirational or socially desirable attitudes rather than actual ones.[907]

6.7 Conclusion

This study has contributed to answering the research question posed: *What is the Australian general practitioner experience of managing patients with multimorbidity across the adult life course, including the palliative and end-of-life stages?* It reveals that Australian general practitioners experience decisional uncertainty under time pressures in managing complex patients with multimorbidity. Some rely on guidelines despite hesitancy over their generalisability to these patients. However, patient-centredness in decision-making appears to be the priority, an orientation that stands at odds with the Australian general practice business model. There is also a deep gulf between the approach to care of general practitioners and how other specialists work. General practitioners describe feeling 'invisible' and incomprehensible to other medical specialists, taking as evidence the quality of the communication between them. Furthermore, they viewed this intersectoral failure as detrimental to the safety of patients and contributing to their own already substantial workload.

This qualitative study has reported Australian general practitioner perspectives on managing patients with multimorbidity with consideration of patients who will progress to an end-of-life phase of care. The next chapter describes a cross-sectional survey of Australian general practitioners, which sought to determine the transferability of these qualitative study findings to a much broader sample of the general practitioner population.

CHAPTER 7 MULTIMORBIDITY IN AUSTRALIAN GENERAL PRACTICE: A CROSS-SECTIONAL SURVEY OF GENERAL PRACTITIONER PERCEPTIONS, ATTITUDES, AND PRACTICES

7.1 Chapter preface

In Chapter 6, the researcher used a qualitative approach to investigate Australian general practitioner perspectives on their management of patients with multimorbidity, factors that supported them in this, and challenges they encountered. It also examined general practitioner attitudes to providing palliative and end-of-life care to patients with a life-limiting index condition and comorbidities.

This chapter reports a cross-sectional survey of Australian general practitioners. Its purpose was to test the generalisability of the findings from the previous three studies using a larger sample of Australian general practitioners. General practitioners indicated their level of agreement with statements covering a range of different issues on managing multimorbidity generally and at the point of transition between chronic management care and the approaching end of life.

7.2 Aims

This study had several aims. First, it sought to quantify the Australian general practitioner level of agreement or disagreement with previous findings across this body of research. It also sought to determine if there were attitudinal or demographic differences between those general practitioners who choose to provide palliative care and those who do not.

7.3 Methods

This cross-sectional study captured quantitative and some qualitative data using an online survey tool. This tool was specifically developed for this study and reflected findings from the previous studies. The study purposively sampled registered general practitioners from across Australia. The methodology and results are reported according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES).[908]

7.3.1 Ethics

The Flinders University Human Ethics Low Risk Panel approved this study on 19 October 2020 (Project number 2744). Appendix A4.1 includes this acceptance, along with all approved recruitment materials. The survey was open to Australian general practitioners between 5 November and 31 December 2020.

7.3.2 The survey tool

In keeping with the exploratory sequential mixed-methods study design, the findings of the previous three studies informed the development of an internet-based survey (Table 7.1). The researcher discussed the scope of the survey's coverage with her supervisors prior to developing the tool. The survey questions needed to represent all the themes and subthemes of the qualitative study. These were: patient complexity, attitudes and practices around research evidence and other sources of knowledge for decision-making, time pressures, patient safety concerns, uncertainty, and multimorbidity management at the end of life. As these questions focus on the difficulties associated with multimorbidity management, it was considered important to ask general practitioners about factors that positively facilitated their work as well.

This survey was created and administered using Qualtrics software (https:///www.qualtrics.com). It included a definition of multimorbidity at the outset to ensure general practitioners interpreted the questions consistently. It then comprised twenty-nine items in three sections with intentionally simple response options (Likert-type, multiple choice, free text) to ensure general practitioners could complete the survey in no longer than five to ten minutes. Only two questions were compulsory and prevented the participant going any further if not answered. The first asked participant's consent to participate. The second (Q9) asked participants for the estimated proportion of their patients they considered as having multimorbidity. At this point, participants who stated they did not manage any patients with multimorbidity departed the survey. Although the survey tool was not formally psychometrically validated, two general practitioners piloted the survey to determine content and face validity. This check led to several refinements of questions for improved readability. Prior to the survey's release, multiple volunteers located at different sites tested the usability and technical functionality of the survey.

Section one (8 questions) sought demographic data such as gender, number of years since first medical qualification, and details of the clinic location, type, and size. Section two (7 questions, 18 items) concerned general practitioner experiences of managing multimorbidity, as well as issues that might facilitate or impede this care. Many of the items in this section employed a 5-point

Likert-type scale with response options ranging from *Strongly disagree* through *Neither agree nor disagree* to *Strongly agree*. Some positively worded Likert-type questions were rephrased using negative wording to guard against acquiescence bias.[909] Respondents could provide more information or clarify a response using the optional open-ended question at the end of this section (*Is there anything else you would like to add …?*). Section three focused on multimorbidity care of progressive illness at the end of life. It comprised three multiple-choice questions. For the survey instrument, see Appendix A4.2.

Table 7.1 Translation of Chapter 6 qualitative findings into Chapter 7 survey questions and items

Theme from the qualitative study of GP perspectives (Chapter 6)	Content of qualitative item	Related question(s) or item(s) in quantitative survey
Table 6.2 Estimated proportion of participant's patients thought to have multimorbidity	Participants estimated the proportion of their patients they considered to be multimorbid based on the definition of multimorbidity as *the presence of two or more chronic conditions in one person.*	Q9. Based on this definition (*the co-existence of two or more chronic, symptomatic conditions in one person),* approximately what proportion of your patients would you define as having multimorbidity? [multiple choice]
Theme 1. Multimorbidity as an encounter with complexity	Patient heterogeneity and the interplay of biopsychosocial factors.	Q11. Compared to managing patients with single chronic conditions, I generally find managing patients with multimorbidity to be: [multiple choice] • More challenging to manage • Just as challenging to manage • Less challenging to manage
Theme 1. Subtheme: Converging system and practice challenges: *Time's the biggest enemy of us all*	Lack of time and remuneration to deal with patient complexity, prevention, and harmonising general practitioner and patient agendas.	Q13. The GP-patient consultation [Likert statements] • A standard consultation is long enough to manage the problems and concerns of patients with multimorbidity. • I spend a lot of time outside of consultation time managing the care of patients with multimorbidity • I usually find time to address lifestyle risk factors and preventative concerns with these patients • Having more consultation time, adequately remunerated, would improve general

		practice care of patients with multimorbidity - I always run late when I see patients with multimorbidity.
Theme 2. Evidentiary constraints in multimorbidity care	Participants described difficulties generalising guidelines to patients with multimorbidity, however, for some it was still preferable to adhere to guideline recommendations than rely on their own clinical judgement.	Q12. Multimorbidity research evidence and guidelines [Likert statements] - There is little available evidence on how to manage patients with multimorbidity - I tend to adhere to guideline recommendations in managing patients with multimorbidity - Single condition guidelines are difficult to generalise to people with multimorbidity
Theme 2. Subtheme: Integrating other forms of knowledge	General practitioners described a range of other sources of information or knowledge they integrated into their decision-making in the absence of guideline evidence. Sources included knowledge of the patient developed over time and information from practice nurses and other colleagues.	Q12. Multimorbidity research evidence and guidelines [Likert statements] - I tend to rely more on what patients want and their personal circumstances than what the guidelines recommend - Peers can be a trusted source of guidance on how to manage patients with multimorbidity Q15. Which of the following makes a positive difference to your management of patients with multimorbidity? [Multiple choice] - Working with skilled practice nurses - Knowledge of my patients, gathered over time - Sharing knowledge and experiences with GP colleagues - Collaboration with secondary care specialists - The availability of clinical practice guidelines

		and other evidence tools
Theme 3. Concerns for patient safety and subtheme: Dangerous lack of communication with specialists	Participants described issues communicating with other specialists about a patient, polypharmacy and interactions between drugs and conditions, and difficult access to allied health and other services in the community.	Q14. Multimorbidity patient care question [Likert questions] • The potential for adverse interactions between drugs and conditions concerns me • Patients with multimorbidity risk being burdened by too much treatment • I usually receive clear and timely information from the other specialists involved in the management of my patients • I am occasionally uncertain as to the best course of action with these patients.
Theme 4. Multimorbidity management at the end of life	When asked if the presence of multimorbidity provided additional challenges to palliative care at the end of life, general practitioners described simplifying treatment and dealing with present symptoms rather than each condition separately.	Q17. Ease of managing multimorbidity at the end of life [Multiple choice] • If the 'end of life' phase is defined as the last 6 months of a patient's life, do you generally find approaching this phase makes managing multimorbidity…
Theme 4. Subtheme: The general practitioner role at the end of life	General practitioners vary in their engagement with patients at the end of life, with most seeing this as an essential part of their role but several viewing this work as belonging to specialist palliative care clinicians.	Q16. If palliative care involves identifying and treating symptoms and issues associated with life-limiting illness (physical, emotional, spiritual, or social) and focusing on maintaining quality of life; which of the following best describes your ***usual*** palliative care practice? [Multiple choice]
Theme 4. Subtheme: Determining and communicating prognosis	General practitioners described the challenges of determining when a person was on a trajectory of decline requiring a conversation around changing goals of care.	Q18. The presence of comorbidities makes determining the transition point between the active management and end-of-life phases of care … [Multiple choice]

7.3.3 Recruitment

The researcher estimated *a priori* an ideal survey sample size of n = 380 based on a national general practitioner population headcount of 31,102,[910] a 95% confidence level, and a 5% margin of error.[911] As general practitioner survey recruitment rates are known to be exceptionally low,[871] the study used several different strategies to reach general practitioners.[872, 912] Recruitment proceeded in three phases.

First phase strategy (5 November 2020)

The researcher engaged AMPCo Data Services,[913] a fee-based electronic direct mail service, to select 2430 general practitioners registered in their medical practitioner database and email them an invitation to participate, information about the study, and a direct link to the survey. AMPCo selected general practitioners independently of the researcher, segmenting them by age (< 55 years, 67%; ≥ 55 years, 33%) and gender (40% male, 60% female) based on Australian national general practitioner workforce demographics.[411] No reminder email was sent after this first email.

Other digital recruitment strategies included promoting the survey in Australian Primary Health Network newsletters, where possible, and Twitter announcements posted from the accounts of the Primary Care Collaborative Cancer Clinical Trials Group (PC4) and the Research Centre for Palliative Care, Death and Dying (RePaDD). After general practitioners had read the information sheet online, they indicated their willingness to participate by selecting the checkbox 'I agree to participate,' which took them into the survey. They were not identifiable through their responses, and the researcher did not offer any financial incentives in exchange for participation.

Second phase strategy (19 November 2020)

Once survey responses appeared to have ceased, a notice describing the study with a link to the survey was posted in the private general practitioner Facebook group ‘GPs Down Under’—a not-for-profit online community of around 8500 general practitioners set up to facilitate general practitioner-led learning and peer support.[914]

Third phase strategy (20 November 2020)

A print copy of the survey with information about the study was mailed to 100 general practitioners. In selecting general practitioners for the mailout, one hundred general practices representing all Australian states and territories were identified using HealthEngine, an online consumer medical directory. One general practitioner from each practice was then selected from each practice's webpage for recruitment purposes. Each envelope was personally addressed and included a reply-paid envelope for ease of return. Although these participants could be identified from their signed, returned consent form, they were guaranteed confidentiality by having the form stored securely and separately from survey responses. Responses from returned print surveys were manually entered in the online Qualtrics survey so that all responses were ultimately in the one form ready for analysis.

7.3.4 Data analyses

Data were exported from Qualtrics as an Excel file and cleaned by removing unnecessary fields and incomplete responses. Some data were reclassified for analysis. For example, participants were asked to state the year they graduated with their first medical qualification. This year was then converted to the number of years since gaining a first medical qualification to have data in a continuous form for analysis. Similarly, the postcodes of general practitioner workplaces were converted to a quintile score (1-5) using the interactive map of the Australian 2016 Index of Relative Socio-Economic Disadvantage (IRSD).[915] This IRSD ranking score summarises a geographic area's relative level of socio-economic disadvantage, with quintile 1 representing areas with a high proportion of disadvantaged people and quintile 5 assigned to areas of least disadvantage.[916]

Quantitative analysis

Data analyses were conducted using IBM SPSS version 25.[917] These included descriptive analyses of categorical and ordinal level data and two types of inferential tests. Firstly, the chi-square test of independence tested for associations between categorical variables. The Mann-Whitney U test was employed to investigate the null hypothesis that general practitioners who report providing palliative care to their patients do not differ in their characteristics or responses from practitioners who state they do not provide this care. This analysis might then contribute to an earlier finding by Rhee et al.[833] that certain general practitioner characteristics were predictive of involvement in palliative care.[833] The data met all assumptions required to get a valid result on the Mann-Whitney U test: a dependent variable measured at the ordinal level, an independent variable comprising two categorical groups, and independence of observations.[918] Furthermore, the Kolmogorov-Smirnov test for normality indicated the data were not normally distributed.[919] For both inferential tests, missing data were not imputed, and significance for all tests was set at $p < .05$.

Exploratory factor analysis

The 14 Likert-type item responses were further analysed using exploratory factor analysis. This procedure sought to identify items that correlated highly with each other to form underlying (or 'latent') factors. The analysis was based on principal axis factoring with oblique (Promax) rotation[920] to enhance interpretation while assuming some correlation between factors.

Firstly, three standard tests assessed the data for suitability for this technique.[919] Sample size was determined to be adequate based on a ratio of ten participants to every one item.[921] The strength of intercorrelations between the items was also deemed satisfactory based on a low, but just adequate, Kaiser-Meyer-Olkin measure of sampling adequacy (KMO = .63)[922] and significance on Bartlett's test of sphericity (X^2 (91) = 337.50, p =.00). Furthermore, the preliminary correlation matrix showed multiple correlations of $r \geq .3$.[923] Determining the number of factors to retain in the final model relied on Kaiser's criterion of eigenvalues greater than 1, visual examination of the scree plot,[924] parallel analysis,[925] and a minimum loading value set at 0.40.

Qualitative analysis

General practitioner responses to the general open-ended question (*Is there anything else you would like to add …?)* were analysed using summative content analysis.[926] This method of analysis groups text expressing common ideas or sharing keywords, before quantifying content occurrences and making sense of the underlying context. These groups and their subgroups are reported with illustrative verbatim quotes.

7.4 Results

7.4.1 The sample

General practitioners returned a total of 201 surveys (Table 7.2). From 2530 personalised invitations sent out by email or post, 125 were not deliverable, leaving a sample of 2405 potential respondents. It was not possible to determine the response rate for personalised versus non-personalised recruitment methods as those general practitioners accessing the survey via personalised email were indistinguishable from those accessing it via e-newsletter, Facebook, or Twitter post. However, assuming the e-newsletter notices resulted in a negligible number of responses, and that general practitioners only responded to the email invitation within the first two weeks of receiving it (5–19 November), the 47 online responses received before the Facebook post on 20 November might be attributed solely to the email invitation. This assumption leads to an estimated maximum response rate to the personalised invitations of 2.3% (56/2405). If responses received after 19 November came from the Facebook post alone, this strategy can be assumed to have contributed approximately 62% (145/201) of responses to the total.

Table 7.2 Summary of GP recruitment strategies and response rates

Method of recruitment	Sent (n)	Received (n)	Responded n (%)
AMPCo email	2430	2308[a]	47[b] (2.0)
Mailout	100	97	9 (9.3)
Subtotal: Personalised invitations	*2530*	*2405*	*56 (2.3)*
Facebook notice	8500	8500	145[b]
Twitter and newsletter notices	NA	NA	Unknown
Subtotal: Social media notices	*NA*	*NA*	*145[b]*
Total			**201**

[a] Of the 2430 emails sent, 2308 (95%) arrived at an inbox. Email opening rate was 37% (AMPCo-reported percentages).
[b] Approximate only. Assumes emailed general practitioners responded before 19 November, and responses received after this date came via the Facebook post (20 November).

Survey completion rates

To be considered a completed survey, respondents had to provide answers across all three sections of the survey, with only one unanswered item allowed per section. Of the 201 surveys begun, 25 (12%) were incomplete and therefore ineligible, leaving 176 complete surveys for analysis. This sample size was smaller than required to meet significance at a 5% margin of error ($N = 380$). It did, however, meet the requirement for a 7% margin of error while maintaining the 95% confidence interval ($N = 176$).

Characteristics of the sample

Table 7.3 presents the demographic characteristics of the sample of 176 general practitioner respondents. It shows that most general practitioner respondents (73.3%) were female, a proportion well above the national female general practitioner headcount proportion of 47%.[411] Agreeing with the national trend, 54.3% (70/129) of female general practitioners in the sample worked part-time compared to 27.7% (13/47) of their male colleagues. Overall, general practitioners in the sample had an average of 21.5 years (*SD* = 12.4 years) since their first medical qualification.

Just over a third of general practitioners (34.1%, 60/176) provided care to people in residential aged care. Of these, 61.7% (37/60) were female, 38.3% (23/60) were male, and 45.6% (26/57) were more than 31 years past their first medical qualification.

Most general practitioners worked in a general practitioner-owned clinic (69.3%) or in a group of 5-9 general practitioners (42%). General practitioners working in an Aboriginal Medical Service may have been over-represented in the sample (8%) when nationally, approximately 2% full-time equivalent of general practitioners work in an Aboriginal and Torres Strait Islander specific primary health care setting.[927]

Table 7.3 Characteristics of GP survey participants

	Participants (*N* = 176)
Gender, *n (%)*	
Female	129 (73.3)
Male	47 (26.7)
Years since first medical qualification^, *mean (SD)*	21.5 (12.4)
Median Range of years	19 3–52
Employment status, *n* (*%*)	
Full-time	90 (51.1)
Part-time	83 (47.2)
Other	3 (1.7)
Type of clinic, *n* (*%*)	
General practitioner-owned	122 (69.3)
Corporate-owned	25 (14.2)
Aboriginal Medical Service	14 (8.0)
Community health centre	1 (0.6)
Other	14 (8.0)
No. of general practitioners at the clinic, *n* (*%*)	
1-4	38 (21.6)
5-9	73 (41.5)
10 or more	65 (36.9)
Clinic location IRSD#, *n (%)*	
1st quintile (most disadvantaged)	23 (13.5)
2nd quintile	35 (20.6)
3rd quintile	37 (21.8)
4th quintile	26 (15.3)
5th quintile (least disadvantaged)	49 (28.8)
Proportion bulk-billed patients, *n* (*%*)	
0-10%	13 (7.4)
11-50%	54 (30.7)
51-90%	59 (33.5)
91-100%	50 (28.4)
Work in special settings, *n* (*%*)	
Residential aged care	60 (34.1)
Health Care Home (trial program)	7 (4.0)

SD = standard deviation; ^Based on n=170 to account for 6 missing item responses to this question; #IRSD: Index of Relative Socio-Economic Disadvantage. Postcodes of clinics converted to a quintile (1-5) score based on the 2016 Census summary of an area's disadvantage relative to other areas.

7.4.2 Descriptive analyses of Likert-type responses

The number of responses at the extremes of the 5-point Likert-type scales (strongly agree/strongly disagree) were often very low. Therefore, responses were collapsed into a 3-point scale for analysis. The two aggregated categories were then titled: (1) Somewhat agree/Strongly agree; and (2) Somewhat disagree/Strongly disagree.

Australian general practitioner experience of multimorbidity (Questions 9 and 11)

Based on the two-condition definition of multimorbidity, 56.8% (100/176) of general practitioners estimated that more than half of their consultations involved patients with multimorbidity (95% CI, 49%–64%). (Figure 7.1) Furthermore, 84.5% (147/174) perceived patients with multimorbidity as more challenging to manage than those with a single chronic condition (95% CI, 79%–89%). No general practitioner viewed management as less challenging than single conditions, although 15.5% (27/174) considered it 'just as challenging'.

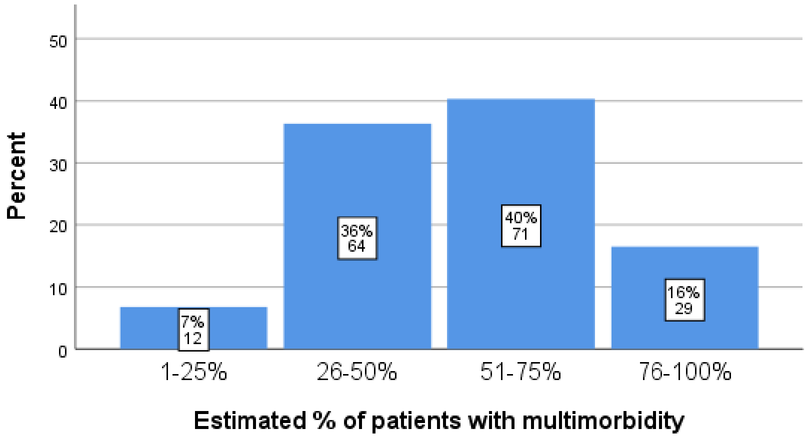

Figure 7.1 Australian GP estimates of their multimorbidity patient load, *N* = 176

Multimorbidity research evidence and guidelines (Question 12)

As shown in Table 7.4, most general practitioners believed single condition guidelines were difficult to apply to people with multimorbidity (86.9%). There was also little available evidence to guide them (69.9%). Moreover, most (60.8%) stated that they relied more on what patients wanted than guideline recommendations and trusted peers as a source of information on complex patients (77.3%). At the same time, however, 69.9% of respondents stated that they tended to adhere to guideline recommendations in managing patients with multimorbidity. Most of the statements on research evidence drew a relatively more robust neutral response from participants than other statements in the survey. This response was particularly evident for the statement *I tend to rely more on what patients want … than what the guidelines recommend* where more than a quarter of respondents (26.1%) answered neutrally.

The general practitioner-patient consultation (Question 13)

Table 7.5 presents the responses to the Likert-type items on the general practitioner-patient consultation. It shows that 98.3% of general practitioners surveyed believed that having more consultation time would improve their patients' care. Similarly, 95.5% did not agree that a standard consultation of 15 minutes was enough time to manage patient problems and concerns. Furthermore, 90.9% reported always ‘running late’ when providing care for people with multimorbidity, while 85.8% spent much time organising care for this group of patients outside of consultation time.

General practitioners were more divided in their views on finding time to address lifestyle risk factors and preventative concerns. Just over half (51.7%) believed they usually found the time to address these factors, while 36.9% indicated they usually could not do so. A fair proportion (11.4%) chose the neutral response. A posthoc chi-square test of independence was conducted to test the null hypothesis that there was no association between the number of years since graduation (a proxy for clinical experience) and agreement with this statement. The analysis identified a positive association between the number of years since graduation and finding time to address preventative issues, X^2 (6, N = 170) = 14.42, p = .025. This association had a moderate effect size (Cramer’s V = .201). Examination of the cell frequencies showed that 70% of those who indicated they usually *could not* find the time to address lifestyle risk and prevention were 1–20 years past graduation (35% for both 1–10 years and 11–20 years). In comparison, only 30% of those who could not find this time were 21 years or more post-graduation. The null hypothesis was therefore rejected.

Multimorbidity patient care (Question 14)

Table 7.6 shows the breakdown of general practitioner responses to the four items of Question 14 relating to clinician safety concerns for their patients. Nearly all general practitioners (95.5%) indicated a degree of concern over the potential for adverse interactions between drugs and conditions in their patients, with 67% strongly agreeing with the statement provided. Similarly, 94.4% agreed that patients with multimorbidity risked being burdened with too much treatment, with 58% indicating strong agreement with the statement. While 79% of general practitioners were occasionally uncertain about the best course of action to take for these patients (59.1% somewhat agree), 5% disagreed with the statement. More than half of those surveyed (57%) did not agree that they usually received clear and timely information for care from other specialists.

Table 7.4 GP agreement with statements on multimorbidity research evidence and guidelines (Question 12, *N* = 176)

Question 12 items	Somewhat disagree/Strongly disagree			Neither agree nor disagree			Somewhat agree/Strongly agree		
	n	%	95% CI	n	%	95% CI	n	%	95% CI
There is little available evidence on how to manage patients with multimorbidity	20	11.4	7.5–16.9	33	18.8	13.7–25.2	123	69.9	62.7–76.2
I tend to adhere to guideline recommendations in managing patients with multimorbidity	18	10.2	6.6–15.6	35	19.9	14.7–26.4	123	69.9	62.7–76.2
Single condition guidelines are difficult to generalise to people with multimorbidity	10	5.7	3.1–10.1	13	7.4	4.4–12.2	153	86.9	81.2–91.1
I tend to rely more on what patients want and their personal circumstances than what the guidelines recommend	23	13.1	8.9–18.8	46	26.1	20.2–33.1	107	60.8	53.4–67.7
Peers can be a trusted source of guidance on how to manage complex patients	9	5.1	2.7–9.4	31	17.6	12.7–23.9	136	77.3	70.5–82.8

CI = Confidence interval

Table 7.5 GP agreement with statements on the general practitioner-patient consultation (Question 13, *N* = 176)

Question 13 items	Somewhat disagree/Strongly disagree			Neither agree nor disagree			Somewhat agree/Strongly agree		
	n	%	95% CI	n	%	95% CI	n	%	95% CI
A standard consultation (15 minutes) is long enough to manage the problems and concerns of patients with multimorbidity	168	95.5	91.3–97.7	5	2.8	1.2–6.5	3	1.7	.06–4.9
I spend a lot of time outside of consultation time managing the care of people with multimorbidity	14	8.0	4.8–12.9	11	6.3	3.5–10.8	151	85.8	79.9–90.2
I usually find time to address lifestyle risk factors and preventative health concerns with these patients	65	36.9	30.2–44.3	20	11.4	7.5–16.9	91	51.7	44.4–59.0
Having more consultation time, adequately remunerated, would improve general practice care of patients with multimorbidity	2	1.1	0.3–4.0	1	0.6	0.1–3.1	173	98.3	95.1–99.4
I always run late when I see patients with multimorbidity	8	4.5	2.3–8.7	8	4.5	2.3–8.7	160	90.9	85.7–94.3

CI = Confidence interval

Table 7.6 GP agreement with statements on providing care to patients with multimorbidity (Question 14, *N* = 176)

Question 14 items	Somewhat disagree/Strongly disagree			Neither agree nor disagree			Somewhat agree/Strongly agree		
	n	%	95% CI	n	%	95% CI	n	%	95% CI
The potential for adverse interactions between drugs and conditions in multimorbidity concerns me	1	0.6	0.1–3.1	7	4.0	1.9–8.0	168	95.5	91.3–97.7
Patients with multimorbidity risk being burdened by too much treatment	5	2.8	1.2–6.5	5	2.8	1.2–6.5	166	94.3	89.9–96.9
I usually receive clear and timely information from the other specialists involved in the management of my patients	101	57.4	50.0–64.5	26	14.8	10.3–20.8	49	27.8	21.7–34.9
I am occasionally uncertain as to the best course of action with these patients	9	5.1	2.7–9.4	28	15.9	11.2–22.0	139	79.0	72.4–84.3

CI = Confidence interval

7.4.3 Exploratory factor analysis of Likert-type responses

When applying the principal axis factoring extraction method with Kaiser's criterion of eigenvalues greater than 1,[923] a five-factor solution was first identified, which accounted for 38.5% of the total variance. The first factor accounted for the largest proportion of the variance (15.1%) with the remaining five factors contributing between 4.7% and 7.3%. However, parallel analysis (14 variables x 176 respondents) (Table 7.7) and visual examination of the scree plot (Figure 7.2) suggested the presence of three rather than five factors.

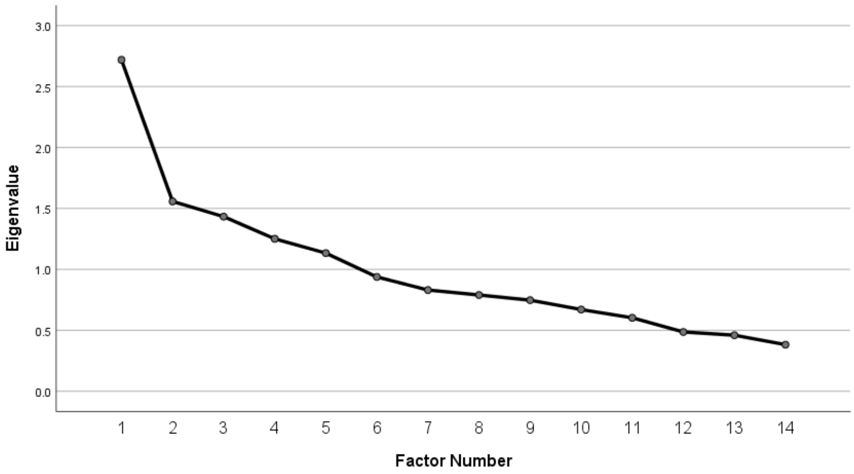

Figure 7.2 Scree plot for exploratory factor analysis of 14 Likert-type questions in the survey

Table 7.7 Parallel analysis: comparison of data eigenvalues with eigenvalues from randomly generated correlation matrices

Factor number	Eigenvalue from data	Criterion value from parallel analysis (Percentile Eigenvalue)	Decision
1	2.72	1.62	Accept
2	1.56	1.48	Accept
3	1.43	1.34	Accept
4	1.25	1.26	Reject
5	1.13	1.19	Reject

Note: Calculated using Parallel Analysis Engine software.[928]

Table 7.8 presents the resulting pattern and structure matrices for the exploratory factor analysis after oblique rotation. These show the loadings, or the relative contribution made by a variable to a factor. The pattern matrix provides regression coefficients, which represent the unique relationships between each of the item variables and each of the latent factors, with the impact of all other latent factors removed.[929] The structure matrix contains the correlation coefficients for each variable on each factor in the data, without controlling for other factors in the model.[923] Together these three factors explain 25.7% of the total variance. This low total variance indicates that these factors only explain a small proportion of the variability between item responses and that factors two and three are not strong. However, all three arguably make conceptual sense. No items loaded on more than one factor.

Factors were named based on the items they contained and the literature on multimorbidity in general practice. Factor 1 was labelled *Impact of consultation time restrictions*. It comprised four items and explained 14.8% of the variance. Factor 2 was called *Uncertainty and its causes* as each of its four items provided an insight into aspects of management that challenged general practitioners' skills and knowledge. This factor explained 6.0% of the variance. Factor 3, which accounted for 4.9% variance, was called *Mitigating sources of knowledge*. Its three items described different sources of information the general practitioner could draw on in making therapeutic decisions. Factors 1 and 2 (*Impact of consultation time restrictions* and *Uncertainty and its causes*) showed reasonable correlation (r = .43) with each other. Figure 7.3 shows a model of these three factors and their corresponding items.

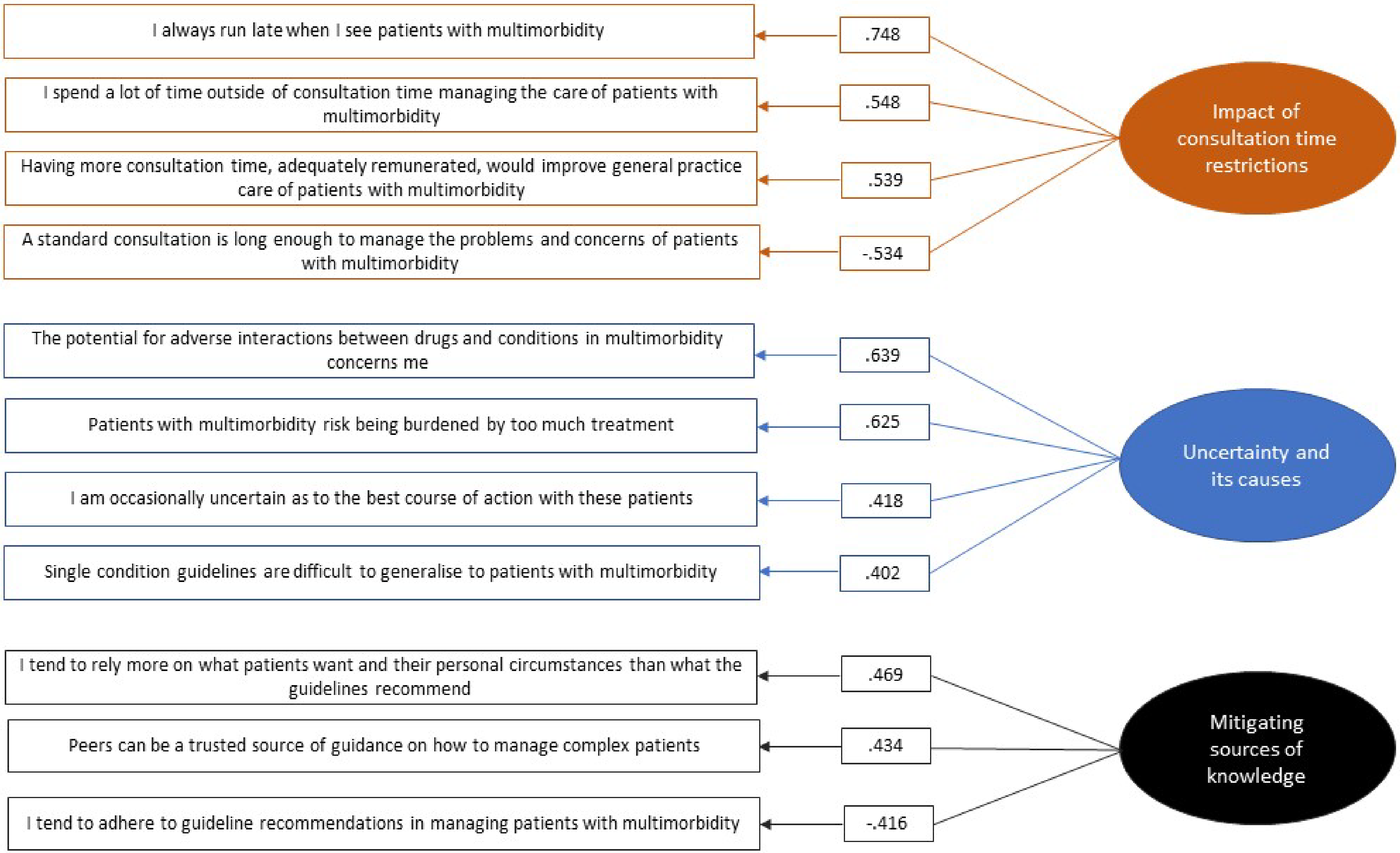

Figure 7.3 Best-fitting three factor model for the survey of Australian GPs

Table 7.8 Pattern and structure matrices for Likert-type items using principal axis factoring and Promax rotation of the three-factor solution

	Items	**Pattern coefficients**			**Structure coefficients**		
		Factor 1	*Factor 2*	*Factor 3*	*Factor 1*	*Factor 2*	*Factor 3*
Impact of consultation time restrictions	I always run late when I see patients with multimorbidity	**.748**	-.014	.041	**.745**	.308	.092
	I spend a lot of time outside of consultation time managing the care of patients with multimorbidity	**.548**	-.021	-.015	**.538**	.213	.022
	Having more consultation time, adequately remunerated, would improve general practice care of patients with multimorbidity	**.539**	-.040	-.019	**.521**	.191	.017
	A standard consultation is long enough to manage the problems and concerns of patients with multimorbidity	**-.534**	-.022	-.026	**-.545**	-.252	-.063
Uncertainty and its causes	The potential for adverse interactions between drugs and conditions in multimorbidity concerns me	.081	**.639**	-.211	.340	**.667**	-.184
	Patients with multimorbidity risk being burdened by too much treatment	-.011	**.625**	.016	.258	**.621**	.036
	I am occasionally uncertain as to the best course of action with these patients	-.134	**.418**	.066	.050	.363	.071
	Single condition guidelines are difficult to generalise to patients with multimorbidity	.138	**.402**	.008	.311	**.462**	.032
Mitigating	I tend to rely more on what patients want and their personal	.110	-.017	**.469**	.135	.047	**.476**

sources of knowledge	circumstances than what the guidelines recommend						
	Peers can be a trusted source of guidance on how to manage complex patients	-.033	.187	**.434**	.077	.188	**.438**
	I tend to adhere to guideline recommendations in managing patients with multimorbidity	.012	.038	**-.416**	.000	.029	**-.414**

Note: Loadings larger than .40 are shown in bold.

7.4.4 *Factors facilitating management of multimorbidity*

Question 15 asked general practitioners to select factors facilitating their management of patients with multimorbidity from a list of 6 options. Table 7.6 shows the frequencies of their selections.

Table 7.9 GP selected facilitators, in order of response frequency (*N* = 176)

Facilitator	n (%)
Knowledge of my patients gathered over time	173 (98.3)
Sharing knowledge and experiences with general practitioner colleagues	146 (83.0)
Collaboration with secondary care specialists	145 (82.4)
Working with skilled practice nurses	123 (69.9)
Availability of clinical practice guidelines and other evidence tools	116 (65.9)
Government initiatives such as GP management plans...	105 (59.7)

Twenty-one general practitioners added a facilitating factor to this list using the ‘other’ option. The most frequently listed items were having longer consultations (n = 5); other Medicare items such as case conferences and Home Medicines Review (n = 2); medical acupuncture (n = 2); involving carers in consultations (n = 2); and telehealth opportunities since the COVID-19 pandemic (n = 2).

7.4.5 *Comments from: Is there anything else you’d like to add …?*

Respondents provided a total of 76 additional comments on multimorbidity management when asked *Is there anything else you would like to add about managing patients with multimorbidity (positive or negative)?* These comments contained 154 content points when broken into their component topics. Using summative content analysis, they were grouped into four themes: (1) the subjective experience of multimorbidity; (2) the general practitioner role; (3) multimorbidity care challenges; and (4) multimorbidity care facilitators. Subthemes were then identified within the ‘challenges’ and ‘facilitators’ categories (Table 7.10). General practitioners raised 10 different types of challenges as well as 14 types of facilitating factors in their care of people with multimorbidity. The most frequently raised challenges were the interlinked *Remuneration for time spent* (n = 12) and *Lack of time with patients* (n = 11). The most frequently expressed facilitators were *Taking the extra time* (n = 12) followed by *Sharing with other health professionals* (n = 11). Additional illustrative verbatim quotes can be found in Appendix A4.3.

Table 7.10 A summative content analysis of GP open responses to 'Is there anything else you'd like to add …?'

Theme	n (%)	Exemplar verbatim quotes
Subjective experience	12 (7.8)	• I enjoy working with comorbidity and why it is a significant amount of my practice. It is intellectually stimulating, and I enjoy working with people on their recovery journey. I think I have become quite good at working in this area, so I suspect it bears less challenge now than for many of my colleagues. • Satisfying but challenging under current system. • I really dislike this part of general practice. • I'm thinking of leaving general practice
GP role	5 (3.3)	• GPs are specialists in looking after people in their entirety; this includes the ability to not only factor into shared decision-making their comorbidities but also their social determinants of health as well as personal and family wishes. This is not always appreciated by non-GP specialists.
Multimorbidity care challenges		
Remuneration for time spent	18 (11.7)	• Medicare penalises us for having complex patients in terms of remuneration. • Better remuneration so I am not forced to fractionate care over multiple appointments in order to not run late and also to generate revenue. • Most of these patients are pensioners or on Centrelink benefits so I cannot charge much of a gap. It is no wonder at all that bulk billing practices doing 6-minute consults are not offering appropriate care for these patients.
Lack of time with patients	15 (9.7)	• I always run late. (I am thinking of leaving general practice) • Even outside the consultation, there is additional work. Note taking can be more lengthy due to the complexity and the story may not always be given sequentially. There may be medicolegal ramifications and interactions with other professionals. • Multimorbidity patients require complex problem solving and thoughtful adaption of guidelines and awareness of their social environment and supports—all impossible to achieve in a 15-minute appointment. • Spending increasingly more of my own time (unpaid) outside the consult time to chase up and catch up, impacting my family/non work time.
Other specialists	11 (7.1)	• I find it difficult to agree with management directions from single organ specialists who aren't seeing the full picture including psychosocial factors. • Lack of specialist correspondence is a massive hindrance, both public and private.
Patient complexity	10 (6.5)	• Often can't get ideal management of any condition as fixing one adversely affects the other. • It is incredibly challenging and seems to be getting more complex with increased patient expectations and more medications to be aware of.

Patient access to services	7 (4.5)	• Access to allied health that the patient can afford!! The 5 assorted visits do not cut the mustard! • It becomes even more complicated for remote patients with limited access to services. • Easier pharmacist involvement for polypharmacy, e.g., removing the domiciliary visit requirement.
Government initiatives for chronic disease management	6 (3.9)	• Scrap the GPMPS and so on… In fifteen years, I've not seen a benefit of a GPMP or TCA for my patients, over what a well-funded rebate and longitudinal relationship with primary care specialist offered. • It also requires lifestyle changes not necessarily supported by government policy. • GP management plans don't remunerate enough to cover the increased time required to cover multimorbidity care. • Govt GP plans are so laborious and designed by bureaucrats so that the system can keep control over data. The actual plans are of minimal value especially for the remuneration. They waste a lot of GP time when we should be listening/talking to our patients.
Evidence	5 (3.3)	• Often the different clinical guidelines can contradict each other (as can the recommendations of non-GP specialists) • Medical research needs to progress towards including in their study populations patients with multimorbidity (and also the elderly) and also those with complex social determinants of health.
Health system factors	4 (2.6)	• If they haven't already experienced trauma, then they often come to me traumatised from previous experiences with the health system which isn't geared up for comorbidity. • Many of my patients with multimorbidity see multiple specialists. This can lead to poorly coordinated care, confusion and simple mistakes. • Other services may not fit comorbidity models (this is quite common) so may refuse care unless one issue is sorted out, and then so does the other service! Or services may not exist.
Prevalence	3 (2.0)	• My practice is loaded with multimorbidity
Patient characteristics	2 (1.3)	• Language or cultural barriers to accessing optimal care
Multimorbidity care facilitators		
Taking the extra time	12 (7.8)	• Slowing things down. 30- or 60-minute appointments. • Longer consults are standard for my patients now
Sharing with other health professionals	11 (7.1)	• Occasional difficult cases shared with colleagues in internet discussion groups. • I am slowly building a database of specialists I can tap on for assistance if I get truly stuck. • Also do HMMR [home medication management review] in most of these patients and learn a lot from the pharmacist who assesses them. • Having more collaboration with secondary care specialists and being able to contact them for advice would be a great asset.
GP personal factors	8 (5.2)	• Patience. Experience. • I have become a pattern watcher and find it helpful to see these conditions not as separate conditions - but as processes that interact - often with a similar underlying stressor - so I find addressing that

		underlying process is my best management skill.
Telehealth	5 (3.3)	• Telehealth consults have allowed me to be much more proactive with preventative health. • Telehealth has been fantastic in facilitating assertive follow up without significant inconvenience to consumers.
Government initiatives	5 (3.3)	• Over years, have seen incremental change for the better (utilising GP management plans, planned reviews to make sure preventative activities are carried out, medication reviews) • Care planning is useful for some compensation for the GP and helps with problems list
Relationship with the patient	3 (2.0)	• In my opinion, now backed up by Level 1 evidence, the best tool is a lifelong relationship between the GP and the patient. • Recently Fellowed. A lot of young patients, but an expanding collection of older patients with comorbid collections. Getting to know them over time definitely is the biggest factor in my ability to care for them.
Medical acupuncture	3 (2.0)	• I find medical acupuncture very useful as it can treat multiple morbidity and reduce mortality without adding more medications
Involving family/carers	2 (1.3)	• Good relationship with their spouse, family member or carer. • Including carers in consults.
Living with uncertainty	2 (1.3)	• I do my best in the shades of grey areas. Many times, things that are frowned upon work out fine. • Learning to sit with uncertainty as in many cases, there aren't clear guidelines.
Communication	1 (0.7)	• Setting clear mutual goals and expectations
Charging more	1 (0.7)	• Patients who are able to afford a gap fee
Patient characteristics	1 (0.7)	• Health literacy in patients
Salaried GPs	1 (0.7)	• Working as part of a salaried team is extremely helpful.
GP self-care	1 (0.7)	• It is important to remember also we as clinicians are human and have our needs too, and ensure those are met and not ignored

7.4.6 Multimorbidity care at the end of life

Of the 174 general practitioners that indicated their level of palliative care provision, 67.8% (118/174) reported having some involvement with palliative care (Figure 7.4). The majority (37.4%, 65/174) shared this care with a specialist palliative care team, while 30.5% (53/174) led the provision of palliative care, bringing in the specialist team if required. Around a third of general practitioners (31%, 54/174) exclusively referred patients to other clinicians to receive palliative care, including specialist palliative care services (27%, 47/174) and other general practitioners (4%, 7/174). Two general practitioners had no experience to date of providing palliative care.

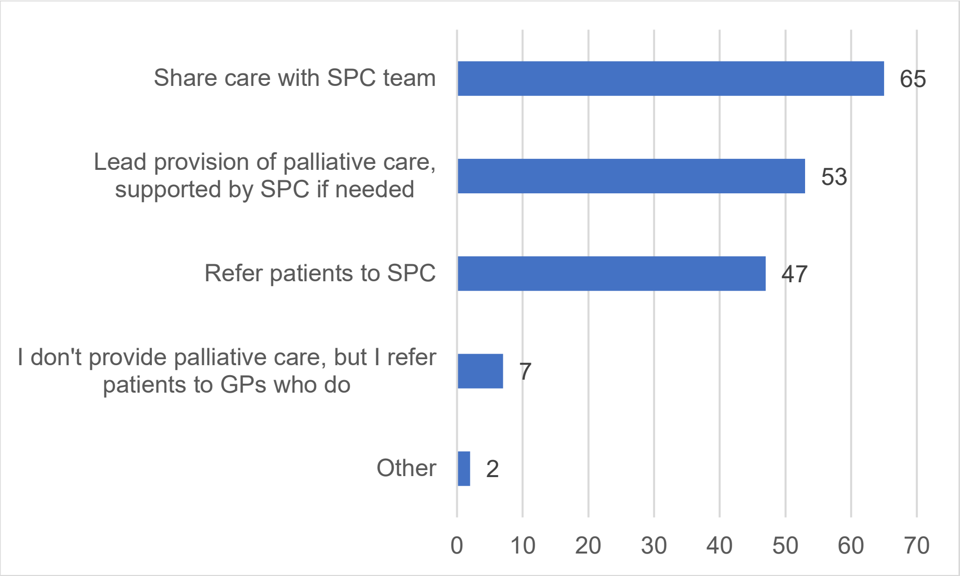

Figure 7.4 Usual palliative care practice of Australian GPs (*N* = 174)

General practitioners were able to select more than one response to the question of whether multimorbidity management became harder or simpler as patients with life-limiting illnesses neared the end of life (Figure 7.5). The question was set up in this way based on several ambivalent general practitioner responses in the interview study of Chapter 6 (*'It gets easier, but it also gets harder'*). General practitioners gave a total of 289 responses or an average of 1.6 selections per respondent. Most general practitioners (59.7%, 105/176) choose *Simpler as the focus becomes symptom management and quality of life*. Fewer (47.2%, 83/176) stated that management of multimorbidity became simpler based on cessation of therapies. A chi-square test for independence was conducted using 2 x 2 contingency tables to identify any association between the different ways of responding to this question.

The analysis found a significant and strong (Phi = .498) association between participant selection of both ‘simpler’ responses, X^2 (1, N = 176) = 43.724, $p < .001$. Conversely, nearly half (44.9%, 79/176) of general practitioners thought that the type of life-limiting condition played a role, while only 12.5% (22/176) perceived care to become more complicated nearer the end of life.

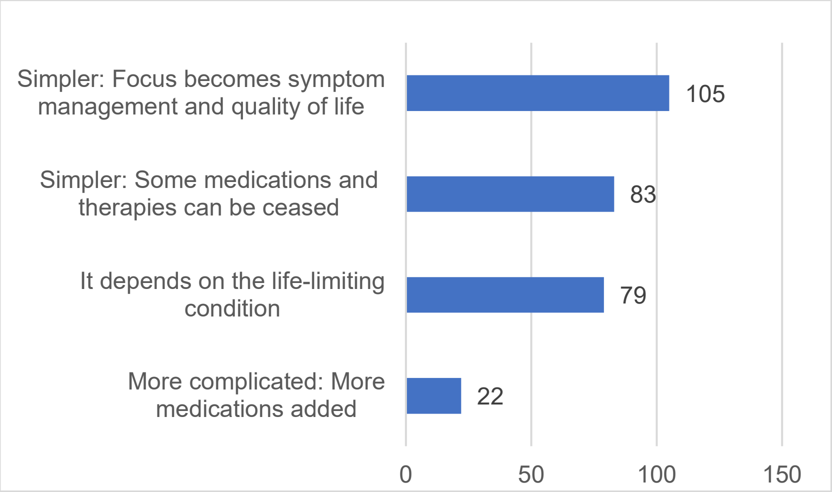

Figure 7.5 Responses to question 18: ***‘[I] generally find approaching [the end-of-life phase] makes managing multimorbidity …’***

General practitioners were more divided in their views on whether comorbidities impacted their ability to determine a transition point between the active management and end-of-life phases of care (Figure 7.6). Although 56.3% (99/174) felt prognostication became more complicated when comorbidities were present, regardless of the index condition, almost a quarter (22.7%, 40/174) singled out the presence of a non-malignant index condition as the more challenging scenario. A further 19.9% (35/174) believed comorbidities had no bearing on prognostication.

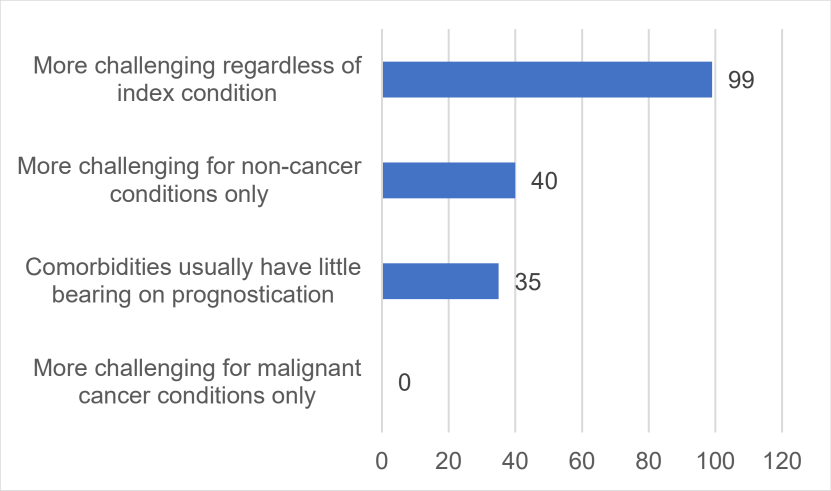

Figure 7.6 GP views on the influence of comorbidities on determining the transition point between the active management and end-of-life phases of care (*N* = 174, 2 missing responses)

Differences between palliative care provider and non-provider groups

The Mann-Whitney U test assessed the null hypothesis that there were no significant differences in demographic characteristics or other responses between those general practitioners who report providing palliative care (*n* = 118) and those who do not (*n* = 56). The null hypothesis was, however, rejected on the basis that the test identified significant, but weak effect differences in the distributions of responses between the two groups on several variables. Firstly, years since graduation were significantly higher in the palliative care provider group (*Md* = 1.5 *n* = 114) than non-providers (*Md* = 1.0, *n* = 55), *U* = 2559.0, z = -2.0, *p* = .046, with a weak effect size *r* = .15. Secondly, palliative care providers reported having a higher proportion of patients with multimorbidity (*Mn* = 3.0, *n* = 118) than non-providers (*Mn* = 2.0, *n* = 56), *U* = 2490.5, *z* = -2.79, *p* = .005 with a weak effect size *r* = .21. The provider group was also significantly less likely (*Mn* = 1.0, *n* = 118) to agree with the statement '*I usually receive clear and timely information from the other specialists involved in the management of my patients*' than the non-providers (*Mn* = 2.0, *n* = 56), *U* = 2556.5, z = -2.51, *p* = .012, with a weak effect size *r* = .19.

7.5 Discussion

This study examined Australian general practitioners' levels of agreement with the key multimorbidity management issues identified within the earlier studies of this thesis. It has also provided data on the relationship between general practitioner's palliative care practice and individual general practitioner characteristics and perspectives on care. Survey data on general practitioner perceptions on multimorbidity is still limited, especially where end-of-life care is concerned, so this data provided a unique opportunity to examine the generalisability of general practitioner attitudes to the issues. The results show that about half of Australian general practitioners consider more of their patients to have multimorbidity than not. They also highlight that multimorbidity management requires more time than they have available to them, and that the uncertainty associated with multimorbidity can be compounded by an incomplete evidence base for care. These findings support those of the earlier qualitative study in this thesis, providing further evidence that multimorbidity has a considerable impact on practitioners as well as their patients.

While several participants said they found multimorbidity care to be stimulating and rewarding, the majority identified factors they perceived made the work challenging, impacting their workday, life outside of clinic hours, and even the attractiveness of general practice as a specialty. Across both the quantitative and qualitative analyses within this study, limited consultation time under the Medicare fee-for-service model emerged as the prime issue of concern for general practitioners. It also emerged as the strongest latent factor in the factor analysis. Nearly all those surveyed believed it hindered patient care and, especially for less experienced general practitioners, did not provide an opportunity to address preventative measures to reduce risks of future problems. The reason for this difference across age lines may reflect the different patient mix seen by younger and older general practitioners. An analysis of data from the Australian Bettering the Evaluation and Care of Health (BEACH) study has shown that general practitioner registrars have significantly less exposure to patients with chronic diseases and deal with a lower average number of problems per consultation than more experienced general practitioners.[930] Study findings do not confirm if the ability to deal with more within the limited space of the consultation develops through maturation of skills, a gradually expanding complex patient base, or both these factors. What is clear, however, is that lack of time leaves most general practitioners constantly running late with appointments, with the majority stating they relied on unremunerated time outside of clinic hours to get work finished.

The survey did not include specific questions on general practitioner remuneration; however, this emerged as an essential issue for general practitioners in the qualitative comments and one closely linked to consultation time. Some general practitioners used words such as 'penalises' and 'insulting' to describe the Medicare rebates available to them, which declines per minute across the length of the consultation.[411] Some compared their work trying to manage patients ‘in their entirety’ with the approach of ‘single organ specialists’ who, according to one general practitioner, ‘just follow the money’. The Royal Australian College of General Practitioners (RACGP) recently highlighted general practitioner concern over remuneration in its 'Health of the Nation' survey of general practitioners. Here general practitioners listed Medicare rebates and funding models for primary care as the two top issues they want the Australian Government to address as a matter of priority.[411]

The exploratory factor analysis suggested an association between the issue of consultation time, general practitioners' perception that they are occasionally uncertain on a course of action, and specific causes of clinical uncertainty. Most general practitioners saw guidelines as unsupportive of multimorbidity care, which may explain their near-unanimous expression of concern that their patients might experience adverse drug interactions or burden of treatment. However, elsewhere general practitioner responses about research evidence appear contradictory. Around 70% stated they adhered to guidelines when providing care to patients with multimorbidity. At the same time, and appearing to be at odds with this view, 70% believed there was little evidence to support multimorbidity care and 61% stated they ignored evidence, basing decisions instead on patient preferences and circumstances. The comparatively high proportion of neutral responses given for questions on research evidence and guidelines may suggest a need for simpler question wording, more questions that drill down to the issues, or more nuanced response options to explore what appears to be a multifaceted issue.

What stands out as a facilitating factor in multimorbidity care for nearly all general practitioners is knowledge of their patients, gathered over time, or through relational continuity. As one recently fellowed general practitioner stated in relation to older patients, ‘Getting to know them over time definitely is the biggest factor in my ability to care for them.’ Again, this accords with findings from earlier studies in this research program.

General practitioners provided a more diverse range of opinions in response to questions about palliative care provision for patients with life-limiting illnesses and comorbidities. Most believed multimorbidity care became more straightforward as the person approached the end of life, while just over one-third perceived it became harder or that difficulty depended on the index condition. Views on the ability to prognosticate in the presence of comorbidities, however, were more clear-cut with only 20% of general practitioners believing comorbidities had no bearing on the general practitioner's ability to determine where a person was in the disease trajectory. Perspectives on multimorbidity care at the end of life were, therefore, somewhat more diffuse and, like general practitioner opinions on evidence for multimorbidity, hinted at areas of grey requiring further investigation.

The study identified a positive association between the general practitioner’s number of years since graduation and engagement with multimorbidity and palliative care. This finding is to be expected if we accept that experienced, usually older, general practitioners have a higher proportion of older patients with multimorbidity approaching the end of life than their younger colleagues.[889] One study suggests a link between exposure to palliative care and confidence and willingness to provide it,[931] highlighting a conundrum for the future of this work. If older general practitioners have more confidence providing palliative care from having more exposure to it, and therefore more opportunities to develop these skills, how might younger clinicians gain entry to this virtuous cycle? More or better palliative care education and training across all levels of medical education and training appears to be a necessity,[890, 932] and a deficiency general practitioners themselves acknowledge.[465, 466] Moreover, any education needs to be complemented by opportunities to gain practical experience. Palliative care has been labelled a ‘low prevalence, high impact activity’ in general practice,[836] estimated to comprise 1 in 1000 encounters,[446] which makes it challenging for clinicians to maintain their skills.[836] However, studies suggest patients with palliative care needs may be more prevalent in general practice than clinicians perceive them to be[465] and that it is possible that general practitioners are already providing palliative care without recognising the activity as such.[890] Certainly, if specialist palliative care sees as few patients with non-malignant conditions at the end of life as research suggests,[328, 933] while at the same time a large proportion of Australians are dying of these same conditions,[300] it follows that general practitioners must be providing a minimum of care to these patients across their often long trajectories.[934]

A further impediment to younger clinicians gaining exposure to palliative care may be the changing nature of the Australian general practice workforce. Currently, fewer medical graduates are showing an interest in entering general practice training and those who do enter are increasingly female[411] and likely to prefer to work part-time.[411, 935] Unlike an earlier study,[465] this research did not find a significant difference between genders for palliative care participation. However, elsewhere an association between part-time work and limited palliative care involvement has been established.[833] Furthermore, Australian general practice has an ageing workforce with 37% of its general practitioners currently aged 55 years and over[411] with many perhaps looking towards retirement. For general practice to cope with the anticipated coming demand on their services, its emerging workforce will have no choice but to become experts in both multimorbidity and palliative care. All efforts should therefore be made to support early career general practitioners to take up education and training opportunities on care of older patients with life-limiting illnesses. General practitioners supervising trainees might do more to ensure their younger colleagues achieve a balanced patient mix. Furthermore, Australia's Primary Health Networks might be proactive in raising the awareness of younger general practitioners as to the palliative care part of their role and the supports available to them. They might also contribute by connecting general practitioners with local residential aged care facilities, locum services with palliative care experience, and supportive contacts from hospital or community-based services within their catchments. The untapped potential for Practice Nurses to lead general practice palliative care, perhaps with home visits as a core feature, might also be investigated further.[454]

7.5.1 Study strengths and limitations

This cross-sectional study was the first to survey Australian general practitioners on their experiences in managing the care of patients with multimorbidity. As such, it has provided valuable insights into the nature of this work. It has also, through near unanimity of general practitioner responses, confirmed and added strength to findings from the preceding qualitative study (Chapter 6).

The survey tool itself had strengths. Its content was derived directly from information gained through in-depth interviews with a sample of Australian general practitioners, thereby ensuring its content validity. The survey was also piloted with two general practitioners who affirmed its face validity and provided beneficial information to improve readability and reduce ambiguity in wording. Furthermore, exploratory factor analysis demonstrated construct validity across the

Likert-type questions. It identified associations between items which, when translated into constructs, aligned reasonably well with the item groupings used by the researcher. For example, four of the five questions on the ‘General practitioner-patient consultation’ became the construct ‘Impact on consultation time restrictions.’ Furthermore, the two other latent constructs that emerged reflected two themes from the preceding interview study (‘Concerns for patient safety’ and ‘Integrating other forms of knowledge’) although the researcher had not grouped question items according to these themes. The survey also used different question types and allowed for open responses at several points which resulted in some rich qualitative data for analysis.

The study was limited by several factors. Firstly, the response rate was lower than needed to adequately power the study according to the power calculation. Although general practitioners are known to be difficult to engage in survey research, the researcher trialled several strategies to maximise response rates, including personalised invitations, limiting survey length to take no more than five minutes to complete, and keeping the questions short and straightforward to minimise cognitive load. Low response rate might be partly attributed to the timing of the survey, which was during the first year of the COVID-19 pandemic when general practices were dealing with unprecedented changes to their everyday operations. The lack of follow-up reminder may have also affected the response rate. It was interesting to note that the print mailout of the survey produced a better response rate than the same information sent via email. This same outcome was observed in a meta-analysis of recruitment techniques[936] and when sampling general practitioners.[871] However, the relative success of the Facebook post may suggest that general practitioners are presently more likely to attend to study invitations delivered via less traditional means.

Several characteristics of the final sample should be highlighted. Female general practitioners and those working for an Aboriginal Medical Service appear to be overrepresented in the sample. Furthermore, 34% of the respondents reported working in aged care, which is a much higher rate than the 11% reported in a recent RACGP survey of 1782 general practitioners.[411] The survey also did not identify overseas-trained general practitioners. Overrepresentation of these general practitioner groups may indicate an element of self-selection bias at work whereby general practitioners working in contexts where multimorbidity is prevalent (aged care and AMS) have a stronger impetus to participate than those with less exposure to multimorbidity or older patients. Self-selection bias cannot be ruled out as an explanation for some of the strong and near unanimous responses seen on several questions. The influence of topic interest on the survey might have been reduced by offering a monetary incentive.[937]

Unfortunately, it was not possible to determine the characteristics of non-responders to understand if they differed systematically from responders, their absence thereby shaping the results in some way. For example, the low number of participating male general practitioners may be indicative of gender differences in attitudes towards the topic of the survey or of higher male general practitioner workloads. Without this information it is not possible to know if important and potentially countering views have been missed. Finally, some nuance in responses may have been lost by collapsing the original five Likert scale options to three to meet assumptions for several of the statistical tests.

7.6 Conclusion

This study confirms many of the findings of the earlier studies in this thesis. It shows that most of the Australian general practitioners surveyed find multimorbidity management challenging, occasionally experiencing clinical uncertainty as to the best approach to take. Furthermore, general practitioners attribute some of this difficulty to health system and policy factors including lack of appropriate consultation time to provide quality care, a considerable requirement to provide unpaid work, and remuneration incommensurate with the complexity of the work. Patient safety concerns featured strongly in general practitioner responses, including the potential for adverse drug interactions and burden of treatment. General practitioners' views on the application of research evidence to patients with multimorbidity appear to be complex and contradictory and worthy of further investigation using more nuanced means. However, most general practitioners valued the relationships they develop with patients, using the knowledge they gained through repeated encounters to help in making decisions in lieu of generalisable research evidence.

CHAPTER 8 DISCUSSION AND CONCLUSIONS

8.1 Introduction

Multimorbidity is a complex public health issue for healthcare systems and the clinicians responsible for its management. This research has shown that the nature and extent of this complexity are readily apparent in the Australian general practice setting. General practitioners have described some of the interrelated uncertainties they face in providing both evidence-based and patient-centred care, from the heterogeneity of patient conditions through lack of multimorbidity evidence, to systems designed for a pre-multimorbidity time. Most appear to negotiate their way through uncertainty by fostering and acting according to their knowledge and understanding of individual patients. Many take on responsibility for coordinating care in the interests of patient safety. However, Australia's population is ageing and, with more people expected to have multiple conditions in the future, this will put pressure on general practices to remain sustainable under the current fee-for-service model. Reform of the current model to fit the new reality of complex, older patients with multimorbidity will be needed to ensure equity of access and quality of care for this population.

Many conditions associated with multimorbidity are life-limiting. Therefore, this thesis also examined the complexities of multimorbidity for end-of-life care in general practice, seeking to understand how general practitioners provide care across the active management and palliative care phases. The findings echo issues reported in the Royal Commission,[28] arising from a substantial proportion of Australian general practitioners not providing a service into residential aged care. Neither do many general practitioners continue to care for their clinic patients once they recognise the end-of-life phase. If this is not addressed, it may diminish general practice's claim to being the discipline most invested in providing continuity of care and relational continuity. Furthermore, general practitioners' lack of exposure to aged, dying people may have significant ramifications for the healthcare sector and Australia's person-centred care aspirations[87, 534] over the coming years.

The thesis followed an exploratory sequential mixed methods design. This design allowed the researcher to gather different forms of data on the issue to form a more faceted and supported overview of the problem. The design proved well-suited to a researcher coming to the topic without a background in general practice and no pre-existing perspective on the issue of multimorbidity management. The exploratory approach allowed the researcher to develop knowledge of the problem inductively and cumulatively. This knowledge then informed the next research phase. Chapter 4 was a systematic review of existing studies reporting the direct experiences of general practitioners from countries with similar healthcare systems to Australia. The verbatim quotes of general practitioners provided the data for analysis and revealed, amongst several issues, a lack of readily generalisable evidence for managing multimorbidity in the general practice setting. To determine if Australian general practitioners similarly found evidence generalisability problematic, the researcher first needed to identify and examine the sources most likely to be used by them within the primary care setting. A content analysis of Australian clinical practice guidelines for life-limiting conditions therefore followed which established guideline level of acknowledgement of comorbidities, drug interactions, or the more limited life expectancy of older people in general (Chapter 5).

The analysis was also an opportunity to understand how guidelines might support general practitioners in providing high quality, whole-person general palliative care to patients once a life-limiting chronic condition had entered its latter stages. Once the researcher confirmed the limited applicability of these guidelines to older people and those with complex multimorbidity, it was possible to develop an interview guide for in-depth exploration of the perspectives of Australian general practitioners on the issues (Chapter 6). Twelve general practitioners provided their insights and perspectives of multimorbidity management based on their own experiences. These interviews revealed some problems unique to the Australian context and others shared with their international counterparts. General practitioner first-hand perspectives informed a survey tool subsequently administered to a larger sample of Australian general practitioners (Chapter 7), thereby providing a means to assess the generalisability of the interview responses.

This Discussion chapter now integrates the findings from all three Australian-based studies using joint display tables to answer the overarching thesis research question: *What is the Australian general practitioner's experience of negotiating evidence-based and patient-centred approaches in managing multimorbidity across the adult lifespan?*

By integrating the results across studies, the researcher can see if the individual study findings confirm or contradict each other. The method also makes it possible to draw meta-inferences across the whole, informing conclusions, implications, and recommendations. This final analysis stage is structured using the conceptual framework of Evidence-Based Medicine and Patient-Centred Care, as described in Chapter 2.

8.2 Negotiating evidence in managing multimorbidity

Joint display tables 8.1 through to 8.4 present integrated data on the Australian general practitioner experience of using research evidence in managing patients with multimorbidity across the care continuum. Each table covers a different domain of the issue. Findings from study 1, the systematic review of international qualitative studies, were also included to facilitate comparison.

Patient complexity

The thesis findings reveal that most Australian general practitioners perceive consultations involving multimorbidity (as defined by WHO[78]) to be the norm rather than an infrequent occurrence in daily practice. This finding, supported by a 2017 cross-sectional study of Australian general practitioners,[89] arguably needs greater acknowledgement by policy-makers for its implications as more of the population reaches an older age. The research also highlights a crucial mismatch between the heterogeneity of conditions seen in Australian general practice, the complex reality of people's lives, and the reductive simplicity of Australian clinical practice guidelines for life-limiting chronic conditions.

As evident in Domain 1 of Table 8.1, Australian general practitioners find patients with multimorbidity more challenging to manage, often because of a significant and intractable interplay between a person's physical concerns—especially poor functional capacity[938]—and problems of a psychological or non-medical nature. Furthermore, these interactions are unpredictable and can have more of a bearing on a person's well-being than their absolute number of conditions.[939] Guidelines are unlikely to address these non-medical contributing factors, which means the challenges inherent in managing the largest portion of patients seen in Australian general practice may lie outside the scope of research evidence. Therefore, it may not be surprising that 79% of surveyed Australian general practitioners representing all levels of experience admit to being occasionally uncertain how to manage this subset of their patients. For some, trying to align patients' real-world needs with recommendations from purified and codified evidence appears to create a sense that 'the map and the terrain simply [do] not match.'[809(p3)]

Table 8.1 Guideline and evidence support for addressing multimorbidity

Domain 1: The heterogeneity and complexity of multimorbidity	
Systematic review	• *There are no guidelines yet which can encompass ‘complexity-based medicine’. To grasp how to work with the complexity we confront as GPs requires a massive, theoretical quantum leap. Perhaps in 10–15 years we will realize that all of today’s reductionist guidelines within the natural sciences were wrong and had led us astray.*[809(p3)] • *The GP feels powerless to solve social, work and family related problems.*[797(p7)]
Qualitative study (In-depth interviews)	• *I saw a lady today, and she has gastric problems, she's osteopenic, she’s hypertensive, she’s got hypercholesterolaemia, she’s got COPD. And she’s also got some fibromyalgia, but now she’s got low iron … And it’s like, ‘where do I really start?’* (GP1) • *I find it very challenging. In general, it can be very draining, especially because the comorbidities will often coincide with mental health issues and things like that. The patients are really complex.* (GP3) • *There are so many factors that aren't just the medical, but they’re social.* (GP4) • *It’s just the sheer complexity of everything that impacts on their lives and their medical conditions that are really hard to grapple with on that intellectual, scientific basis.* (GP6) • *It’s the full biopsychosocial model in managing them.* (GP6)
Guideline content analysis	Guidelines with specific recommendations for patients with one comorbid condition: 8/11 Guidelines with specific recommendations for patients with two or more comorbid conditions: 1/11 Guidelines discussing possible interactions between medications related to comorbidities: 3/7
Quantitative study (Survey)	Compared to managing patients with single chronic conditions, I *generally* find managing patients with multimorbidity to be more challenging to manage: 84.5% (147/174) • *Often can’t get ideal management of any condition as fixing one adversely affects the other.* • *It is incredibly challenging and seems to be getting more complex with increased patient expectations and more medications to be aware of.* • *Presentation can be ambiguous or confused or there can be weird stuff which there isn't literature on at all.* • *I am seeing comorbidity associated with trauma, intellectual disability or non-neurotypical presentations, unusual genetic disorders, inflammatory conditions.*

	• *Multimorbidity with MH [mental health] and A+D [alcohol and drug dependence] is highly complex but ubiquitous.* • *Hugely complex social conditions, family issues, financial problems all connected with disease.*
Data convergence	Convergent
Meta-inference	Australian general practitioner participants experience many of their patients with multimorbidity as complex in their variable disease combinations, the interactions between conditions and drugs, and the interplay between health, psychological and social factors. Most describe patients with multimorbidity as more difficult to manage than those with single issues. Australian guidelines for major life-limiting chronic conditions might address one additional condition but provide few specific recommendations for managing patients with more than two comorbidities, despite this being a commonplace scenario. With only a few exceptions, the evidence does not acknowledge cumulative comorbidity, either biomedically or psychosocially, insofar as it might impact on the management approach.
Domain 2: Availability and generalisability of evidence to patients with multimorbidity	
Systematic review	• *But you don't have guidelines a lot in the elderly, do you? That's the hardest thing.*[780(p7)] • *[A] guideline for diabetes or hypertension is based on, I don't know, research on 40-60 year olds ... with mono-morbidity, probably. …. And what's that worth for an 80-year-old patient with multimorbidity?*[793(Suppl p[3])] • *A lot of situations are more complex than CARPA can handle because of multiple comorbidities.*[785(p6)] • *The map and the terrain simply [do] not match.*[809(p3)]
Qualitative study (In-depth interviews)	• *So, the guidelines aren't necessarily based on our age group. And usually, they nearly always pick patients who don't have other co-morbidities to develop their guideline.* (GP8) • *Almost always the multimorbidity modifies what you do … [W]e just look at a guideline or protocol and just shake our heads sometimes and just go 'we cannot do it with this person.'* (GP8) • *Well, just that single disease guidelines rarely take account of multimorbidity. They do to some degree. So, for instance, the diabetic guidelines, you can cross reference with hypertensive guidelines and so forth.* (GP9) • *I'm not sure whether these studies recruit people with multiple morbidities and I don't know whether they necessarily apply to the patients I have in front of me either.* (GP12)
Guideline content analysis	Guidelines addressing treatment for older patients with multiple comorbid conditions: 3/11

	Guidelines addressing quality of evidence for older people: 5/11 Guidelines addressing quality of evidence for older people with multiple morbidities: 2/11 Guidance example: ‘Comorbid conditions are common in patients with COPD (NHMRC: III-2, GRADE: Strong)’[854]
Quantitative study (Survey)	There is little available evidence on how to manage patients with multimorbidity: 69.9% agree; 11.4% disagree; 18.8% neutral. Single condition guidelines are difficult to generalise to people with multimorbidity: 86.9% agree; 5.7% disagree; 7.4% neutral. **Facilitator:** Availability of clinical practice guidelines and other evidence tools: 116/176 (65.9%) • *Medical research needs to progress towards including in their study populations patients with multimorbidity (and also the elderly) and also those with complex social determinants of health.* • *Often literature has exclusions for ‘other significant conditions’, so then it means extrapolating from this to the person in front of us.* • *GP led research will help develop better guidelines for these patients.*
Data convergence	Convergent
Meta-inference	General practitioners across studies appear to hold contradictory views on the availability and applicability of the research evidence for patients with multimorbidity. Most, but not all, Australian general practitioners believe there is little available evidence to guide their work with these patients. However, a sizable proportion (19%) remain neutral on the question of availability. More general practitioners consider single condition guidelines difficult to generalisable to their patients with multimorbidity, although 66% cite the availability of guidelines as a positive facilitator in their care to this population. General practitioners appear aware that underlying trial evidence excludes their older and more morbid patients to favour efficacy over effectiveness. They also viewed information on benefits and harms as applicable to the mean of a very narrowly defined target population. Older patients, who are those proportionately more likely to have multimorbidity, are infrequently referred to within guidelines.

As experienced by the clinicians in this study, the complexity of multimorbidity led several participants to question its prevailing two-condition definitional threshold[109] as overly simplistic and incapable of conveying the impact of multimorbidity on their patients' lives. Some suggested the term should be kept in reserve for people with physical or mental morbidities made more difficult to manage by the presence of developmental or learning problems, cognitive or functional impairment, disability, or a lack of social or economic capital. This view of multimorbidity accords well with conceptual frameworks of patient complexity such as the Cumulative Complexity Model,[122] the Vector Model,[121] and the Complexity Framework.[127] These models emphasise what general practitioners appear to know already—that multimorbidity is often complex across various factors at the level of the disease, patient, environment, or healthcare system.[120] Furthermore, multimorbidity is dynamic with minor changes in one domain capable of creating cascading changes in other domains.[120]

Evidence availability and generalisability

Most (70%), but not all, Australian general practitioners in this study believed there was little available evidence to help them manage multimorbidity; however, more (87%) considered the available evidence challenging to apply to their patients. This gap between perceived availability and applicability is interesting, considering general practitioners appear cognisant of a bias in the evidence arising from non-inclusion of older patients and those with frailty in the underlying research (Domain 2, Table 8.1). The Chapter 5 content analysis of Australian guidelines for life-limiting chronic conditions confirmed this bias when it found only 3 of 11 guidelines suggested, often minimally, that older patients may require a different or modified approach to that put forward by a recommendation. Fewer guidelines again discussed the quality of the evidence pertaining to older people. However, the marginalisation of older people in guidelines is not a new problem. Researchers have reported on it across numerous studies over the past 20 years.[100, 103, 700, 703, 940]

The content analysis also confirmed the inadequacy of guidelines to help general practitioners deal with more than one condition at a time. While 8 of 11 guidelines referred to the management of two problems concurrently, only one addressed more than this. Moreover, the guidance focused on specific conditions with no use of the general term 'multimorbidity' or reference to the lived experience of cumulative morbidity. Despite the well-known Australia-wide National Prescribing Service MedicineWise campaign,[941] only three of the guidelines warned of the potential for adverse outcomes in prescribing medications across conditions. Fewer referred to *polypharmacy*. Integrated advice on when and how to deprescribe safely, a task known to cause uncertainty and variability in practice amongst general practitioners,[779, 781, 942] was not apparent in the guidelines assessed. These omissions may undermine the usefulness of guidelines for general practitioners where risks of drug-drug and drug-condition interactions are possible. This patient safety risk emerged as a significant concern for most Australian general practitioner participants (95.5% in the survey), perhaps because of this lack of guidance to support decision-making. The systematic review revealed it to be also a prime concern of general practitioners internationally.

There may be practical reasons why guidelines omit to include direct, gradable evidence covering the concurrent management of more than two conditions. Firstly, little research has been conducted into the aetiology of multimorbidity to allow for solid conclusions on what is needed to prevent it or its complications.[49] However, researchers into multimorbidity's causes appear to be making some progress in viewing multimorbidity as a predictable cluster of diseases that share common genetic, behavioural, and environmental pathways rather than a random coalescence of conditions.[943] Although guidelines are unlikely ever to address a comprehensive range of disease combinations, these clustering studies may make it possible for them to include the most interrelated ones and their pharmacotherapies. As a matter of course, guidelines might also include advice on diagnosing and managing comorbid mental disorders as these appear to have a two-directional and detrimental bearing on an individual's overall management capacity and quality of life.[173] Second, guidelines are silent on management interventions for multimorbidity as trials of their effectiveness continue to prove inconclusive.[99, 944] Furthermore, innovative care models, which might otherwise influence policy, remain unvalidated at scale[945, 946] or unable to demonstrate impact on important patient outcomes.[596]

Table 8.2 General practitioner uncertainty and risk perception associated with multimorbidity

Domain 3: Clinical uncertainty associated with evidence and multimorbidity	
Systematic review	• *The insecurity that a 'guideline hell' brings is negative, but that is not talked about very often.*[809(p3)] • *[W]hen that kind of person comes in my heart sinks a little because I'm thinking what do I do now? I'm thinking what am I going to do this time? Will I be able to cope?*[947(p5)] • *The problem is that you are trying to weigh up unmeasurable harm quite often against unmeasurable benefit. We are trying to do that in our minds and trying to work it out. Is it more likely to be doing benefit or more likely to harm? The truth is that, in many cases, I don't know.*[781(p1939)] • *Struggling yeah, it's just not feeling that confident, not feeling that confident about managing one condition, but realising it has an impact on the other one, affecting it adversely. I'm not sure what balance to strike.*[786(p4)]
Qualitative study (In-depth interviews)	• *You have rough ideas, and things are always changing as well. And you go, 'Well, what do we do?'* (GP1) • *It's kind of higher stakes, because it can be harder to resolve clinical uncertainty because of less access to tests and whatnot. And people are, generally speaking, people are more sick.* (GP2) • *[I]f somebody's got diabetes, and they've got a bleeding score, and they've got dementia? How do you craft the diabetes guidelines for that person?* (GP5) • *[T]he hard core intellectual aspects of dealing with their medical conditions is really complicated. Especially if you are new to the game and haven't built up that level of experience and knowledge.* (GP6) • *The challenges of looking after people with multiple chronic conditions is it's hard to harmonise the care for each of the conditions tailored to the patient. So sometimes treating one might not be helpful to the treatment of the second condition or the third condition.* (GP12)
Guideline content analysis	Guidelines with specific recommendations for patients with two or more comorbid conditions: 1/11 Guidelines discussing possible interactions between medications related to comorbidities: 3/7
Quantitative study (Survey)	I am occasionally uncertain as to the best course of action with these patients: 79.0% agree; 5.1% disagree; 15.9% neutral. The potential for adverse interactions between drugs and conditions concerns me: 95.5% agree; 0.6% disagree; 4.0% neutral. • *Often the different clinical guidelines can contradict each other*

	• *I do my best in the shades of grey areas. Many times, things that are frowned upon work out fine.* • *Learning to sit with uncertainty as in many cases, there aren't clear guidelines.*
Data convergence	Convergent
Meta-inference	A large proportion of Australian general practitioners across the studies in this thesis describe experiencing uncertainty in determining what to do for their more complex patients. Following guideline recommendations requires them to balance potential benefits against harms of multiple medications across a range of conditions with few, if any, tools to guide them. Australian guidelines for life-limiting conditions provide little support. The uncertainty associated with multimorbidity management raises safety concerns and appears to affect experienced and relatively inexperienced general practitioners alike.
Domain 4: Perception of risk of guideline-induced inappropriate polypharmacy and burden of treatment	
Systematic review	• *You sometimes find that they have become over-medicated, but according to the various guidelines, you just have to do it. You can't really treat people like that, right?'*[791(p4)] • *But when the patients have several diseases, there are too many guideline recommendations. Especially when patients are getting older, how much medicine should you give them?'*[809(p4)] • *'It's also very overwhelming to them. They're on 15 different medications because everybody has been giving them all, but taken altogether, it's just too much'.*[796(p8)] • *If you follow guidelines, they must take more than 20 drugs, and the role of the GP is to reduce it to four or five drugs. Otherwise, the patients do not take it . . . which we observe from their electronic records.*[788(p5)]
Qualitative study (In-depth interviews)	• *So, you know, if we gave them all the recommended tablets for all of these conditions, they would be on 35 tablets, and not many people will take 35 tablets. So, then there's a possibility that they won't take any.* (GP2) • *I think a lot of patients are put off by the amount of things that get done and things that get done because of protocols ... We've got too much guideline work.* (GP4) • *It's something I haven't come to terms with how to sort out, other than recognising a number of these people we overmedicalise, we don't do enough lifestyle work and we don't regularly enough review their medications and aggressively or actively deprescribe* (GP6). • *And sometimes you know, if you've got someone on say 26 different medications, one certainty is there's going to be a problem.* (GP7) • *People are on a lot of medications and that's not actually very good for you when you're old ... And even though I've sent*

	[specialists] the medication list … they're definitely not totally across … what interactions might occur. (GP8) - *Polypharmacy is a problem in an ever-aging population, and it is also a problem stemming from … the specialisation of medicine and medicalisation of conditions, plus the worries around litigation* (GP12)
Guideline content analysis	Guidelines addressing burden of treatment on patients or caregivers: 6/10 Guidelines discussing possible interactions between medications related to comorbidities: 3/7
Quantitative study (Survey)	Patients with multimorbidity risk being burdened by too much treatment: 94.3% agree; 2.8% disagree; 2.8% neutral. The potential for adverse interactions between drugs and conditions in multimorbidity concerns me: 95.5% agree; 0.6% disagree; 4.0% neutral. - *Some older patients are reluctant to follow through at times as they are 'sick of seeing specialists' and the endless trips out each week for investigations* - *Difficult to apply guidelines when someone has multiple conditions on multiple medications, and I don't fully understand why they are what they are on.* - *Massive increased risk of drugs ADRs and drug-drug ADRs.*
Data convergence	Convergent
Meta-inference	Adhering to guideline recommendations in the context of multimorbidity carried the risk of overburdening the patient with treatment to which they would struggle to adhere. General practitioners attributed some of the blame for too much treatment to specialists who focused solely on their own area of responsibility, consequently failing to see the whole patient. They also blamed the medicalisation of problems, and their own lack of time to review patient medicines to deprescribe those no longer proving beneficial and non-harmful.

Clinical uncertainty and risk perception

As shown in Domain 3 of Table 8.2, many general practitioners experience uncertainty and a sense of risk working in the 'shades of grey areas' of multimorbidity. High clinician uncertainty, more often a characteristic of less experienced general practitioners,[948] should be of concern to policy-makers as it associates with stress, poorer job satisfaction,[405, 949] and increased use of healthcare resources.[950, 951] Part of this uncertainty lies in weighing the benefits and risks of alternative management approaches across multiple guidelines without jeopardising patient safety. It is not possible to know the extent to which clinician statistical literacy or the omission of absolute benefit and harm statements in guidelines contributes to this problem. Several studies have reported generally poor general practitioner quantification of the absolute chance of benefits or harms of treatment to the extent that their knowledge would impede clinical decision-making.[952-954] General practitioners have expressed a desire for more of this information,[800, 954] and there may be scope for guidelines to provide it as part of their recommendations.

Australian general practitioners were also concerned for risks associated with cumulatively applying guideline recommendations to individual patients (Domain 4, Table 8.2). Many associated this with a high burden of treatment carrying its own set of risks such as inappropriate polypharmacy, non-adherence, medication errors, litigation, and harm to the trust between the doctor and patient. General practitioners attributed much of this problem to the guideline-concordant behaviour of other specialists involved in a person's care. Many of those interviewed were able to narrate specific episodes where they had to take responsibility for the problems siloed prescribing created for patients.

Table 8.3 Resolving uncertainty through action

Domain 5: Protocol adherence versus using clinical judgement	
Systematic review	**Reasons for adhering to guidelines** • *We could always go back to CARPA [guideline developer] and say, 'Look, this is how we're doing it and that's what's in the book. So leave us alone.'*[785(p7)] • *When I deviate from the guidelines, I am careful to write down my reasons down in the patient record … Good record-keeping helps protects me.*[809(p4)] • *I have difficulty not following the guidelines if I don't have good reasons to do so.*[800(p5)] • *It's also dangerous, doing your own thing, because then it's just like the way it used to be ... and you do wish that some things were sorted out.*[793(Suppl p[2])] **Reasons for deviating from guidelines or satisficing**[706] • *[Multimorbidity] gives you a lot of freedom to use your experience and own ideas as a doctor to help the patient's problem.*[793(Suppl p[4])] • *I think, as you get older, you realize that [a patient safety recommendation] is not really true because you have done it so many times and they have not had a stroke the next week.*[781(p1943)] • *I think, not perfectly managed, but managed well enough within that person's individual parameters.*[806(p4)] • *I see how patients go into the hospital and have new medications added because the hospital has followed the guidelines. We often have to take responsibility later for having the patients discontinue some meds and we thereby 'break the rules'. That's no easy job! But we have to try to see the whole patient.*[809(p4)]
Qualitative study (In-depth interviews)	**Reasons for adhering to guidelines** • *If [patients] go on to see someone else, they are not going to necessarily question why you've suddenly tried to reduce that PPI they may not need* (GP1). • *If you've got evidence-based guidelines, it's easier to … you know what you're doing.* (GP1) • *[I]f we're not following a consensus guideline then we are all ... We are counteracting what everyone else is doing* (GP1) • *I think because the patients are so complex, and one thing can affect the other so easily, I tend to always look to guidelines.*

	Yeah, I rely on them a lot. (GP3) • *I love guidelines because … guidelines are evidenced-based* (GP11) • *I would not modify it. I'd go by it. But I would discuss the pros and cons on treatment options.* (GP12) **Reasons for deviating from guidelines or satisficing** • *If the guidelines say to keep adding but the patient either can't afford them or, you know, doesn't … they've got too many risk factors for it, then I won't follow it to a tee but try and have a balance between what the guidelines say and what would suit the individual patient.* (GP3) • *[U]ltimately, they're often not terribly helpful.* (GP4) • *Guidelines are good but they're good for populations. They don't apply to individuals.* (GP6) • *We should all be following these guidelines. But if you actually look at the guidelines, the evidence base for them is very low.* (GP6) • *And that's where guidelines and protocols sort of go wrong. They stop people thinking and analysing properly.* (GP6) • *Almost always the multimorbidity modifies what you do ... [W]e just look at a guideline or protocol and just shake our heads sometimes and just go 'we cannot do it with this person'.* (GP8) • *Yeah, but if you happen to have really old patients, and they have other problems ... You would rather put up with a slightly higher HbA1c than risk them becoming hypoglycaemic.* (GP9)
Guideline content analysis	Most of the guidelines studied included a disclaimer directing clinicians to exercise their own independent skill or judgement.
Quantitative study (Survey)	I tend to adhere to guideline recommendations in managing patients with multimorbidity: 69.9% agree; 10.2% disagree; 19.9% neutral I tend to rely more on what patients want and their personal circumstances than what the guidelines recommend: 60.8% agree; 13.1% disagree; 26.1% neutral. **Facilitator:** Availability of clinical practice guidelines and other evidence tools: 116/176 (65.9%) • *I have become a pattern watcher and find it helpful to see these conditions not as separate conditions - but as processes that interact - often with a similar underlying stressor - so I find addressing that underlying process is my best management skill.* • *Even guidelines do not necessarily follow best evidence. For example, why do we continue to measure lipids (annually per guidelines and quality measures) if someone is already on cholesterol lowering drugs.*

Data convergence	Convergent
Meta-inference	Despite uncertainty, a belief that there was little available direct evidence, and concerns for guideline generalisability, 70% of Australian general practitioner study participants said they tended to adhere to guideline recommendations for patients with multimorbidity. For some, multimorbidity gave them license to rely more on their clinical judgement in weighing up management options. They might feel justified in deviating from recommendations based on their perception that the evidence was of low quality, too prescriptive, or impractical for the patient based on contextual factors. Others viewed guidelines as important for standardising practice across sectors and providing a solid foundation for justifying decisions under conditions of uncertainty.
Domain 6: Reliance on alternative forms of information, evidence, knowledge	
Systematic review	• *I think there are two important things with this case, firstly how well the GP knows the patient so he can compare them to their baseline and secondly an objective assessment, oxygen saturations, respiratory rate, heart rate, all these sort of things, a clinical consultation, I think.*[798(p5)] • *[T]o bounce [ideas] off your colleagues just helps, even if it is just something like ‘what in the name of God am I going to do about this’, it’s really important.*[788(p188)] • *It’s easier in a face to face consultation, you can judge it much better. Especially when you know them and if they walk the corridor to your room you can tell how good or bad they are.*[790(p3113)] • *I suppose when you deal with people for so long you can, you know when they’re different, and you know … it’s more of an … intuitive thing, more often than not. You know when they’re not happy.*[805(p1060)]
Qualitative study (In-depth interviews)	• *I certainly know that our nurses here will come and say 'Mrs. [name] doesn't look too good today'. Well, they just know what they are like or how well they're functioning.* (GP5) • *It’s that relationship that builds up over time that you both know what the next answer’s going to be and what the next question is going to be. And what is most appropriate for that person. Because you both have that same sort of shared, you know, ‘these are the things that are important to me.’ That sort of shared understanding of the situation.* (GP6) • *But that only comes with experience and actually building that relationship with a person and seeing what happens over time with different scenarios and situations and just getting that ... a bit more of a feel about how you manage people rather than conditions because that’s what we’re treating. Individuals, not conditions.* (GP6) • *I frequently go and ask my registrars questions because I know that they're sharper on protocols and stuff like that … I think that general practice is much better in a team environment when you're dealing with multiple morbidity.* (GP7) • *I can't see [with telehealth] how they're walking. I can tell if they're on a bad day when I get them from the waiting room because*

	they sort of walk very slowly down the corridor to my room …So that gives me a wealth of information … [A]nd I could see if they're short of breath, hear if they're wheezing. I don't have any of that happening with the telephone. So that's really challenging. (GP8) • *I mean you've patients who you've known for so long and you see them, you just glance at them in the waiting room and you think, 'Gee there's something going on there.'* (GP11)
Guideline content analysis	NA
Quantitative study (Survey)	I tend to rely more on what patients want and their personal circumstances than what the guidelines recommend: 60.8% agree; 13.1% disagree; 26.1% neutral. Peers can be a trusted source of guidance on how to manage complex patients: 77.3% agree; 5.1 disagree; 17.6% neutral. **Facilitators:** Knowledge of my patients gathered over time: 173/176 (98.3%) Sharing knowledge and experiences with GP colleagues: 146/176 (83%) Collaboration with secondary care specialists: 145/176 (82.4%) • *[G]etting to know them over time definitely is the biggest factor in my ability to care for them, and the help of my colleagues.* • *Occasional difficult cases shared with colleagues in internet discussion groups.* • *I am slowing building a database of specialists I can tap on for assistance if I get truly stuck.* • *Also do HMR [Home Medicines Review] in most of these patients and learn a lot from the pharmacist who assesses them.*
Data convergence	Convergent
Meta-inference	General practitioners volunteered a diverse range of information or knowledge sources which they drew on in making clinical decisions with their patients. These included colleagues, practice nurses, specialists, experiential knowledge, sensory clues, and intuition. Chief amongst these important alternative sources was the general practitioner's tacit and explicit knowledge of the patient developed over a long period of time.

Resolving uncertainty through action

Like many of their international counterparts,[706, 793, 809, 955] Australian general practitioners differed in how they might act to resolve their uncertainty regarding multimorbidity. As shown in Domain 5, Table 8.3, most of those surveyed (70%) reported following guideline recommendations, and 65.9% cited them as a positive facilitator to this kind of care. This reported behaviour is difficult to interpret when set against the finding that 87% of the same cohort thought guidelines were difficult to generalise to patients with multimorbidity, and 70% said there was little available evidence. It suggests that guidelines are, at the very least, a base upon which to act and to work through uncertainty. Similar incongruity has been shown in a survey gauging Australian general practitioners' attitudes to polypharmacy in older patients. Here, 80% of clinicians expressed a belief that applying guideline-concordant care would burden older patients, although only 61% said they would feel confident deviating from guidelines to avoid this (27% neutral).[956]

Several interviewees who professed following guidelines may have provided some insight into this apparent discord. They perceived that because guidelines are *evidence-based*, they provide a reliable and rational alternative to chaos, and a transparent way to communicate decision-making to others without having to justify oneself. Personal fear of being criticised for providing non-standard and, by extension, substandard care may also lie behind their preference. A further study might delve deeper into the motivations of these general practitioners to understand if the approach represents pragmatism—using the best (or only) tools available for the job at the time—or a subtle pressure on general practitioners to demonstrate an evidence-based approach to decision-making, even if it causes them mental discomfort.

In comparison, a substantial segment of general practitioners (61%) said they tended to rely more on what patients wanted than guideline recommendations where multimorbidity was concerned. This attitude might resonate with those interviewees who believed it more important to exercise clinical judgement on a case-by-case basis than to rigidly apply standardised, population-based recommendations to unique individuals. Many of the general practitioners who described preferring a more fluid approach to decision-making could describe a range of other sources of knowledge which they cultivated to guide their decisions (Domain 6, Table 8.3). Chief amongst these was a reliance on knowledge of their patients, developed over time. Most of those interviewed could convey detailed knowledge of their complex patients' circumstances and capacities which they used pragmatically to rule in or out a particular course of action. This form of intelligence under conditions of uncertainty and contingency might be likened to the Aristotelean notion of *phronesis,* which Montgomery'[475(p5)] defines as the 'flexible, interpretive capacity that enables moral reasoners … to determine the best action to take when knowledge depends on circumstance.' Phronesis was particularly evident when those general practitioners working for an Aboriginal Community Controlled Health Organisation articulated their process of situational reasoning which served the practical end of achieving a better outcome for a particular patient.[957] Their reasoning engaged awareness of social determinants of health such as intergenerational trauma, kinship relations, experiences of socioeconomic hardship, housing and food insecurity, cultural beliefs about health and illness, and accessibility of services when living in geographic isolation, amongst others. Attuned as they are to these factors, it is not surprising therefore that ACCHO general practitioners cited social and cultural determinants of health and health equity and equality as their top two health policy concerns in a recent RACGP survey.[411]

Some of the more experienced general practitioners interviewed also described a practical wisdom approach to decision-making. Those with training responsibilities did so when they urged registrars and medical students to look for the unsaid and implicit when listening deeply to patients' stories. This might be interpreted as teaching their trainees to exercise and negotiate 'both explicit and unconscious elements of cognition'[958] when confronted by complexity. Practical wisdom was also evident when a general practitioner lamented the loss of patient visual clues when care moved to telehealth during the COVID-19 pandemic or when, under time pressures, it was not possible to encourage an older person's narrative when it ranged beyond medical problems. Greenhalgh et al.[486] call for more clinical judgement of this kind when questioning if Evidence-Based Medicine is a movement in crisis, using its poor fit for multimorbidity as one example of its limitations.[486] Instead of mechanically and defensively following rules and protocols, this call for an Evidence-Based Medicine *renaissance* bids clinicians to provide individualised care for the patient based on a judgement of their circumstances at a point in time, as well as a well-developed interpersonal patient-clinician relationship sensitised to context and individual goals.[486] Interestingly, this depiction of what Greenhalgh et al. call *real* Evidence-Based Medicine could describe Stewart's model of the Patient-Centred Clinical Method.[92]

General practitioners in this study also find support for their decision-making in sharing problems with colleagues or by drawing on the knowledge of their practice nurses when navigating areas of uncertainty. This finding, supported across the qualitative and quantitative phases of the study, resonates with the concept of collectively constructed *mindlines* in general practice,[959] which may more accurately describe the pragmatic way in which general practitioners have been observed to acquire and use knowledge in practice. Mindlines are the 'collectively reinforced, internalised, tacit guidelines' which general practitioners produce by combining information from a wide range of sources.[959(p1)] Sources may include guidelines and evidence from studies, training experiences, events relayed by colleagues and opinion leaders, and their own reading, amongst others.[959] These flexible 'amalgams of different kinds of knowledge'[960(p402)] can be iteratively modified over a long period by being shared and discussed with others, through accumulated personal experience, and by social, economic and organisational demands.[961] They are also inherently social, being formed within communities of practice. Furthermore, clinician acceptance of knowledge of various origins might contribute to more appropriate healthcare than what is achievable by purely following the 'linear rationalism' of guidelines.[960] If so, mindlines should be acknowledged as a suitable decision-making approach in multimorbidity.

Evidence and multimorbidity at the end of life

Most study participants perceived that multimorbidity care became simpler as their patients entered the end-of-life phase, although nearly half (45%) thought it depended on the specific condition. (See Domain 7, Table 8.4.) This finding was unexpected considering patients with multimorbidity at the end of life have been considered vulnerable to new or intensified symptoms,[962, 963] the adverse effects of polypharmacy with changes to drug metabolism,[104,964] and a cascade of prescribing as new treatments get added to treat symptoms of other treatments.[104] Instead, general practitioners described a sense of relief at being able to reduce or stop therapies to focus on the single goal of providing adequate symptom control. Firstly, this suggests that general practitioners may find the active management phase of care more cognitively demanding because of the numerous, simultaneous, and competing tasks in play which become less important at the patient's end of life. These tasks include supporting self-care, monitoring medications and symptoms, and working to maintain function while trying to prevent new conditions from occurring or existing ones from deteriorating further. General practitioners also seem aware of the concept of time to treat to benefit as they actively deprescribed, even though guidance on these matters was sparse in the guideline content analysis. They also appear to find permission at the end of life to prioritise their patient's quality of life over strict control of processes such as dietary intake and blood sugar levels which patients find onerous. General practitioners did not express concern that patients might view this approach as 'giving up on them' or that it might cause them to lose hope, as expressed in other studies.[282, 965]

This research also confirmed that a significant proportion of Australian general practitioners do not provide palliative or end-of-life care to their patients.[465, 466, 889] This finding underscores a gulf between the reality of professional practice and rhetoric hallowing palliative care as 'everyone's business'[253] (p7) and 'an ethical duty of health care professionals.'[452(p2)] Rich Australian qualitative data exists providing insights into the reasons for this reticence or why general practitioners find this work challenging.[278, 889, 966] Many cite lack of knowledge, skills or confidence, suggesting a need for more education and better support structures.[967] Guidelines for life-limiting conditions might be considered a form of support, capable of bolstering general practitioner knowledge and confidence. However, this study found little overlap between stated areas of general practitioner uncertainty and the actual topics covered in guidelines. This lack of alignment could constitute a lost opportunity that future guideline iterations might address. For example, research has shown that many Australian general practitioners have a limited view of what palliative care entails and often conflate the terms *palliative care* and *end-of-life care*.[465] Guidelines might start by providing explicit definitions for these concepts, perhaps helping some general practitioners recognise that they are already providing this form of care without labelling it as such. Second, clinicians report finding prognostication and symptom management of non-malignant conditions such as heart failure and COPD as challenging,[285, 290, 327, 890] which may result in eligible patients missing out on adequate palliative care.[328] The content analysis found patchy coverage of symptom management across guidelines for these conditions and little guidance on how common comorbidities might mask or heighten specific symptoms. Furthermore, few guidelines promoted prognostication tools to help clinicians judge approaching end of life, despite their ready availability.[259] A further area of challenge is initiating timely communication on end-of-life considerations with patients and families.[968] Despite evidence that patients often would like their general practitioners to raise the subject with them,[269, 969, 970] many avoid doing so,[278] often right up until the terminal phase.[971, 972] Here again, guidelines might provide advice encouraging general practitioners in this process.

Table 8.4 Evidence and multimorbidity at the end of life

Domain 7: Approach to evidence for multimorbidity at the end of life	
Systematic review	• *You know what, when you are 85 years old you don't have to perform anymore and at the same time there is this 'time to effect', that means, it takes more than 10 years before a patient at 85 is getting a marginal effect, marginal!*[791(p4)] • *[I]f we adhere quite as tightly is that person going to live to 88 or 89, you know? What are we trying to achieve with people? Are we trying to make them all live until they're a hundred and have nursing homes packed with people who ... sitting in nappies all day or are we going to improve their quality of life for the people who are alive now?*[802(p287)] • *With a 40-something year old, the treatment aim is clear … to reduce risk over a long-term period. But for an 80-something year old, it becomes less clear cut … What can the patient get out of it, and also, what are the possible side-effects?*[793(Suppl p[2])] • *[Deprescribing is] … a riskier, less certain, and more cognitively and socially demanding process, with minimal decision support.*[781(p1945)]
Qualitative study (In-depth interviews)	• *And if you know the duration of their life is limited, and they really hate certain therapies, you know, you have to ask, 'what's the point of continuing them?'* (GP2) • *Less following guidelines and just more going by the quality of life and what will benefit them.* (GP3) • *Palliative care is pretty straightforward. You're dying. My role is to keep you happy, comfortable, as much as possible. Doesn't matter what your condition is, that's fine*. (GP7) • *With an aim to keep them symptomatically as comfortable as possible. Good quality of life. … The goals change* (GP8) • *I said, 'you're on a statin and you're 86 and you've got muscle pains. So, let's just get rid of that. It doesn't really matter whether the muscle pains are being caused by the statin or not or their cholesterol medication. Let's just get rid of it because it's not going to do any good. It's an extra tablet to take. It's more expensive. And we need to keep things simple because the statin is going to help you in five years' time, and to be honest, you're not going to be here in five years' time.* (GP7) • *[D]oes the person want to live to be 105 years old while taking 20 different medications? Or were they comfortable trading that last 10 years and dying at 95 with fewer medications and a better quality of life? A lot of people would say 'yes, that would be fine with me'* (GP8) • *So, it is reasonable for you to prescribe adequate pain relief for someone who's dying. The guidelines about painkillers should take that into account* (GP8)

	• *Well, it becomes not worth worrying about some of the other things, you know … Your perspective changes in that situation.* (GP9) • *The co-morbidities are still – Are still important yes, but with the end of life it definitely changes thing.* (GP11)
Guideline content analysis	Time needed to treat to benefit from treatment in the context of life expectancy discussed: 5/10 Guideline discussed burden of comprehensive treatment on patients or caregivers: 6/11 Guideline discussed patients' quality of life: 11/11 Guidelines addressing treatment for older patients: 5/10 Guidelines addressing treatment for older people with multimorbidity: 3/10 Guidelines providing graded recommendations for palliative care: 2/7 Guidelines addressed deprescribing: 2/7
Quantitative study (Survey)	Management of multimorbidity becomes more complicated as more medications are added: 12.5% Management of multimorbidity becomes simpler approaching the end-of-life phase as: • the focus becomes symptom management and quality of life: 59.7% • some medications and therapies can be ceased: 47.2% • it depends on the life-limiting condition: 45%
Data convergence	Convergent
Meta-inference	Most Australian general practitioners across studies believed multimorbidity care became simpler, rather than more challenging, at end of life. Here, management decisions narrowed to become predominately about symptom control. At the same time, there was substantial acknowledgement (45%) that the type of life-limiting condition could influence the remaining course of management with non-malignant condition symptoms considered more challenging than those associated with cancer. Interviewed participants were alert to the significance of burden of treatment, time to treat to benefit, and deprescribing in formulating new care goals as the end of life phase approached. The guidelines, however, all mentioned the importance of quality of life but only a half suggested the clinician consider burden of treatment, older age, or life expectancy in planning care.

General practitioners might also benefit from guideline coverage of their expected role within the end-of-life care multidisciplinary team.[889] This information could make explicit an overarching coordinating role for the general practitioner, emphasising to other providers the importance of sharing information in a timely way and working from the one care plan for the patient's benefit. Palliative Care Australia states a need for general practitioners to have core generalist skills to support Specialist Palliative Care services in providing a sustainable model of care.[253] By working with this peak body and the Royal Australian College of General Practitioners, guideline developers might first determine these core skills and then ensure guideline coverage and recommendations were synergic with them. Until these core skills are defined, there may be little point in investing in data capture mechanisms for auditing general practice palliative care activity or its quality, as is done successfully within Australian specialist palliative care via the Palliative Care Outcomes Collaboration.[973] It is noted that building primary care capacity for providing palliative care and capturing activity data were two action areas for the Commonwealth Government in the *Implementation Plan for the National Palliative Care Strategy 2018.*[974]

8.3 Negotiating patient-centred care in managing multimorbidity

This research elicited Australian general practitioner views on providing patient-centred care to their patients with multimorbidity. Where these views relate to what happens within the context of the consultation, they have been integrated into a joint display table (8.5) and discussed according to the framework of Stewart's Patient-Centred Clinical Method (outlined in Chapter 2).[92] General practitioners also described a range of factors outside the consultation that impinged on their ability to provide patient-centred care. These findings have been integrated into joint display table 8.6, while evidence of the personal impact of these issues on the general practitioner has been collated into joint display table 8.7.

Table 8.5 Multimorbidity and the patient-centred consultation

Domain 1: Knowledge of the particular (exploring disease and the illness experience; understanding the whole person)	
Systematic review	- *I [need to] get a better complete idea about the background, that is, what's the priority of this old lady, what's the priority of this man…. [If] I get a better idea [of the background] this will solve many problems.*[804(p124)] - *When you have known people for so many years then you really do not need to ask very much about self-care, because you know their work situation, who they are married to, their children and all these things.*[787(p4)]
Qualitative study (In-depth interviews)	- *So, you know, if somebody's got insecure housing and their diabetes is very poorly controlled such that you would like to start them on insulin, but they're not sure they're going to be able to access refrigeration and where they're going to sleep is an issue. Yeah, that would be relevant to the approach to managing that. (GP2)* - *It actually takes time to get to know them, as a person, know their medical conditions and know their social environment, their support, … what their home environment is like. (GP6)* - *And people want to tell you about how anxious they are or, you know, the next-door neighbour's dog, or something. Or … they had to go down to the vet with the cat and how much the vet cost. And it's relevant … to their mental and physical health. And it's relevant to the relationship between us as, as a health professional with a patient. So, it's important to listen and that takes time as well. (GP8)*
Guideline content analysis	NA
Quantitative study (Survey)	**Facilitator:** Knowledge of my patients gathered over time: 173/176 (98.3%) - *GPs are specialists in looking after people in their entirety; this includes the ability to not only factor into shared decision-making their comorbidities but also their social determinants of health as well as personal and family wishes.* - *Multi morbidity patients require complex problem solving and thoughtful adaption of guidelines and awareness of their social environment and supports. All impossible to achieve in a 15 minute appointment.*
Data convergence	Convergent

Meta-inference	Study participants appear to foster a whole-person approach to care during the consultation. Through attentive interactions with their patients, they work to develop trustful therapeutic relationships which would, in turn, make it easier to gain important contextual background information for diagnostic and management purposes.
Domain 2: Finding common ground (shared decision-making, negotiating agendas, goal setting)	
Systematic review	• *You have to go ‘this is your life, your decision’ and then give them my advice but they have to make the decision for themselves.*[706(p188)] • *If it is an important decision, then I'll involve the family. But with some decisions, the family don't need to know everything.*[780(p7)] • *I just worry about it myself … rather than imparting a huge amount of knowledge.*[706(p188)]
Qualitative study (In-depth interviews)	**Shared decision-making** • *And very much for us in a remote Aboriginal setting, it … depends a lot on the patient's priorities and their social circumstances as well in terms of the approach to managing the multimorbidity a lot, you know, in partnership with them. (GP2)* • *It's not always what you think is the best treatment. It's their opinion as well. (GP7)* • *And there’s a lot of patients where that’s what they want. They want someone who has the knowledge, experience, the balanced approach to work it out for them. … [T]hen you’ve got this bunch in the middle who want to be involved but don’t actually have the knowledge or understanding to really make the decisions. (GP6)* • *But sometimes you know, there are options. You can do this; you can do that. But it’s tough on patients to make decisions. And sometimes … and often you need… you have to… you’re forced to sort of encourage them in one direction that you perceive is the way they really want to go. (GP6)* • *People will have different priorities. You’ve got to explore that so that you engage with the patient so it’s a journey you’re taking together. You’re not the authoritarian saying, ‘Oh this is what you’ve got to do.’ People may not have any interest in doing those things. Regardless of how much you think it’s helpful. (GP11)* • *I want to know that my patient understands and that they are keen to embark on these decisions together, otherwise I’ll write the script but what does it mean? It may mean that I’ve just written a script. (GP12)* • *I don’t tell my patients what to do so it takes a lot more time. (GP12)*

	Negotiating agendas • *Everyone’s agenda has got to be satisfied. And it depends on your relationship with the patient. I just, sort of, do everything because otherwise it’s going to be a long wait before they come back. So, I decide ‘I’ve got to sort them out.’ (GP6)* • *[A]s a GP, you can say, 'well, I'm going to concentrate on this particular problem you've got. I think it's really important.' But the person will arrive and bring up something else. And if you're a psychiatrist and they say, 'I've got a cold today,' you can ethically ignore that. But as a GP, you can't ignore something they bring up. So, it's very hard to deal adequately with each problem. (GP9)* • *Goal setting at the end of life* • *So, if you hadn't had that conversation and planning in advance, you then had staff who were completely unfamiliar with the community, the client and the family, responsible for managing a person. Which always ends up in them going to hospital. And if that's not what they want, if they want to die on country, then that's really unfortunate. (GP2)* • *Because of the way we structure health care into little blocks of time for which we get paid, then we don’t have that [end of life] conversation. It would be a GP conversation because certainly the specialists assume that they want the optimal guideline directed treatment. (GP8)* • *Sometimes it’s quite straightforward and it’s you know and it’s a conversation that just happens so naturally, you know them, they know you, you’ve known them you know there’s a trust relationship, they’re ready to talk about it. (GP11)*
Guideline content analysis	Guideline discussed burden of comprehensive treatment on patients or caregivers: 6/11 Guideline discussed patients’ quality of life: 11/11
Quantitative study (Survey)	I tend to rely more on what patients want and their personal circumstances than what the guidelines recommend: 60.8% agree; 13.1% disagree; 26.1% neutral
Data convergence	Convergent
Meta-inference	Patients’ priorities and preferences appear to be explicitly factored into management decisions which are shared with the patient to ensure patient understanding and investment in the care plan. General practitioners also acknowledged that patients occasionally come to the consultation with a different agenda which must be negotiated and accommodated in some way—often by deferring a less time critical problem to a subsequent appointment. At the end of life, it appears the depth of the patient-clinician relationship could make it easier for general practitioners to initiate a conversation around changing goals of care. In remote Indigenous communities, timely conversations involving clinicians known to, and trusted by, patients and their

	families were critical for ensuring people could get to where they needed to be at the time of death. However, shared decision-making took time and, for some, could be conceived of as an unrealistic goal. A general practitioner might believe the patient unwilling or incapable of being involved in a health decision. While this may be the case, there is a risk that the long-standing relationship might lead a clinician to assume to know the patient's wishes without asking directly, resulting in a unilateral decision.
Domain 3: Enhancing the patient-clinician relationship (relational continuity, trust)	
Systematic review	• *So it does make it easier when you do build up that relationship with patients, that you do see the same ones for these conditions, because then you realise, partly you don't have to deal with it all in one go, these are chronic conditions and you are going to be seeing this patient regularly, they build up that trust with you that they can come out with things that are bothering them, and that very, very frequently happens.*[783(p582)] • *I think, if it is somebody who I know, I know their background, what the plan is and where we are heading, I am involved in the care relationship with them, that gives me confidence.*[781(p1942)]
Qualitative study (In-depth interviews)	• *It's that relationship that builds up over time that you both know what the next answer's going to be and what the next question is going to be. And what is most appropriate for that person. Because you both have that same sort of shared, you know, 'these are the things that are important to me.' That sort of shared understanding of the situation. (GP6)* • *So, you have to know them. You have to relate to them well and have regular interaction and a good relationship. (GP7)* • *Sometimes the strategy is developing a trust and rapport which may not yet have been developed. (GP11)* **The Aboriginal Community Controlled Health Organisation context** • *But it's something we have to think about and address with every patient. Otherwise, you just end up recommending a completely inappropriate management plan that might be unsafe, is unlikely to make your patient … improve the rapport that you have with your patient. They'll probably just think you're … you don't know what you're talking about. And they might not come back again. (GP2)* • *But if you are the one doctor coming back all the time, you know, within a few months, you'll often… can develop quite strong relationships with the community and various family members such that, you know, you do have that perhaps more traditional experience of general practice before the world became so interconnected and fast. Where you treat every member of the family and you know what's going on in the community and people come back to see you all the time. (GP2)* • *You need that relationship to establish what's going on, to figure out an individualized way of going about things. (GP4)* • *Because Indigenous people, particularly in remote communities, see so many different doctors and programs start and stop*

	and come and go, they do watch you and see what you do at first. And then suddenly, when they think 'Yeah, okay, this person is genuine,' then you start to get that relationship. And there's no way you are going to get good results, I think, until you establish that relationship. (GP4) • *All of our GPs work part time as well, if there isn't that continuity. You know, for example someone's away or whatever, and they're coming in. A lot of those things don't get optimally managed you know for the patient. (GP3)* **The palliative and end-of-life care context** • *I quite enjoy palliative care. I find it quite rewarding. If it goes well, it's quite a rewarding experience. (GP1)* • *A lot of doctors don't think about it because it's not … it's probably perceived as being a little bit too hard or 'who wants to do that?' or whatever. For I don't know what reason. (GP1)* • *GPs are doing much less nursing home visits, many less home visits now than we used to … And unless they go out and get themselves trained. They really don't do extra training. They really are not getting much training in palliative care. (GP10)* • *Quite a few doctors are actually doing palliative care extended skills posts, and I think that's to be welcomed. (GP5)*
Guideline content analysis	NA
Quantitative study (Survey)	General practitioner palliative care providers: 118/174 (67.8%); non-palliative care providers: 54/174 (31%) **Facilitator:** Knowledge of my patients gathered over time: 173/176 (98.3%) • *In my opinion, now backed up by Level 1 evidence, the best tool is a lifelong relationship between the GP and the patient.* • *In fifteen years I've not seen a benefit of a GPMP or TCA for my patients, over what a well-funded rebate and longitudinal relationship with primary care specialist offered* • *Longitudinal care accumulating complex patients is challenging, rewarding clinically and appreciated by our patients.* • *My colleagues don't really like seeing my complex patients when I'm away and I sense this as do the patients.*
Data convergence	Convergent
Meta-inference	There was strong support for the idea that the long-term relationship between the general practitioner and a patient could be used as a 'tool' in managing patients with multimorbidity by building the general practitioner's store of knowledge about the patient and increasingly the likelihood that the patient will trust in the general practitioner's judgement. Relational continuity

	was particularly important in the ACCHO environment. It could also be disrupted by part-time working practices of general practitioners with less than optimal outcomes for patients.

Knowledge of the particular

Many of the general practitioners interviewed could convey specific details of individual patient's lives which they needed to factor into their clinical decision-making. Furthermore, almost all survey respondents (98.3%) believed their knowledge of their patients, accumulated over time, was a facilitating factor in their ability to manage their health concerns. As evident from Domain 1, Table 8.5, the presence of multimorbidity appears to heighten the need to be aware of the non-medical contextual factors that often associate with it as these might represent an enabling force or an obstacle to effective multimorbidity care. Contextual awareness helps general practitioners provide appropriately tailored care and recommendations that patients could practically incorporate into their life. This strategy appeared to be especially important in the ACCHO setting. Here, if care advice was impractical or ignorant of sociocultural particularities, people were likely to 'vote with their feet' (GP4). Furthermore, this approach appears frequently to override an evidence-based one where multimorbidity is concerned. In the words of a general practitioner, 'Almost always the multimorbidity modifies what you do' (GP8). According to one study, patients often appreciate general practitioners probing them for personal context on family, interests, and priorities, as this indicated interest in them beyond the level of their diagnosis.[819] Moreover, in a discrete choice experiment, patients nominated 'attention to their personal situation' and 'orientation to what matters to them' as their two most valued aspects of patient-centred care.[975] It has also been shown that where patients choose not to disclose personal information beyond the biomedical with their general practitioner, therapies potentially more appropriate to the patient's circumstances may not get explored.[976]

General practitioners also saw the importance of aligning their goals for the patient's health with the patient's life goals (Domain 2, Table 8.5). They perceived an exploration of individual goals as necessary for shared decision-making; otherwise, patients would be unlikely to engage with any management decision. As one said, 'I know what's important to their health. They know what's important to them' (GP6). Aligning management decisions with a person's goals might be especially useful when different treatment options have well-defined trade-offs to consider.[977] However, here a long-term patient-clinician relationship might work against shared decision-making by inducing a clinician to assume to know a patient's mind or to perceive someone as incapable of interpreting complex information.

A discussion of goals could also lead to the general practitioner working to accommodate a person's wish to achieve something of meaning to them, despite logistical challenges. For example, it might mean helping an Indigenous person near the end of their life make their way home to a remote Australian community in time to die *on country* (GP2) or weighing the impact of cancelling a driver's licence on a geographically isolated person's social connectedness (GP5). Mapping what matters most to a person to an action-oriented management care plan remains challenging.[977] However, evidence supports personalised care planning that involves patients setting realistic goals, as it shows improvements in patients' physical and mental health and self-care ability.[978] General practitioners have also found goal-setting to be feasible in their practices and conducive to patient-centredness.[730]

Under time pressures and confronted by numerous issues to address, general practitioners also negotiated priorities within the consultation. Negotiations could be facilitated by a well-developed relationship when general practitioners appealed to a patient's understanding, assuring them all issues would be dealt with and not overlooked. General practitioners disliked having to fractionate care across consultations when time was short as this transferred their own struggle with time and costs onto the patient. Several general practitioners described addressing all issues in the one consultation to spare patients this inconvenience.

Enhancing the patient-clinician relationship

A study conducted in obstetrics has found that when faced with clinical uncertainty, clinicians might use the patient-doctor relationship as a toolkit for decision-making, relying on 'value-related and social information' they had accumulated throughout a therapeutic relationship to guide their actions.[979] This strategy also seems to take place in general practice[825] (Domain 3, Table 8.5). General practitioners in this study describe nurturing the relationship and safeguarding its continuity, not for its own sake, but as an effective heuristic for making more effective, safe, and patient-centred decisions. As one ACCHO general practitioner stated:

> '[It's] then suddenly, when they think "Yeah, okay, this person is genuine" that you start to get that relationship. And there's no way you are going to get good results, I think, until you establish that relationship' (GP4).

Several general practitioners in this study spoke of providing their more vulnerable and complex patients with almost a bond of continuity. They did this by requesting to see them more frequently to avoid unexpected complications and ensure they dealt with all problems systematically and comprehensively.

Although Australia has no formal mechanism, such as practice enrolment, that facilitates continuity of general practice care, relational continuity does not appear to be under threat in Australia. According to a government study, around 98% of Australians over the age of 45 report having a usual general practitioner or attending a usual general practice.[980] This study also found an association between the length of time spent seeing the same general practitioner and how highly people rated their care experiences.[980] In Australia, general practice bulk-billing makes it possible for older patients, the disadvantaged, and those with disabling illness to return to their general practice frequently and experience no out-of-pocket costs. Currently, 66% of Australian patients have all their general practitioner services bulk-billed. However, as this results in a financial cost to the practice,[981] the RACGP expects this rate to decrease over time as general practices struggle to remain viable.[411]

While most people report a usual practice or practitioner, this does not stop a substantial proportion of Australians from seeking care at other general practices. One study found the rate of this behaviour over a year to be as high as 25%, fragmenting both informational and relational continuity.[982] However, most of those seeking care in this way were under 30, perhaps indicating non-serious acute needs and inability to access a usual practice on short notice.[982] In the United Kingdom, younger, fitter people are being targeted to register with private online consultation services, which explicitly exclude people with multimorbidity and mental health problems.[983] These services, which require people to deregister from their regular National Health Service general practice,[984] appear to be popular with younger, healthier working people as they offer improved and timely access, even if that comes at the cost of relational continuity with a regular provider.[983] General practitioners’ concerns over these services include the risk of reduced support for publicly funded services,[983] a lack of evidence as to their safety and quality,[984] and the potential for these services to recruit general practitioners away from the National Health Service, further eroding the workforce in conventional practices.[983] There is also the concern that private providers segment the population by cherry-picking the least unwell for their service.[984] Although this might provide a solution to the workload problem in general practice, it risks further fragmenting care while challenging the perception of general practice as providing comprehensive cradle-to-grave care.

At the start of the COVID-19 pandemic in March 2020, the Australian Government rapidly introduced general practice whole of population telehealth services to protect the health of practitioners and patients.[985] This constituted a significant change within Australian primary care as, before this, Medicare rebates for general practitioner-led telehealth consultations did not exist.[986] However, one of the stipulations placed on this new service model was that patients could only claim a Medicare rebate when consulting with their regular general practitioner or general practice.[987] This policy was instrumental in safeguarding the continuity of care during the pandemic and discouraging Australians from using the 'low-value pop-up telehealth services' that appeared during this time.[988] Many patients with chronic health needs found telehealth convenient and effective, emphasising the importance of the pre-established patient-doctor partnership to its success.[989] It remains to be seen how newer disruptive technologies such as artificial intelligence diagnostic services might impact the human element of the general practice patient-doctor interaction in the coming years.[990]

If general practice is set apart from other medical disciplines by its provision of comprehensive, accessible, and continuous care, the decision of around a quarter of Australian general practitioners to cease providing care to their patients once they reach the end of life is of consequence. So too is the declining proportion of clinicians providing home visits to the housebound and care into residential aged care facilities.[991] With an ageing general practitioner workforce, this situation is expected to worsen unless a solution is found that entices an increasing number of new general practitioners into these care settings. Appropriate referrals to specialists aside, a rupture in the therapeutic relationship at a time when the patient has heightened emotional and physical vulnerability is likely to produce poorer outcomes for patients and their families. The finding in this research that 31% of general practitioners *routinely* refer patients elsewhere at the end of life is hard to interpret considering the subsequent statement from most survey respondents that multimorbidity care became simpler, not more complicated, at the end of life. However, the survey found a positive association between general practitioner length of time in practice and provision of palliative care. The reason for this is unclear; however, it may indicate more maturity, life experience, as well as clinical competence and confidence on the part of the general practitioner. It might also support the finding that general practitioners are more willing to provide palliative care to people with whom they have a long-standing relationship.[889] Many of the reasons for Australian general practitioner disengagement with palliative care have been elucidated[278, 889] and some of these factors could be addressed with training opportunities and closer working relationships with specialist palliative care. Canada's INTEGRATE project has demonstrated significant effectiveness in building general practitioner palliative care capacity. The programme comprises interprofessional palliative care education, systematic efforts to forge or strengthen networks with other providers, and the implementation of a care model based on the Gold Standards Framework.[992] It might be timely in Australia to explore a similarly systematic and consistent approach to palliative care in a peri-pandemic and post-aged care Royal Commission world.

Table 8.6 Threats to patient-centredness from outside the consultation

Domain 4: Impact of policy on patient-centred care	
Systematic review	• *[H]ow on earth can you really, in a busy practice, deal with someone with multimorbidity, multi-polypharmacy in a 10-minute consultation? And to be fair to patients you can't, so you spend longer and therefore your day is longer, and you know, that's the nature of the job, but it does contribute to an increased workload.*[802(p288)] • *We can try to understand (social problems) and we can try to (sighs) back people up in some way. But in a ten minute consultation there's a limit to what we can do.*[795(p51)] • *To be honest, you often get that sense [of opening Pandora's box], and you don't say anything, because you know you're at the beginning of the afternoon or whatever.*[56(p290)] • *[Y]ou want the truth? The truth is when you remember, when you are not rushed, then you can do that [deprescribe].*[794(p295)]
Qualitative study (In-depth interviews)	**Time limits** • *And, you know, I could spend an hour with my patients easily, but it's just not viable. And I could do some amazing stuff within that time and get through a lot of issues but it's just not viable for a practice. (GP3)* • *The financial models of medical practice don't reward people taking time and doing things properly. The rewards are for high turnover, which usually, in terms of these patients, means things are done wrong, medication errors, unplanned hospital admissions, unplanned events, high risk of complications played a major complication because someone hasn't taken the time to sort them out properly. (GP6)* • *The amount you get paid for doing [home and residential aged care visits] and the time that it takes you, it's charity. I remember our accountant saying to us one day, 'why don't you earn more money?' And I said, 'Because of the way we choose to practice.' (GP10)* **Medicare** • *I don't think there's been much development in nurse practitioners in aged care where nurses can engender their own Medicare item numbers. (GP5)* • *I think there's a limit to the number of patients with complex multimorbidity that a practice can carry.' (GP5)*

	Care plans and Team Care Arrangements • *You can press a button, you get a full computer generated care plan with about 30 minutes of exercise a day and quit smoking, and so on and so forth, but it's not tailored to the patient. (GP4)* • *Most of my elderly patients with multimorbidity are on a disease management plan. The disease management plan is possibly not worth the paper it's written on. That's a very cynical approach of mine, but it aids them in accessing some services, a limited number of services. (GP6)* • *I would have thought it would be quite reasonable to subsidise a certain number of podiatry visits for diabetics regardless of any management plan system. (GP9)* • *[The care plan is] so inadequate, and then people will rely on it, and there will be things that aren't there or are wrong. And there's been no attempt, again, to fund GPs for the extra time it would take to do it properly. (GP9)* **Chronic disease strategy** • *[I]f the care could be augmented, we'd keep a lot of people out of hospital and would save millions of dollars. There's the will and the way to do that, but still, the dollars are not stacking up enough for the average practices to take on more and to want to do more. (GP5)* • *That's the only goal. It's to keep them out of the hospital system but then they won't invest in the community stuff to keep them out of the hospital system. (GP9)* • *It's like when they kept proposing all this Health Care Home stuff. I was really worried that there was going to be a two-tier system. If you're a chronic disease person, you'll get treated in one way and if you're not, you know? I think that's a definite risk. (GP9)*
Guideline content analysis	NA
Quantitative study (Survey)	A standard consultation is long enough to manage the problems and concerns of patients with multimorbidity: 1.7% agree; 95.5% disagree; 2.8% neutral. • *I need 30-60 mins per appointment.* Having more consultation time, adequately remunerated, would improve general practice care of patients with multimorbidity: 98.3% agree; 1.1% disagree; 0.6% neutral. • *Many people I see with multimorbidities are financially disadvantaged, as a GP I cannot in good conscience request a gap fee.*

	It means overall I am limited in how many patients which multimorbidities I can 'take on' • *Our fee for service Medicare model doesn't work well for caring for increasingly complex needs.* I usually find time to address lifestyle risk factors and preventative health concerns: 51.7% agree; 36.9% disagree; 11.4% neutral. • *Education to patients about their health is poor and time consuming, not much help/remuneration for it.* • *I can often find an underlying cause for their issues, which is often lifestyle related. However, management requires time, and the patient's Medicare rebate does not reflect the true cost.* **Facilitator:** Government initiatives such as GP management plans: 105/175 (59.7%) • *Care planning is useful for some compensation for the GP and helps with problem list* • *Govt GP plans … waste a lot of GP time when we should be listening/talking to our patients.*
Data convergence	Convergent
Meta-inference	Across the qualitative and quantitative studies, Australian general practitioners were almost unanimous in describing policy-directed features of the healthcare system which impacted on their ability to provide safe quality care for their patients with multimorbidity. The main problem was the parcelling up of time into short slots under fee-for-service model which created a perverse incentives for practices to push through as many patients as possible to generate their revenue. Although it was possible to book in more complex patients for double appointments, these paid proportionally less than the single 15 minute consultation. Those whose clinics bulk-billed their patients were especially under pressure to move patients through quickly, at the risk of suboptimal outcomes. Conversely, general practitioners working at clinics that charged a gap payment might feel conflicted in charging those on lower income higher fees for their care. Time pressures meant preventative health was addressed opportunistically rather than proactively under this system. Despite the extra funding they received for GP management plans and Team Care Arrangements under Medicare, some general practitioners thought they only added to their administrative workload. Although many patients with multimorbidity could benefit with additional work with allied health professionals such as podiatrists, nutritionists, and physiotherapists, only a few visits per year were subsided under Medicare. Some general practitioners felt an obligation to their patients and to their own professional standards to provide less financially rewarding forms of care to patients, such as visits to the home or the residential aged care setting.
Domain 5: Lack of coordination across sectors of care	
Systematic review	• *If we could stop hospital physicians prescribing single issue medicines for compromised older people, we'd reduce our*

	problems by 50% overnight.[780] • *If the medicine has been changed at the hospital, without you knowing why, it creates uncertainty, because it may be medicine that I think is necessary for the patient.*[791(p3)] • *You need to be able to join forces more freely, getting hold of the different stakeholders that are involved with the patient. I often experience that it can be difficult.*[791]*(p4)*
Qualitative study (In-depth interviews)	**Complex systems and operational failures** • *So often with every condition there's another person involved … And you end up with a very complex system and a lot of the time when we see people with problems, the complexity is now, 'When are you seeing the specialist?' (GP5)* • *So again, there was a whole lot of extra coordination and liaison. It wasn't just managing her medical problems. (GP5)* • *They go to hospital; they have multiple medication changes and they come home totally confused. Often doubling up on drugs, often being put on drugs they shouldn't have been put on because instead of someone managing their chronic diseases and knowing them, it's people who see them for a one-off time … (GP6)* • *Tests get done and nothing comes through. The results don't get sent through, so you have to go chasing which is more time. (GP6)* • *We rely on a discharge summary written by a very junior doctor who may or may not have known the patient in fact. (GP8)* • *I don't understand it. We just seem to be invisible. (GP8)* • *Increasingly people are more and more subspecialised. And if you've got something, you have to go and see one person. And then something else in the next bit of your body requires a different person … And then we're expected to pull it all together for people. (GP8)* • *But it is hard to navigate the systems, the different billing systems, private-public, health insurance. Oh, gosh. Yes, I think it's hard for people. Particularly if they're unwell. (GP12)* **Communication with specialists** • *Every GP anywhere will say … we're not getting timely letters from consultants or from reports (GP1)* • *And it can be very difficult with the communication between us. Delayed discharge summaries, discharge summaries that don't arrive for whatever reason, a gap between what the specialists have prescribed and what's on their scripts. (GP4)* • *You sometimes look on the health record and the relevant documents aren't there. And I can say that one of the reasons may well be that they're not being uploaded. (GP4)* • *Lack of communication is the really dangerous aspect in looking after these people. What you don't know often becomes a big issue. 'I don't know what tablets you're on. I don't know whether they found cancer. I don't know whether the doctors thought*

	you had leukemia.' (GP5) • *What communication are you talking about? [Laughs]. It's very poor, very poor. And the quality of information coming back is poor. (GP6)* • *And it's hard to actually get to talk to them. So, it's not a simple thing to chase them up, to do something quickly. And then doing it by fax or letter is slower. So, there's a sort of a gap of a week or two where you kind of best guess what to do for the patient as the GP (GP8)*
Guideline content analysis	NA
Quantitative study (Survey)	I usually receive clear and timely information from the other specialists involved in the management of my patients: 27.8% agree; 57.4% disagree; 14.8% neutral. **Facilitator:** Collaboration with secondary care specialists: 145/176 (82.4%) • *Having more collaboration with secondary care specialists and being able to contact them for advice would be a great asset.* • *Having a funding model available for secondary care specialists to come into primary care on a regular basis (either virtually or F2F) to assist in patient care and collaborate with the primary care team would be a great asset too.* **Complex systems and operational failures** • *Many of my patients with multimorbidity see multiple specialists – this can lead to poorly coordinated care, confusion and simple mistakes. Its challenging because the specialists also bring a lot of value to the patient's care.* • *Consistent adherence plan of treatment by all involved in the patient's care* • *Can get very challenging with multiple specialist involvement and no one taking charge.* • *As the GP, I am often the ONLY person who looks at the patient's situation as a whole. The specialists tend to only pay attention to their own part and defer to others about everything else.* • *Unpaid time spent chasing results, appointments and information about hospital visits interferes with care* • *Appalling information from public hospitals (clinics or emergency)*

	Communication with specialists - *Lack of specialist correspondence is a massive hinderance both public and private.* - *The quality of the discharge summaries can be very inadequate and key information is often left off the diagnosis list or the management plan section of the discharge summaries.* - *Multiple private non-GP specialists do multiple tests without any consideration of previous tests, don’t always pass results on.*
Data convergence	Convergent
Meta-inference	General practitioners expressed frustration at having to chase up vital information about their patients from hospitals and specialists who do not appear to have systems in place to communicate effectively with them. They were also sympathetic to the burden experienced by their patients when having to navigate Australia’s disjointed public/private, primary/secondary/tertiary split healthcare system. Traversing this system put patients at risk of safety failures at multiple points. Medications could be changed, and unnecessary tests ordered, creating confusion for patients, and much unpaid work on the part of the general practitioner who volunteers responsibility for trying to coordinate all the various strands. A little more than a quarter of Australian general practitioners in this study considered they received clear and timely information from other specialists in the management of their patients. This was a hindrance to patient care and the general practitioner’s workload. General practitioners felt alone in trying to create a coordinated sense of care for their patients. Many (82%) described collaboration with specialists as a facilitating factor in their management of patients with multimorbidity and others felt they could learn a lot from them. However, the qualitative data seems to indicate this might be less an actuality and more an aspiration.
Domain 6: Quality and accessibility of community supports (residential aged care, home care)	
Systematic review	- *[Aged care]. You try and find the notes, hard to find. You can’t find the medicine chart; it could be on the rounds somewhere. It’s not computerised, it doesn’t link with our technical notes at the medical practice, so quality just goes down. It shouldn’t be, but at the practice we’ve got the computer, we’ve got light, we don’t have a darkened room in a rest home, and we can actually see what’s going on.*[780(p16)] - *Your first challenge is you go to the rest home. You try and find a nurse. You can never find one.*[780(p16)]
Qualitative study	- *I think there is potentially a real role in having more outreach nurses, particularly going to nursing homes. There's a huge crisis*

(In-depth interviews)	*here with nursing homes, because there are probably patients in nursing homes in this area that don't have a doctor. A couple of practices have pulled out. It's really, really hard to service large numbers. And yet we all feel very uncomfortable about it. (GP5)* • *And then you get into the next layer of the system which is the support systems out there. Which [are] really difficult to navigate. I mean, aged care packages for home care, you know. You wait ages to get approved then you're told there's a two year wait to get your package. (GP6)* • *But the services are not there to support wound management, to support assistance with home care. Even someone popping in to make sure someone's OK. It's all difficult to access. (GP6)* • *But they never provide enough resources. I mean, look at the waiting lists for aged care packages now. People die on the waiting list. (GP9)*
Guideline content analysis	NA
Quantitative study (Survey)	I provide care to a residential aged care facility: 60/176 (34.1%) • *The wait for the public pelvic floor clinic at our metropolitan hospital, for example, is 8-9 months and the aged care continence nurses have largely been relegated to sending out pamphlets with phone numbers for yet more pamphlets because of staff attrition.*
Data convergence	Convergent
Meta-inference	Australian general practitioners in this study saw inadequacies in the aged care services available to people living in the community or residential aged care. A third of the participants worked in aged care. This was considered challenging for its own set of reasons, including patient record systems that did not connect with the general practice system, lack of trained staff, and low payment for the time involved. Services providing care in the home could also be patchy and some older people struggled to use the online systems required to activate the support they needed.

Threats to patient-centred care from outside the consultation

Australian general practitioners do not work in isolation but as part of a patient's care team within a system of interconnected and interacting components.[993] This system includes those working alongside them within the clinic, such as practice nurses, as well as allied health practitioners, community health workers, and private and hospital specialists. Where general practitioners differ from the other 'components' within this system, however, is that they are often physically distanced from the wider members of their team, which may foster a sense of professional isolation. Furthermore, as systems theory states:

> The behaviour of the whole system is not only determined by the properties of its parts – the behaviour of the parts is to some degree constrained by the properties of the whole.[994] (p273)

General practitioners involved in this research were highly aware of system factors, both within and outside of their own immediate network, which threatened their ability to provide safe and patient-centred care. The most problematic appears to be the normative pressure on general practitioners to provide short consultations to maximise earnings under the fee-for-service model of general practice. As shown in Domain 4, Table 8.6, most of those general practitioners (95.5%) surveyed did not believe a standard consultation was long enough to deal with the problems associated with multimorbidity. Furthermore, almost all (98.3%) thought increased consultation time would improve patient care. While a few spoke of using practice nurses in more strategic ways to help offset some of the time pressures, most did not, which may indicate general practitioners perceive their two roles as best working in parallel rather than overlapping.

Australian general practice provides a comparatively generous mean consultation time of 15 minutes compared with many other countries, including the United Kingdom (10 minutes).[393] However, a recent systematic review[995] could only find one study which examined the specific impact of multimorbidity on consultation time, which suggests the problem remains under-researched.[996] Australian general practitioners are not alone in wanting more consultation time with complex patients to feel they have performed their work properly.[706, 797, 806, 815, 997] The problem appears to be particularly serious in the United Kingdom where general practitioners describe increasing workloads and a reducing workforce.[998] There, general practitioners have attributed low morale and exhaustion to limited time and resources for dealing with increased patient complexity, combined with non-commensurate financial recompense.[822] Furthermore, a two-year ethnographic study of multimorbidity care in general practice identified many patient safety issues that arose during that time due to general practitioner workload strain and limited consultation times.[999] It is also a concern for the comprehensiveness of general practice care that, in this study, a considerable proportion (36.9%) of mostly less experienced general practitioners could not always find time to address lifestyle risk factors and preventative care with their patients. This finding may have implications for successfully reducing risk factors such as obesity and smoking, which contribute heavily to multimorbidity onset. It is also concerning considering Australians have a high life expectancy but spend more years in ill health than the populations of other OECD countries.[1000]

Lack of time in the consultation is also a social equity issue. As the inverse law demonstrates, people living in socioeconomically deprived areas, who already tend to have the poorest health, receive the least amount of time with their general practitioners.[395, 1001] As Mercer et al.[126(p1)] point out, when this happens, 'healthcare itself becomes a social determinant of health'. A trial of the complex CARE Plus intervention in general practices in Scotland investigated the impact on patient outcomes of providing substantially longer consultations with disadvantaged people with multimorbidity. It found that longer consultations, combined with training and support for clinicians and self-management education for patients, improved patient well-being and quality of life and were cost effective.[946] It also found that general practitioners experienced less work-related stress when relieved of consultation time pressures.[396, 1002] This is not the only study to highlight the benefits of longer consultation times. In another randomised controlled trial, patients receiving more time with an empathetic clinician (an *augmented consultation*) demonstrated significant global improvements compared to patients receiving the same treatment without the extra consultation time.[1003]

Government initiatives for managing chronic conditions were seen as a facilitating factor for care by around 60% of Australian general practitioners. Medicare provision for drawing up a care plan or coordinating a team arrangement for a patient provided some financial compensation for the time involved in doing so. However, general practitioners did not think these incentives were worth the extra administrative labour involved for the small gains in allied health service access granted to patients.

Only the will of the government to invest further in the primary care sector can remedy the twinned issues of general practitioner time and remuneration and their ramifications for patient care quality. General practices run on small profit margins, often choosing to keep gap fees down to maintain accessibility. As the Productivity Commission has pointed out, 'Australia's messy suite of payments are largely accomplices of illness rather than wellness, only countered by the ingenuity and ethical beliefs of providers to swim against the current.'[1000(p52)] Australian government spending on general practice is not only decreasing over time; spending on public hospitals far exceeds it and continues to grow.[411] Furthermore, a comparative study of 11 high-income countries has found Australia lags significantly behind the others for total primary care spending.[1004] Several general practitioners interviewed were aware of this declining investment in general practice, perceiving it as ironic that the onus was on them to 'keep a lot of people out of hospital' to reduce healthcare costs.

A further burden on general practitioners' ability to provide safe and patient-centred care to their patients was the lack of coordination inherent in Australia's multi-tiered healthcare system (Domain 5, Table 8.6). Since 2019, each Australian has access to their own Electronic Health Record (*My Health Record)*, unless they elected to opt out of the scheme. This record is designed to allow individuals and their health providers to share information such as discharge summaries, prescription records, and pathology and diagnostic reports.[21] Despite this initiative, Australian general practitioners in this study described the flow of patient information across Australia's healthcare sectors as dangerously slow and unreliable where patients with multimorbidity were concerned. They described having to take on the responsibility of following up test results, trying to obtain hospital patient records, and writing to other specialists to try to piece together the various strands of information required to have a full picture of their patient's healthcare management. Hospital and clinic discharge summaries were frequently mentioned as providing inadequate information which made general practitioners concerned for patient safety. This compensatory work took hours and had to be done in the general practitioner's own time. General practitioners absorbed these system shortcomings or 'operational failures',[1005] and although they were costly to them, they perceived they went unnoticed and unappreciated by the specialists who, directly or indirectly, were the cause of them. Therefore, it is not surprising that only 27.8% of Australian general practitioners in the survey could agree with the statement that they usually received clear and timely information from other specialists involved in the care of their patients. Research backs this finding by showing that less than 20% of general practitioners are notified when their patient has been seen in the emergency department.[1000] At the same time, general practitioners value the input from specialist colleagues, with 82.4% stating collaboration with them is a facilitating factor in their care of people with multimorbidity. Therefore, there may be the scope and perhaps even urgency for Primary Health Networks to work with hospitals and specialists in their catchment areas to strengthen intersectoral communication processes that impinge on patient safety and general practitioner workloads. Guidelines might also serve to remind specialists of their responsibility to provide timely, appropriately detailed information on patients, and consultative advice to their general practitioner colleagues as an integral part of the multidisciplinary care team and in the interest of patient continuity and safety.

In addition to challenges communicating with secondary and tertiary care systems, some general practitioners found it difficult to mobilise community health and care services for their older patients with multimorbidity or frailty living in their own homes. (See Domain 6, Table 8.6.) One general practitioner (GP7) labelled the unfriendly *My Aged Care* online portal as ‘Darwinian selection’ for older people. Furthermore, many of those eligible to access a government Home Care Package were reported as dying whilst on the waiting list. However, the central area of concern, and one for which some general practitioners expressed a sense of regret, was general practitioner level of involvement with residential aged care. Around 34% of those general practitioners participating in this research saw patients in residential aged care. The interviewees gave reasons for lack of enthusiasm for this work which resonate strongly with those of general practitioner participants in other studies.[780, 1006] They mainly amount to discontent with the time required to travel to and from the setting, unskilled and scarce staff, and inefficient and incompatible communication systems. The Royal Commission into Aged Care Quality and Safety has provided recommendations addressing this disparity between the time required to deal adequately with residential aged care patients’ needs and insufficient general practitioner remuneration. The Commissioners have recommended that general practices register with the government to become accredited aged care general practices, receiving an annual capitation payment based on the number and complexity of patients enrolled with their service.[28] It is yet to be seen if general practitioners, the Australian Medical Association, and the RACGP embrace this suggestion. However, the preference of several general practitioners in this study was for a salaried model of aged care provision.

Table 8.7 Personal impact of multimorbidity’s challenges on the general practitioner

Domain 7: General practitioner personal difficulties managing multimorbidity	
Systematic review	• *[It’s] wearing on a day to day basis.*[795(p52)] • *Exhausting … demoralising … overwhelming … soul destroying.*[795(p52)]
Qualitative study (In-depth interviews)	• *I think if I worked in a private practice, particularly, I would be at … really high risk of burnout. Because patients who have chronic conditions or complex comorbidity, because they, you know, they really seek out doctors who actually care. (GP3)* • *The money for going to a nursing home is not that good. Sometimes you do it as a community service, I guess. (GP1)* • *And the more patients you have that are complex and elderly, who you bulk bill, the harder it is to make it financial. So that's something that nobody likes saying. (GP5)* • *This morning I spent two hours just going through all the specialists' letters and pathology results for myself and my registrar. You know, that's not funded. (GP5)* • *You don't earn as much money when you have long appointments, but I can afford to book double appointments and just spend the time that's necessary so that I feel I'm doing a reasonable job. (GP8)*
Guideline content analysis	NA
Quantitative study (Survey)	I always run late when I see patients with multimorbidity: 90.9% agree; 4.5% disagree; 4.5% neutral. I spend a lot of time outside of consultation time managing the care of people with multimorbidity: 85.8% agree; 8.0% disagree; 6.3% neutral. **Workload pressure** • *I always run late. (I am thinking of leaving general practice)* • *The admin burden and risk of burn out is significant due to multiple system deficiencies.* • *I’m finding my caseload getting increasingly heavy and unmanageable sone days with dealing with complex multimorbidity cases.*

	- *Spending increasingly more of my own time (unpaid) outside the consult time to chase up and catch up, impacting my family/non work time.* - *It also means work becomes more challenging, exhausting and less financially rewarding.* **Financial recompense** - *I am lucky my family are grown up and can afford to be paid the insulting amounts the Medicare rebate offers.* - *Patients themselves, the public at large and Governments lack an understanding of the challenges and costs (personal and financial) in managing multi-morbidity.* - *I love a challenge, but the future of bulk billing general practice is not geared towards managing complex care. In fact, I am punished for doing it.* - *I really resent being paid much less for my time than if I chose easy single issue patients.* - *The remuneration is appalling and soul destroying* - *My practice is loaded with multimorbidity, I earn significantly less than my colleagues as a result* **GP self-care** - *I also think those who work with these groups of people (I am aware some colleagues don't), also need more awareness of self, their own vulnerabilities and must have resources of mentoring or peer or individual supervision. It is important to "not take things home" and remember it is the patient's journey, not your own.* - *It is important to remember also we as clinicians are human and have our own needs too and ensure those are met and not ignored.*
Data convergence	Convergent
Meta-inference	General practitioners describe a heavy workload which impacts their life away from the clinic in terms of incommensurate income and unpaid work out of hours. They describe feeling demoralised by the low remuneration they receive for what is highly skilled and challenging work. Being aware of limitations and exercising self-care were seen as important for avoiding professional burnout.

Finally, while the impact of these challenges associated with multimorbidity on patient-centredness has been outlined, it is also essential to acknowledge their personal cost to the general practitioner (Domain 7, Table 8.7). Across these studies, general practitioners describe always running behind the appointment schedule, excessive workloads, and stress which prevents them from feeling they have done a good job and interferes with their home life. Other Australian studies support this finding. One identified that general practitioners worried by time-bound consultations, burnout, and the need to sequester time for family were increasingly seeking to reduce their work hours.[823] Meanwhile, a recent RACGP survey of general practitioners found that nearly half (47%) are concerned for their work-life balance, and 23% thought excessive workload prevented them from providing high-quality care.[411] Furthermore, those with more complex patients were much less likely to report satisfaction with their remuneration.[996] Figure 8.1 shows the various beneficial and harmful factors that threaten general practitioners' current and future ability to provide care to people with multimorbidity.

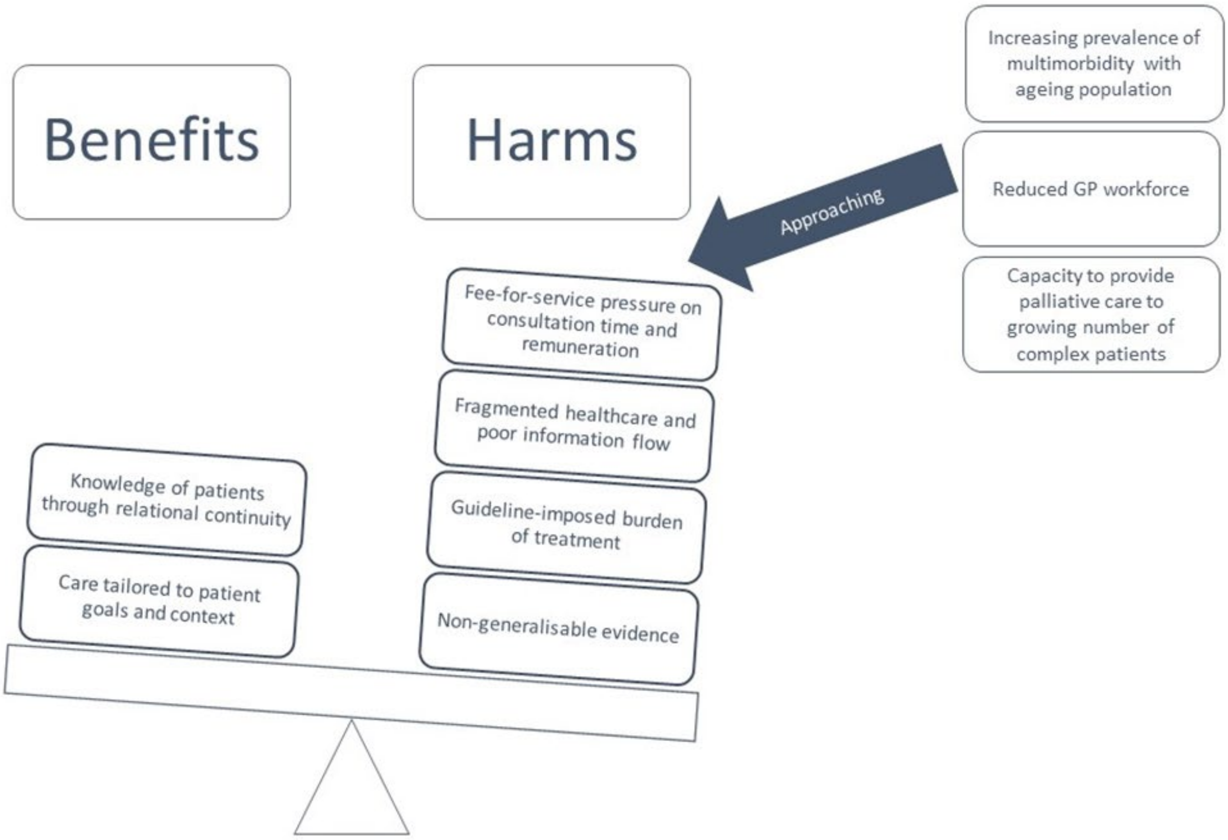

Figure 8.1 Current and future impacts on Australian GPs' ability to provide quality care to patients with multimorbidity showing impending threats

8.4 Contribution of this research to the body of knowledge

The research constitutes the first exploration of Australian general practitioners' experiences of managing multimorbidity across the adult lifespan. Furthermore, it has given general practitioners a voice on the issue at a time of unprecedented change in their sector. The study coincided with the global COVID-19 pandemic, which highlighted the extreme vulnerability of older people and those with multimorbidity to acute emergencies of this kind,[1007] and the essential but risky nature of the work performed by general practitioners at the frontline of the Australian care system. This public health crisis was instrumental in marshalling the Australian Government to relax long-term restrictions on telehealth services in general practice, with practitioners having to quickly come to terms with a new way of consulting with patients.[1008] At the same time, a Royal Commission was telling Australians of the poor quality of care, including medical care, many older Australians have been receiving within residential aged care.[28] Meanwhile, Australia is still in the process of trialling a Health Care Home model of primary care for patients with chronic conditions.[1009] Coinciding as it has with all these developments, this study contributes a unique perspective on how general practitioners experience providing care to older, more complex patients at a historical point in time.

This research is also the first to interpret these experiences through the lens of patient-centred and evidence-based expectations on general practitioner care provision. It is also unique in exploring general practitioners' views on if and how multimorbidity care changes once a person transitions from requiring chronic disease management to end-of-life care. To the researcher's knowledge, few, if any studies have examined the generalist's perspective on multimorbidity management during this last phase of care.

8.5 Strengths and limitations of this research

While each study has outlined strengths and weaknesses specific to that piece of research, a few need to be highlighted. The mixed methods approach was a strength of this research programme because it provided a way to triangulate data and methods to build the findings sequentially and cumulatively. The first part of the study comprised a comprehensive systematic review of international studies, which identified a gap in the Australian research where this topic was concerned. It also showed that Australian general practitioners share issues in common with their international counterparts but operate under some conditions unique to this country, largely deriving from Australia's geography and legacy of political federalism. For example, Australian general practitioners appear to struggle more with an incommensurate fit between the intensity of care required by patients with multimorbidity and what they can provide within existing funding and practice models. They have also highlighted the flow-on effects of this for older patients in residential aged care and how a different model—that of the ACCHO—appears to be more suited to meeting the needs of the specific population it serves. The systematic review also produced themes that provided an empirical basis for the interview guide and survey tool used with Australian general practitioners. Furthermore, the final quantitative study demonstrated the generalisability of the smaller qualitative study findings to a larger and more diverse group of general practitioners.

The time pressures under which general practitioners were operating at the height of the pandemic made recruitment for interviews difficult but not impossible. Those with more time available to be interviewed eventually agreed to participate, resulting in a sample with a higher than expected proportion of part-time, female general practitioners, those working in remote Australia, and clinicians with a part-time academic role. Qualitative research does not require sampling for a statistically representative sample; however, the researcher notes an underrepresentation of younger, male, and metropolitan general practitioners in the interviews. The strong agreement between participants on many survey responses suggests that interviewees' opinions are shared by their colleagues more generally.

The researcher as interviewer would have liked, in retrospect, to have delved further into seemingly contradictory views in the interviews, such as the gap between general practitioners' beliefs about guidelines and their application to their patients. Additionally, there were several topics the researcher expected participants to raise naturally, but they did not do so. Nor were they prompted in the interests of keeping the interviews to the time available. One of these topics was general practitioner engagement with informal caregivers and their awareness of the burden of care. Caregivers are an essential source of support and unpaid labour to people with debilitating morbidities, often sacrificing their own healthcare and income to fulfil this role, willingly or otherwise. Furthermore, caregivers are likely to be present at consultations and influencing general practitioner decision-making processes. Whether they represent allies to general practitioners, or a source of additional concern remains unknown in the context of this research.

The survey study had potential limitations. Firstly, it was not possible to determine the reasons for non-participation, leaving the possibility that the sample was biased in favour of a particular, but unknown, general practitioner characteristic. Non-participants may be general practitioners who find no difficulties managing patients with multimorbidity. Conversely, they may be those most burdened by a multimorbidity patient mix and therefore unable to find time to participate. This information would have added strength to claims of survey generalisability. Although two general practitioners piloted the survey tool, it may have benefited from further testing before being applied. The researcher aimed to create a short, uncomplicated survey to maximise the number of general practitioners willing to participate. To achieve brevity, the researcher had to keep the survey to a few questions, with each question exploring a single dimension of an issue. The few significantly sized neutral responses gained on several of the questions may signify that some questions were more complicated or ambiguous than they should have been. Further piloting may have identified this. Furthermore, simplifying some questions, or providing more follow-up ones, may have increased the variability accounted for by the latent factors identified in the factor analysis.

Finally, evidence-based and patient-centred approaches represent normative and desirable expectations of general practitioners. This research has analysed what general practitioners say they believe and do; however, a desire to appear to conform with professional expectations may have influenced their responses. The only way to confirm this would be through a supplementary observational study.

8.5.1 Implications for practice

There are several implications for practice to come out of the experiences of Australian general practitioners presented here. Firstly, from what general practitioners have reported, there seems to be little recognition from policy-makers that a growing proportion of people are presenting with multiple conditions, making patient care complex, uncertain, and time-consuming. Most consultations are no longer for simple transactions and well-defined problems, but this needs to be more widely known. Even Australia's National Strategic Framework for Chronic Conditions makes little reference to multimorbidity.[42]

Second, general practitioners require more consultation time, or a different style of consultation, to manage patients with multimorbidity safely and adequately and feel that they have done a good job in the process. This research shows that the quality of the patient-doctor interaction within the consultation is essential for more than purely disease-based outcomes. Relational trust and continuity can allay clinician uncertainty, promote shared decisions around individualised goals, and build relational capital to be drawn upon when needed. A first step to protecting and building on this relationship aspect of multimorbidity care may be to encourage people to register with a general practitioner or practice of their choice.[1010] Providing more time in the consultation for those who most need it is also a question of social equality. To prevent the deficient outcomes evident in places where the inverse law operates freely, Primary Health Networks will need to identify those areas requiring more primary care services and those services in need of more resources to meet demand. The extra funding will be crucial if general practices are expected to address upstream social determinants of health, as has been suggested,[1011, 1012] over and above opportunistically delivering advice on individuals' health behaviours.

Now may be the most opportune time for reviewing and implementing system reform, being as we are at the juncture of the Royal Commission's calls for an alternative primary care model and the government's extemporised introduction of telehealth. Although the outcomes of Australia's Home Health Home trial with its blended payment approach are yet to be known, the conventional small business model of general practice will not be sustainable in the face of a growing number of older patients. If what general practitioners have reported is so, multimorbidity care is unlikely to be absorbed by general practice without a substantial spill-over into emergency departments and the hospital system as access dwindles or is actively discouraged by practices.

Therefore, arguably the most important factor in the complex equation of multimorbidity, and the one most immediately amendable to change, may be patients' ability and willingness to self-manage their conditions. Regardless of what primary care funding models is in place, chronic condition prevention and management relies on the person at the centre of care actively engaging in health practices with known benefits. To this end, Primary Health Networks might work with individual general practices to implement tailored programs in self-care serving the demographic requirements of the area in which they sit. For example, individual practices might group patients with the same self-care needs and schedule them to attend a regular health education session facilitated by a practice nurse. Grouping might be based on any number of demographic variables such as age or gender but should focus on self-care for a specific condition or a cluster of symptoms associated with multimorbidity.

There are several clear advantages to this model. Firstly, it addresses the secondary prevention and self-care issues GPs expressed regret at not having the time to address proactively. Furthermore, patients may come to rely less on individual appointments with their GP, thereby reducing the proportion of complex patients GPs need to see over the course of a day. As patients have an opportunity to discuss their self-care concerns with people confronting similar issues, there is potential for them to form peer-support networks and to extend any trust or 'preferred' status held in an individual clinician to the practice itself. Group health education sessions may also create new opportunities for practice nurses to take on public and preventative leadership roles within the community. Aided by an adequate funding model and promoted by Primary Health Networks, these multimorbidity clinics might bridge the gap between hospital and primary care sector care for these patients as practitioners on both sides encourage patients to attend. This group model might even extend beyond purely medical issues to address very low level psychosocial concerns. Sessions could be facilitated by a mental health professional on a regular basis or may be led by GPs and PNs with special interest and training in psychosocial behavioural healthcare.[1013] An approach of this kind would go some way to finding workable management strategies for the predominant physical-mental multimorbidity pattern that many GPs say they find challenging.

As mobile health apps and other digital health initiatives become more ubiquitous and shown to be effective at scale, these might also play a role in supporting patients to provide better care for themselves. The general practice of the future might even be capable of taking real-time readings of important clinical indicators such as blood glucose level or hypertension so that medication modifications are made and appointments scheduled in time and as needed. However, the uptake of even basic digital health technologies such as telehealth continues to be slow in Australia.[1014] For example, it is unclear why more health professionals are not using the My Health Record to communicate with other health professionals about individual patients, as this is its stated purpose. Efforts to coordinate communication by this means, or any other integrated, real-time digital system, rather than continuing to rely on print-based letters and faxes, might go some way to reducing the administrative burden described by general practitioners. Furthermore, general practitioners might contribute to change by alerting hospitals and clinics to insufficient discharge summaries and stipulating the requisite level of detail for optimal patient care continuity.

With greater numbers of frail elderly or incapacitated patients expected, we also need to invest in strategies to support GPs to do home visitations. Current GP workload and trends in work practices being what they are, a home visitation model may be needed that sits outside and runs parallel to the prevailing GP business model. One approach may be to create a system of salaried GPs and community nurses who manage a registered list of elderly, housebound patients. As the patients seen by this workforce reach the end of life, these clinicians move into providing primary palliative and end-of-life care for them, thereby securing a smooth transition between phases of care and maintaining the relational continuity valued by many patients and their families at this time. Geriatric flying squads—rapid response teams that assess geriatric patients during periods of acute decline, may be a supplementary component to this model.[1015] A team of this kind might be called on to support carers in the home, or care aides in residential aged care facilities, to know when hospital transfer is an appropriate action or able to be avoided.

Finally, these findings suggest the growing importance of integrating theoretical and clinical training in multimorbidity care into medical school curricula, if only to acclimate medical students to its many uncertainties. Multimorbidity is a relatively new phenomenon, borne out of a historically unprecedented period of health and medical advancements that allow us to live longer lives. As such, it possibly remains a novel concept for medical educators versed in imparting and assessing knowledge based around single diseases or organ-based systems. According to a 2016 systematic review, there is a lack of published research on medical students' training on multimorbidity.[1016] Furthermore, those studies which have been conducted on multimorbidity training do not include pre-registration medical practitioners. These include a trial of the SHERPA patient-centred consultation model with general practitioner trainees in the United Kingdom,[1017] and a Spanish pilot of the eMULTIPAP course, based on the Ariadne Principles.[1018] Over the past decade, there have been numerous national reviews of palliative care content within medical curricula.[1019-1021] It may be time to investigate the extent to which the clinical reality of multimorbidity is being imparted to tomorrow's medical practitioners across Australian medical schools.

8.5.2 Implications for research

This research has identified a range of knowledge gaps around multimorbidity and the general practitioner, which is not surprising considering the general scarcity of research on this issue. The most pressing research need for Australian general practitioners may be the production of evidence on the impact of consultation times on the care of patients with multimorbidity. However, policy-makers may not prioritise this concern if approached from the angle of professional remuneration and practice sustainability alone. It may be better received if it can be shown through cost-benefit analysis that longer consultation times are as cost-effective as shorter ones or fractionated care while producing superior patient-prioritised outcomes.

General practitioners also need better decision support for multimorbidity. As exercised through the application of clinical practice guideline recommendations, evidence-based practice has contributed to producing a better standard of healthcare by reducing unwarranted and often potentially dangerous variability within clinical practice.[1022] However, the tools of evidence-based practice, as they exist currently, do not appear to be serving a general practice audience as well as they might. It seems unlikely that individualised, computerised algorithms for every potential disease combination will be available anytime soon.[1023] However, modifications to the way guideline development is approached may greatly reduce general practitioner uncertainty and safety risks for patients.[18, 704] Some potential changes are outlined here.

First, if we accept that multimorbidity is now a norm in general practice, we need clinician guideline panels to craft recommendations framed through a lens of multimorbidity and advanced age, where appropriate.[1024, 1025] These guidelines could provide clear information on the importance of interpreting prescribing advice in the context of limited life expectancy, time to treat to benefit, and the trade-offs individual patients are willing to make according to their preferences and goals.[1026] They might also prompt concern for inappropriate polypharmacy by including information on why and how the clinician should consider deprescribing medications while promoting validated tools to help with the task.[1027] Furthermore, palliative care content within guidelines for life-limiting conditions could be written by general practitioners and palliative care specialists in partnership, drawing on the advice of other specialists as needed. The approach might focus on questions that disquiet general practitioners most about end-of-life care and the areas where specialist services would like more generalist support.

Second, general practitioners may benefit from primary care-led guidelines that incorporate evidence from studies undertaken in the primary care setting. Research originating from primary care has expanded since the start of this century[1028] and has led to some interesting evidence initiatives. For example, a National Research Agenda for General Practice established in the Netherlands has brought together general practitioners to analyse guideline gaps and create a general practice research agenda based on 'the most compelling questions and issues in general practice.'[1029] Meanwhile, the United Kingdom's Clinical Practice Research Datalink database of anonymised electronic health record data has provided *real world evidence* to inform guidelines.[653] In Australia, however, funding that supports general practice research capacity is diminishing,[1030] prompting the RACGP to highlight the following to the Federal Government:

> There is a significant misalignment between where research is conducted and where most Australians access healthcare. GPs and their teams manage the majority of patient health issues, yet most medical research continues to be conducted in the hospital sector.[87(p8)]

Strong funding support might facilitate Australian general practitioners to organise themselves to develop guidelines specific to primary care, prioritising evidence produced within general practice and based on general practice patients.[661] Where high-quality studies exist outside the general practice setting, their relevance to a primary care population should be made explicit.[690] Where no evidence exists, practitioners might commission primary care researchers to produce it. This research might use methodologies not conventionally considered valid conceptual sources for decision-making by guideline developers. Mixed methods could map a better composite picture of the outcomes of importance to older people with multimorbidity and the elements of patient-centred care demonstrably able to achieve those outcomes.[1031] The collective and accumulated experiential knowledge of general practitioners could be drawn upon in developing consensus recommendations where evidence gaps remain. Furthermore, expert opinion—traditionally spurned as a legitimate source of evidence by guideline development panels[1032]—might be acknowledged as playing an essential tacit role in helping guideline panels interpret the existing evidence for the general practice context.[1033] This would give general practitioners a voice in determining the format of their guidelines, ensuring they are concise, accessible and easy to use when needed.[1034] However, one criticism of maintaining separate generalist and specialist guidelines is the potential to create contradictory recommendations, allowing policymakers to select the evidence that best suits their interests.[1035]

Third, guidelines currently do not make explicit the characteristics of the people included in the trials informing their recommendations.[1024] Although general practitioners appear to be aware of differences affecting generalisability, such as age and comorbidity status, many will still feel pressure to follow these recommendations. Guidelines might give clinicians greater confidence to rely on their clinical judgement and patient preferences by highlighting to whom the recommendations apply and groups for whom the evidence is weak or non-existent.[1026] They might also prompt those still intending to follow recommendations to consider specific modifications. Furthermore, general practitioners need to interpret complex information across various sources in making individualised patient decisions. Guidelines might reduce some of the cognitive burden this creates by providing information on risks and benefits in absolute, rather than relative, terms with numbers needed to treat or harm for every therapeutic recommendation.[1036] Guthrie et al.[1024] also suggest creating measures of absolute benefit to allow clinicians to compare the net benefit across treatments for different conditions.

Fourth, guidelines that seek to convey epistemic certainty by only covering topics where evidence exists could be doing a disservice to general practitioners. It might be beneficial for them to know where there are existing gaps, debates, or uncertainties in the research.[1037] Making this information explicit may help normalise the uncertainty for general practitioners and encourage them to relay it honestly to their patients, thereby fostering transparent communication and trust. It could also strengthen opportunities for shared decision-making based on patient preferences and goals. Furthermore, explicit acknowledgement of knowledge gaps might also give much-needed momentum to the multimorbidity research agenda by provoking the question, ‘why is there no research evidence?’

Fifth, with advances in digital platforms, it might also be possible to provide better cross-referencing within and across guidelines, incorporating plug-in drug interaction advice from standalone resources such as Australia’s *MIMs Online*. Guidelines might also be contextualised to a geographic or governance-defined jurisdiction to make them more useful to general practice. This approach is already available to Australian general practitioners through state-based *health pathways* portals which integrate clinical and referral information with relevant locally available health services and resources.[1038] In New Zealand, where the *HealthPathways* product was pioneered, the platform has already demonstrated better quality referrals, more care provision in the community rather than the hospital, and improved working relationships between general practitioners and hospital clinicians.[1038] South Australia’s HealthPathways portal, a partnership between two regional Primary Health Networks and the State Government’s health service, currently provides clinicians access to over 120 clinical and service referral pathways localised to the state.[1039] As of late August 2021, however, the information provided does not refer to multimorbidity, and the most viewed content includes information on headaches, chronic cough in adults, and COVID-19 vaccination information.[1039]

Perhaps most importantly, there is scope for Australian chronic condition guidelines to frame management of the patient with multimorbidity using the general principles approach of NICE[720], American Geriatrics Society[715], and the Ariadne Principles.[722] The RACGP Aged Care Clinical Guide[448] has already adopted this approach, prompting a new way of clinical thinking which cuts across all a person's conditions and challenges, prioritising individualistic patient-centred care rather than standardised care. Guiding principles are also evident in the RACGP's handbook for the management of type 2 diabetes[861] where they are presented in a standalone chapter on multimorbidity but carefully cross-referenced throughout the text where needed.

If this patient-centred guiding principles approach became ubiquitous across chronic disease guidelines, guideline developers are likely to want evidence that it impacts patient outcomes. The large, randomised 3D trial, which incorporated many of the principles of the NICE multimorbidity guidelines, improved patient satisfaction but not quality of life.[762] However, the trial's linear, cause-and-effect approach to outcomes was highlighted as a potential problem with commentators suggesting multimorbidity research methods 'must address non-linearity, incorporate unpredictability, and acknowledge that health care occurs within complex adaptive systems.'[1040(p127)]

Finally, future research might further clarify the findings and meanings of the studies presented here for practice and system improvement. Bringing together relevant multilevel stakeholders from general practice and specialist palliative care to find some common ground in the meaning of 'core skills' in generalist palliative care could lead to a palliative care guideline chapter template. Within guidelines for conditions where end of life is a foreseeable pathway, this template would cover those aspects of palliative care of importance to general practitioners. Furthermore, tracking a set of patients with multimorbidity and a life-limiting non-cancer illness using the established methodology of patient process mapping[1041] could illuminate how various multimorbidities are managed and by whom, and if patients face a burden of care or systemic operational failures along the way. The role of the general practitioner in their multimorbidity and palliative care, as well as any lost opportunities for greater involvement, might also be identified to support care and practice changes.

8.6 Conclusion

According to Pellegrino and Thomasma[957(p124)]

> The criteria of a right or good decision lie not in its certitude, rigor, logical or mathematical soundness … These qualities must be secured wherever possible, but they are not sufficient for a "right" decision. They can … be displaced by or modulated by the more complex criteria of a decision "good" for this patient.

This research has looked at the experience of multimorbidity from the perspective of general practitioners. It has found that the complexity in which these clinicians are operating runs across all levels: from the biological aspects of a patients' conditions, their non-medical problems, recognising palliative and end-of-life needs, clinic pressures, and intersectoral operational failures. At the level of the consultation, Australian general practitioners involved in this research have revealed a deep concern for developing and maintaining strong therapeutic relationships with their patients as a form of toolkit for providing contextual, tailored care, or decisions that are 'good' for individual patients. They have shown that they use their clinical judgement to prioritise patient-centredness over evidence-based recommendations in the awareness that patients with multimorbidity are poorly represented within the underlying research. Relational continuity also appears to motivate efforts to coordinate care for patients and provide palliative care at the end of life. Therefore, it is vital that any structural impediments to the general practitioner's ability to foster ongoing trustful therapeutic relationships with patients with multimorbidity be identified and mitigated or removed altogether. This includes consultation times that leave insufficient time for exploring the complex patient's needs and goals. Achieving such reform is likely to require a timely overhaul of Australia's overarching fee-for-service model of general practice, which assumes that general practice consultations involve simple, well-defined problems.

At the level of the system, the current COVID-19 pandemic has showcased daily public policy decisions being made quickly in response to an acute and constantly evolving health crisis. These decisions have not always been right in hindsight, and policy actions have often illuminated the problems, as well as the strengths, of Australia's federalised healthcare governance structure. However, multimorbidity is also a pandemic,[1042] albeit one approaching in slow motion.

It too will have ramifications for the economies of countries and the productivity of their societies. It will also hit those hardest who are already vulnerable and disadvantaged. Unlike the current pandemic, this one will be felt first at the level of primary care whose practitioners will likely be charged with protecting the secondary and tertiary care system while being judged on their ability to do so. However, general practitioners are telling us already that this care is unsustainable under legacy policy and system constraints designed for less complex times. As this pandemic should have taught governments, some disasters are predictable and anticipatory efforts to future-proof the systems required to deal with them would not be in vain. Multimorbidity is already proving a recalcitrant problem and one which general practitioners will not be able to manage alone. It is also a problem likely to require a complex systems thinking approach, beginning with a massive reorientation of research to find effective, rather than efficacious, interventions that have currency for general practitioner clinical practice.

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APPENDIX 1

Chapter 4. General practitioner perspectives of managing patients with multimorbidity: A systematic review and thematic synthesis of qualitative research

A1.1 Published journal article based on the Chapter 4 systematic review

Damarell RA, Morgan DD, Tieman JJ. General practitioner strategies for managing patients with multimorbidity: A systematic review and thematic synthesis of qualitative research. BMC Fam Pract. 2020;21(1):131.

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RESEARCH ARTICLE Open Access

General practitioner strategies for managing patients with multimorbidity: a systematic review and thematic synthesis of qualitative research

Raechel A. Damarell*, Deidre D. Morgan and Jennifer J. Tieman

Abstract

Background: General practitioners (GPs) increasingly manage patients with multimorbidity but report challenges in doing so. Patients describe poor experiences with health care systems that treat each of their health conditions separately, resulting in fragmented, uncoordinated care. For GPs to provide the patient-centred, coordinated care patients need and want, research agendas and health system structures and policies will need to adapt to address this epidemiologic transition. This systematic review seeks to understand if and how multimorbidity impacts on the work of GPs, the strategies they employ to manage challenges, and what they believe still needs addressing to ensure quality patient care.

Methods: Systematic review and thematic synthesis of qualitative studies reporting GP experiences of managing patients with multimorbidity. The search included nine major databases, grey literature sources, Google and Google Scholar, a hand search of *Journal of Comorbidity*, and the reference lists of included studies.

Results: Thirty-three studies from fourteen countries were included. Three major challenges were identified: practising without supportive evidence; working within a fragmented health care system whose policies and structures remain organised around single condition care and specialisation; and the clinical uncertainty associated with multimorbidity complexity and general practitioner perceptions of decisional risk. GPs revealed three approaches to mitigating these challenges: prioritising patient-centredness and relational continuity; relying on knowledge of patient preferences and unique circumstances to individualise care; and structuring the consultation to create a sense of time and minimise patient risk.

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Conclusions: GPs described an ongoing tension between applying single condition guidelines to patients with multimorbidity as security against uncertainty or penalty, and potentially causing patients harm. Above all, they chose to prioritise their long-term relationships for the numerous gains this brought such as mutual trust, deeper insight into a patient's unique circumstances, and useable knowledge of each individual's capacity for the work of illness and goals for life. GPs described a need for better multimorbidity management guidance. Perhaps more than this, they require policies and models of practice that provide remunerated time and space for nurturing trustful therapeutic partnerships.

Keywords: Multimorbidity, General practice, Patient-centred care, Evidence-based practice, Qualitative, Meta-synthesis

Background

Primary care providers and the systems in which they operate are increasingly called upon to manage patients with two or more co-occurring chronic medical conditions, or 'multimorbidity' [1]. This epidemiological shift has been attributed to the greater longevity offered by improvements in therapeutic technologies along with the increased risks associated with unhealthy lifestyles [1, 2]. One systematic review has estimated prevalence in general practice to be 12.9% for adults and 95.1% in a community-dwelling population aged 85 years and older [3]. While much of this variance can be attributed to inconsistencies in the way multimorbidity is defined and measured across studies, it nevertheless points to a significant problem that rises sharply with age.

Multimorbidity appears to be socially patterned, appearing more frequently [3] and 10 to 15 years earlier in populations living in areas of socioeconomic deprivation [4]. Furthermore, simulation modelling based on current risk factors estimates a two-fold increase in the prevalence of complex multimorbidity (four or more conditions) by 2035 [5].

Multimorbidity impacts on patient quality of life in significant ways [6–8]. Conditions might impart a high symptom burden [9] while their treatments can result in adverse side effects or inappropriate polypharmacy [10]. Functional or cognitive decline leading to reduced autonomy might also impact on an individual's psychosocial health [11] and sense of life purpose [12, 13] and some long-term progressive conditions, such as heart failure and chronic obstructive pulmonary disease (COPD), reduce life expectancy [14]. Patients with multimorbidity are often heavy users of health care, frequently traversing primary and secondary care sectors to visit a range of specialists, each focused on a particular condition or body system in isolation [15]. This siloed model can leave patients struggling to harmonise and adhere to complex medication regimens [16, 17]. When multiple appointments and therapeutics are added to the challenges presented by their illnesses, patients and their families/carers may experience an excessive burden of treatment [18, 19]. At times, this burden may exceed the patient's capacity to do the 'work' being asked of them.

Patients with multimorbidity desire care which is less fragmented and better coordinated across the system [20, 21]. General practice may be best suited to take an increased share of responsibility for coordinating care across sectors being based on 'longitudinal continuity of care as determined by the needs of the patient' [22]. Patients with multimorbidity are already high users of general practice in countries such as England and Australia where the general practitioner (GP) acts as gatekeeper to other health specialists [23, 24]. In many places, however, models of general practice may remain structured around single disease management, reflecting the traditional approach that still dominates secondary care, medical education curricula, and the research agenda behind the production of the evidence that informs clinical practice [4].

A 2013 systematic review of GP experiences in managing multimorbidity revealed several challenges to care provision including the inadequacy of the evidence base for multiple chronic conditions and the prevailing structure of the primary health care system [25]. Since this review, awareness of multimorbidity and its impact on patients and health care systems has grown with the Academy of Medical Sciences labelling it 'a priority for global health research' [1]. New primary care models for managing multimorbidity are being discussed and trialled, such as the patient-centred 3D study in the United Kingdom [26] and the Australian government's Health Care Homes pilot [27]. Furthermore, organisations such as National Institute for Health and Care Excellence (NICE) and the American Geriatrics Society (AGS) have produced multimorbidity guidelines in the form of general guiding principles of care [28, 29]. The research literature on multimorbidity has also increased exponentially in this time [30], including the number of primary qualitative studies investigating GP perspectives. (See Fig. 1.)

For these reasons, this systematic review seeks to build on the 2013 review by asking whether the challenges put

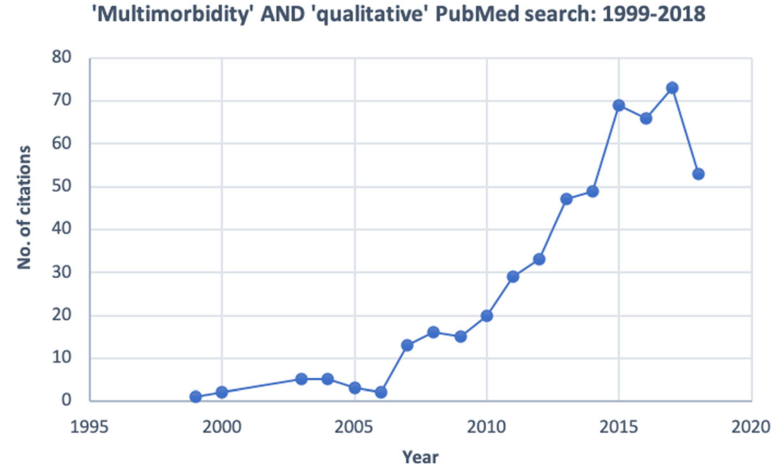

Fig. 1 Growth in qualitative multimorbidity research literature: 1999–2018

forward by GPs in the literature prior to 2013 remain the same today. Moreover, do GPs adapt their approach to care when managing patients with multimorbidity, and are these approaches working?

Rather than create a new, more recent review to complement the first, we chose to integrate studies from the previous synthesis with any newer studies to produce a more convenient single set of findings. This 'knock the house down and rebuild it' approach [31] also allowed us to use a different search strategy, broader inclusion criteria and a different method of synthesis to the original review. It also avoided drawing an arbitrary dividing line between the two reviews, the first of which only included two years' worth of studies (2010–2012). This systematic review is reported according to the ENTREQ framework [32].

Objectives

This systematic review aims to understand if and how multimorbidity impacts on the work of general practitioners by analysing the collective firsthand data within existing qualitative primary studies. It also seeks to identify GP strategies and proposed solutions for dealing with challenges to ensure quality care provision.

The review questions are therefore:

- Which aspects of patient care are considered challenging for GPs in the therapeutic management of patients with multimorbidity?
- What strategies do GPs engage to handle these challenges in order to provide satisfactory patient care?
- What changes do GPs believe necessary to improve the care of patients with multimorbidity and their own experiences?

Methods

Qualitative studies were deemed best suited to answering the review questions as their methods provide 'an approach for exploring and understanding the meaning individuals and groups ascribe to a social or human problem.' [33] To synthesise this qualitative research data we employed the 'thematic synthesis' methodology of Thomas and Harden [34]. We chose this approach for several reasons. Firstly, we anticipated having to synthesise a large number of studies and this methodology is considered better suited to that purpose than other methodologies [32, 35]. Secondly, this approach does not integrate data merely to quantify the prevalence of certain concepts. The integrated data undergoes interpretation which can lead to new, novel insights on an issue [36]. Thirdly, thematic synthesis provides a systematic and transparent approach to conducting and reporting the review through its three clearly delineated stages. These stages are line-by-line inductive coding of findings within the primary studies; organising any related 'codes' into descriptive 'themes'; and the creation of more abstract 'analytic themes' [34].

Search strategy

We used a diverse range of search strategies in the interests of comprehensive retrieval for 'conceptual saturation' and 'maximal variability in findings' [34], as well as to counter known challenges in identifying qualitative research using electronic databases [37, 38].

A database search strategy was first developed and tested in the Ovid Medline database. This comprised a combination of database subject headings and free text terms for three distinct concepts: 'multimorbidity' AND 'general practitioners/general practice' AND 'qualitative research'. Once finalised, the Medline search was translated for additional databases: PubMed, Embase (Ovid), PsycINFO (Ovid), Ageline (EBSCOhost), CINAHL (EBSCOhost), Scopus, Web of Science, and the health and medicine subset of ProQuest. All database searches were conducted on 17 September 2018. The Medline version is provided as Additional File 1.

We also performed a general web search using Google and Google Scholar to identify relevant unpublished literature and organisational websites of relevance to primary care and multimorbidity. Multiple different combinations of terms and their synonyms were searched in order to overcome the limitations of web searching; however, we only reviewed the first 50 websites returned per search variant.

We used the following resources to find theses: ProQuest Dissertations & Theses Global, Networked Digital Library of Theses and Dissertations, Theses Canada, British Library's Electronic Thesis Online Service, TROVE (National Library of Australia), and nzresearch.org.nz. Other reputable sources of grey literature searched include CORE (an open access research aggregator), Grey Literature Report, OpenDOAR, and OpenGrey.

As final measures, we scanned both the online contents pages of the highly relevant *Journal of Comorbidity* (2011–2018) and the reference lists of included studies.

Eligibility criteria

An eligibility checklist was developed and iteratively tested using a small sample of retrieved citations.

Types of participants

Studies needed to provide the perspectives of general practitioners. For the purpose of this review 'general practitioner' is defined according to The European Definition of General Practice/Family Medicine by WONCA Europe:

> … [GPs] are personal doctors, primarily responsible for the provision of comprehensive and continuing care to every individual seeking medical care irrespective of age, sex and illness. They care for individuals in the context of their family, their community, and their culture, always respecting the autonomy of their patients. They recognise they will also have a professional responsibility to their community. In negotiating management plans with their patients, they integrate physical, psychological, social, cultural and existential factors, utilising the knowledge and trust engendered by repeated contacts. General practitioners/family physicians exercise their professional role by promoting health, preventing disease and providing cure, care, or palliation and promoting patient empowerment and self-management… [22].

Studies investigating experiences of GPs as part of a broader group of health professionals (e.g. pharmacists) were included if the first-person contributions of GPs could be independently extracted.

Phenomena of interest

The phenomena of interest were the perspectives, views, attitudes, or beliefs of general practitioners on the therapeutic management of patients with multimorbidity. Therapeutic management might be pharmacological or non-pharmacological in nature, or involve interventions such as referral, screening, prevention, diagnostic testing, or follow-up [39].

Patients could be 18 years and over with any combination of chronic conditions providing their health care provider considered them a 'patient with multimorbidity'. Furthermore, we considered an article relevant if multimorbidity was the explicit focus, covered as a subject of interview questions, or emerged as a theme within the study results.

Context

General or family practices operate differently across countries in terms of practitioner training requirements, funding models, speciality recognition, and the degree to which they serve a gatekeeping role, authorising access to specialty and hospital care. GPs working across significantly different models of general practice will have divergent challenges and experiences which may be difficult to compare. We therefore made a pragmatic decision to limit this review to countries with somewhat similar general practice models, these being Australia, New Zealand, United Kingdom, Ireland, Canada, Netherlands, the Nordic countries, Poland, Portugal, Slovenia, and Spain [40–42].

General practices may be situated within primary care centres where they function as part of a wider health care team, or independently within a private practice. We also included other settings where GPs work such as nursing homes.

Types of studies

This review considered any study design providing the study reported the verbatim quotes from general practitioners conveying their views, opinions, beliefs, attitudes, and perspectives on the impact of multimorbidity on their clinical practice.

Studies were limited to those in English language. No date restrictions were applied.

Study selection

Citations were imported into an EndNote X8 Library where duplicate citations were removed. Using an eligibility checklist, one author then screened all titles and abstracts for relevance, moving each to one of three groups created within the Library titled ‘relevant’, ‘irrelevant’, and ‘uncertain’. A second reviewer then screened 20% of the ‘irrelevant’ group citations as a check on first reviewer decision making consistency. Full text articles were obtained for each citation in the ‘relevant’ and ‘uncertain’ groups. Both reviewers then independently reviewed each full text report to determine its relevance. Disagreements between reviewers were discussed until consensus was reached.

Quality appraisal

The appropriateness of including or excluding qualitative studies in a synthesis based on an appraisal of their quality remains contentious [36, 43]. We chose to conduct a quality appraisal of all included papers in order to gain a richer understanding of the methodological choices within each study. We did not, however, exclude studies judged to be of lower quality as they might still contribute unique themes to the synthesis [36]. One author (RD) used a 10 question qualitative research checklist developed by the Critical Appraisal Skills Programme (CASP) to appraise quality [44]. Quality judgements are provided as Additional file 2.

Thematic synthesis

PDF versions of all included articles were imported into QSR International’s NVivo 12 qualitative data analysis software.

Stage 1. Free coding of study data and findings

One reviewer (RD) performed detailed coding of participants’ verbatim quotes (herein ‘data’) and author ‘findings’ as provided in the Results and Discussion sections of each primary article. This involved reading the relevant parts of text line by line to ensure all concepts were accounted for. This ‘initial coding’ method created ‘tentative and provisional’ codes to be further refined in stage two [45].

Stage 2. Developing descriptive themes

Once all data and findings were coded, one reviewer (RD) examined the list of codes for duplicate, overlapping, or redundant codes. Next, each code’s assigned text was reread to check for consistency in coding across the full range of articles. From this process, some further codes were created, and nondescript code names were replaced with more descriptive labels (‘axial coding’) [45]. The resultant list of codes was then sorted by highest to lowest frequency of text assignment to see which codes were predominant and recurrent across the whole set of articles. Using this view as a basis, all codes were then iteratively and hierarchically arranged into conceptually similar or related groups. For example, ‘communication between providers’ was grouped with ‘conflicting advice to patients’ and both put under the broader code ‘Interface of primary care and other sectors.’ These resultant codes become the ‘descriptive themes’ of the review.

Stage 3. Developing analytical themes from descriptive themes

All three authors (RD, DM, JT) then discussed the descriptive themes and their relationships, testing new ways of organising and labelling them. From this, more abstract ‘analytical’ themes which ‘go beyond the content of the original studies’ [46] were developed by discussion and consensus between all three reviewers (i.e. triangulation). These analytical themes had to encapsulate and explain the descriptive themes and be richly supported by the data itself.

Results

Search strategy and study selection

Electronic database and grey literature searches, together with reference list checks, retrieved a total of 8374 citations. This total reduced to 4214 citations once duplicates were removed. After scanning titles and abstracts against the inclusion criteria, 127 citations remained requiring further review by full text article. More detailed full text analysis reduced the set to 33 articles for the final synthesis. Of these, four pairs of studies shared the same data but were retained because they reported on different aspects of it. This process is outlined in Figure 2 as a PRISMA flow diagram [47].

Fourteen individual countries were represented across the 33 studies: Netherlands [48–54], England [55–59], Australia [60–63], Denmark [64–67], Norway [50, 67–69], Ireland [70–72], New Zealand [73–75], Canada [76, 77], Wales [50, 69], Sweden [67, 78], Finland [67], Iceland [67], Portugal [79] and Scotland [80]. Together these studies included a total of 593 unique GP participants (range: 4–74 GPs). The median date across all studies was 2016 (range: 2010–2018).

Studies focused on multimorbidity were usually oriented towards a particular aspect of multimorbidity care. Some used the broad lens of ‘patient management,' [48, 53, 55, 59, 63, 67, 72, 77–80] while others focused on medication management [51, 52, 60, 62, 66, 70, 71, 73, 74]; clinical practice guidelines [49, 58, 61, 68]; GP decision making [50, 69, 75]; care goals [54, 76]; patient self-care [57, 64]; disease management programs [65]; and health service orientation [56].

Further characteristics of the included studies are provided as Table 1.

Quality appraisal

The quality of each of the 33 included studies was considered high as judged by the CASP Critical Appraisal

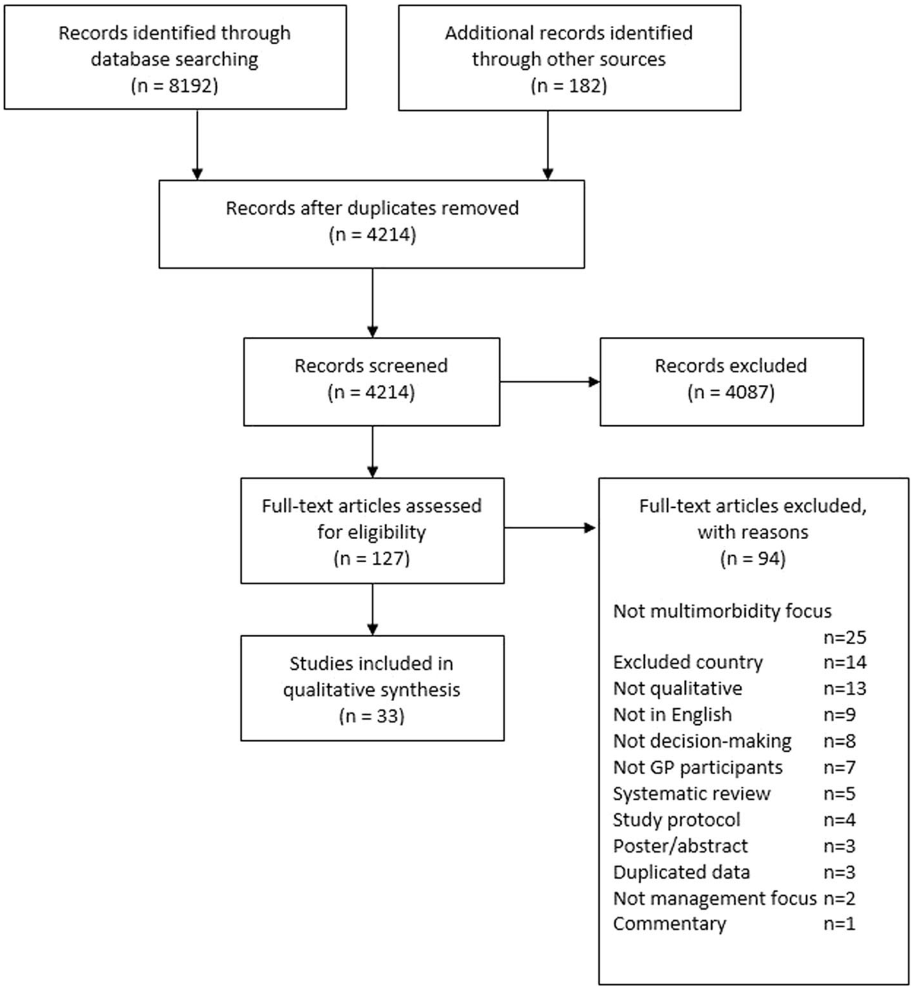

Fig. 2 PRISMA flow diagram of article selection decisions

tool for qualitative research. Only two areas were inconsistently reported: consideration of the nature of the researcher/participant relationship and of ethical issues. It is not possible to know if these elements had been considered by researchers and not reported or not considered at all. We have therefore marked these areas with a question mark rather than a 'No' response (Additional file 2).

Thematic synthesis

The thematic analysis of GP experiences of multimorbidity focused on three broad areas established a priori to answer the specific review questions. These were challenges of patient management, strategies for dealing with challenges, and suggestions for improvement.

In looking at inherent challenges, we identified three predominant analytical themes: *Practicing at the bounds of evidence*; *Confronting patient complexity;* and *Intersectoral failures and problematic policy.* Two themes emerged from the data to help our understanding of how GPs manage these challenges: *Prioritising a patient-centred approach to care*; and *Strategies for managing the consultation*. To answer review question three, we extracted GP views on what is needed to help them better serve this patient population. Further illustrative quotes supporting all themes are provided as Additional file 3.

GP perceptions of challenges in multimorbidity management

Theme 1. practising at the bounds of evidence

GPs questioned the applicability of existing therapeutic research to patients with multiple chronic conditions and their awareness of evidential limitations in this context created uncertainty and risk. It also induced a tension between practicing according to guideline recommendations—which might be mandatory within a specific national or regional primary care system—or deviating towards a more patient-centred, less evidence-based approach.

Table 1 Individual study characteristics

Author (Year) and country	No. of GP participants and their characteristics	Patient population and topic focus	Multimorbidity content	Method of data collection	Theoretical framework and form of analysis
Ailabouni (2016a) [73] New Zealand	10 GPs No. of years' experience prescribing in residential care: 2–32 years	A hypothetical patient with multimorbidity Deprescribing	Focus. Uses a hypothetical patient with multimorbidity to stimulate discussion of multimorbidity	Semi-structured interviews	Theoretical Domain Framework Content analysis
Ailabouni (2016b) [74] New Zealand	10 GPs No. of years' experience prescribing in residential care: 2–32 years. Gender: 7 males; 3 females	Older patients in residential aged care Deprescribing	Derived theme	Semi-structured interviews	Theoretical Domain Framework Content analysis
Anderson (2017) [60] Australia	32 GPs Mean age: 47 years (range: 28–70 years). Mean time in practice: 18 years (range: 1–50 years). 63.3% full-time. Gender: 18 males; 14 females.	Older patients with multimorbidity in primary care Deprescribing	Focus. Uses a hypothetical patient with multimorbidity to stimulate discussion of multimorbidity	Focus groups	Not stated Thematic analysis using Framework Method
Austad (2016) [68] Norway	25 GPs Not stated	Patients with multimorbidity in general practice Clinical practice guidelines	Focus	Focus groups	Phenomenological approach Systematic text condensation
Blakeman (2012) [55] England, UK	11 GPs Median age: 45 years (range: 30–62 years). Gender: 6 males; 5 females.	Patients with early-stage chronic kidney disease in primary care Patient management	Focus. Section on multimorbidity included in interview guide	Semi-structured interviews	Normalisation Process Theory Deductive analysis using framework
Bower (2011) [56] England, UK	15 GPs 'A mix of males and females'; 'significant variation in age and experience among participants'	Patients with multimorbidity in general practice Service organisation; Decision making	Focus	Semi-structured interviews	Not stated Framework analysis
Clyne (2016) [70] Ireland	17 GPs *N* = 14 GPs in practice > 10 years. Gender: 13 males; 4 females	Older patients in primary care Potentially inappropriate prescribing	Derived theme	Semi-structured interviews	Not stated Thematic analysis
Jones (2018) [61] Australia	14 GPs Mean time in practice: 21 years.	Remote Australian Aboriginal patients with complex health problems Clinical practice guidelines	Focus	Semi-structured interviews	Critical theory and a realist paradigm Thematic analysis
Kenning (2013) [57] England, UK	16 GPs Mean time in practice: 17 years. Gender: 7 males; 9 females.	Patients with multimorbidity in general practice Working with patients; self-care	Focus	Semi-structured interviews	Not stated Thematic analysis
Kristensen (2017) [64] Denmark	12 GPs Median time in practice: 16 years (range: 1–41 years). Gender: 6 males, 6 females.	Patients with multimorbidity living in rural, socioeconomically deprived regions Self-care	Focus	Semi-structured interviews	Not stated Systematic text condensation
Kristensen (2018) [65] Denmark	See Kristensen (2017) as duplicate data	Patients with multimorbidity and lowered self-care ability Disease management programs	Focus	Semi-structured interviews	Not stated Systematic text condensation
Kuluski (2013) [76]	4 Family Physicians	Older patients with	Focus	Semi-	Not stated

Table 1 Individual study characteristics *(Continued)*

Author (Year) and country	No. of GP participants and their characteristics	Patient population and topic focus	Multimorbidity content	Method of data collection	Theoretical framework and form of analysis
Canada	Time in practice: 3 GPs > 10 years; 1 = 1 year.	multimorbidity in primary care Care goals		structured interviews	Thematic analysis
Laue (2016) [69] International but only extracted data and findings for Norway, Wales, and the Netherlands	23 GPs (Norway: $n = 7$; Netherlands: $n = 6$; Wales: $n = 10$) Norway. Time in practice: 2 months-20 years. Netherlands. Time in practice: 3–30 years. Wales. Time in practice: 4–28 years.	Patients with COPD and exacerbations Decision making	Derived theme	Focus groups	Grounded theory Thematic analysis
Laursen (2018) [66] Denmark	14 GPs Mean time in practice: 15 years. Gender: 7 males; 7 females.	Poly-medicated patients with multimorbidity Medication review	Focus	Semi-structured interviews	Phenomenological/ hermeneutic orientation Content analysis
Luijks (2012) [48] Netherlands	25 GPs Mean age = 50 years. Mean time in practice: 20 years (range: 2–36 years). Gender: 18 males; 7 females.	Patients with multimorbidity in general practice Patient management	Focus	Focus groups	Realism paradigm Constant comparative analysis
Luijks (2015) [49] Netherlands	See Luijks (2012) as duplicate data	Patients with multimorbidity in general practice Clinical practice guidelines	Focus	Focus groups	Not stated Constant comparative analysis
Mc Namara (2017) [62] Australia	5 GPs (26 health care professionals in total) Not stated	Patients with multimorbidity in general practice Patient management	Focus	Semi-structured interviews	AGS Guiding Principles (cite) used as a framework for analyis Constant comparative analysis
O'Brien (2011) [80] Scotland, UK	15 GPs Gender: 8 males; 7 females	Socioeconomically deprived patients with multimorbidity in general practice Patient management	Focus	Semi-structured interviews	Modified grounded theory approach Constant comparative analysis
Ploeg (2017) [77] Canada	4 Family Physicians Not stated	Older, community dwelling patients with multimorbidity Patient management	Focus	Semi-structured interviews	Thorne's interpretative description approach Constant comparative analysis
Prazeres (2016) [79] Portugal	74 GPs Mean time in practice: 16 years (range 1–37 years). Gender: 23 males; 51 females	Patients with multimorbidity in general practice Patient management	Focus	Online survey	Not stated Thematic content analysis
Risor (2013) [50] International but only extracted data and findings for Norway, Wales, and the Netherlands	See Laue (2016) as duplicate data	Patients with COPD and exacerbations Decision making	Derived theme	Focus groups	Grounded theory Not stated but 'line-by-line coding' used
Sandelowsky (2016) [78] Sweden	59 Primary Care Practitioners Mean age: 46 years (range 28–68 years). Mean time in practice: 14 years (range 1–39 years). Gender: 30 males; 29 females.	Patients with COPD Patient management	Focus	Semi-structured interviews and focus groups	'Inspired by the grounded theory method' Constant comparative analysis

Table 1 Individual study characteristics *(Continued)*

Author (Year) and country	No. of GP participants and their characteristics	Patient population and topic focus	Multimorbidity content	Method of data collection	Theoretical framework and form of analysis
Schuling (2012) [51] Netherlands	29 GPs Mean age: 54 years (range 39–65 years). Gender: 27 males; 2 females.	Older patients with multimorbidity in primary care Deprescribing	Focus	Focus groups	Not stated Thematic analysis
Sinnige (2016) [52] Netherlands	12 GPs Mean age: 56 years (range 46–63 years). Mean time in practice: 25 years (range 10–35 years).	Older people with polypharmacy in general practice Medication management; Polypharmacy	Focus of clinical vignettes	Focus groups	Not stated Framework approach
Sinnott (2015) [71] Ireland	20 GPs Length of time qualified: 6 GPs < 10 years; 14 GPs > 10 years.	Patients with multimorbidity in general practice Prescribing decisions	Focus	Semi-structured interviews and chart-stimulated recall	Grounded theory approach Constant comparative analysis
Smith (2010) [72] Ireland	13 GPs Not stated	Patients with multimorbidity in general practice Patient management	Focus	Focus group	Not stated Framework analysis
Solomon (2012) [58] England, UK	8 GPs Not stated	Patients prescribed a statin or a PPI in primary care Clinical practice guidelines; Patient-GP partnership	Derived theme	Semi-structured interviews	Not stated Framework analysis
Sondergaard (2015) [67] Nordic countries: Denmark, Finland, Iceland, Norway, Sweden	62 GPs Not stated	Patients with multimorbidity in general practice Patient management	Focus	Plenary session and short open-ended questionnaires	Not stated Framework analysis
Stanners (2012) [63] Australia	8 GPs Time in practice (range): 20–40 years. Gender: 7 males; 1 female.	Patients with multimorbidity and depression in general practice Patient management	Focus	Semi-structured interviews	Grounded theory Constant comparative analysis
Stokes (2017) [75] New Zealand	12 GPs Not stated	Patients with multimorbidity in general practice Patient management	Focus	Semi-structured interviews	Not stated Thematic analysis
Tonkin-Crine (2015) [59] England, UK	19 GPs Mean age: 46 years (range: 31–60 years). Mean time in practice: 16 years (range: 3–32 years). Gender: 12 males; 7 females.	Patients with advanced chronic kidney disease in primary care Patient management	Derived theme	Semi-structured interviews	Not stated Thematic analysis
van de Pol (2015) [53] Netherlands	20 GPs Mean age: 48 years (range: 32–60 years). Gender: 11 males; 9 females.	Older patients in residential aged care Patient management	Derived theme	Focus groups	Not stated Constant comparative analysis
Vermunt (2018) [54] Netherlands	15 GPs Mean age: 51 years. Mean time in practice: 16 years. Gender: 6 males; 9 females.	Older patients with multimorbidity in general practice Patient management	Focus	Semi-structured interviews	Not stated Thematic analysis

The existing evidence base: insufficient, non-generalisable, and potentially unsafe

GPs considered clinical practice guidelines to be oriented around the management of single conditions—an approach aligned with secondary, rather than primary care [49, 51, 57, 62, 65, 67, 68, 72, 74, 75]. This could render guidelines 'reductionist' [57, 68] and an inadequate foundation on which to base clinical decisions [49, 50, 58, 67, 70–72]. GPs described guidelines as silent on the cumulative effects of prescribing different medications for concurrent conditions. This left them in the difficult position of having to weigh the potential benefits and risks of each patient's unique therapeutic cocktail. GPs were therefore operating in the knowledge that treating one problem risked exacerbating or creating new problems for other conditions [49, 51, 57, 60, 65, 67–69, 72, 74, 77, 79].

> The problem is that you are trying to weigh up unmeasurable harm quite often against unmeasurable benefit. We are trying to do that in our minds and trying to work it out—Is it more likely to be doing benefit or more likely to harm? The truth is that, in many cases, I don't know [60].

GPs were concerned that following a different guideline for each condition might jeopardise patient safety by driving polypharmacy, overdiagnosis and overtreatment ('… we're poisoning our patients.') [72] This approach also imposed a high burden of treatment on patients putting patient adherence at risk [65].

Guidance on deprescribing medications in the face of problematic polypharmacy was regarded as similarly inadequate [60, 62, 68, 72–74] with one GP describing it as 'a riskier, less certain, and more cognitively and socially demanding process, with minimal decision support.' [60] Knowing when and how to deprescribe *preventative* medicines for older patients or those with a poor prognosis was considered particularly important but often challenging as it meant reconciling statistical concepts such as absolute/relative risk reduction, number needed to treat, and time-to-benefit with questions of life expectancy and quality of life [49, 51, 62, 72–74].

> With a 40-something year old, the treatment aim is clear...to reduce risk over a long-term period. But for an 80-something year old, it becomes less clear cut [...] What can the patient get out of it, and also, what are the possible side-effects? [49]

GPs attributed the lack of useful and generalisable multimorbidity guidance to the hegemony of the clinical trial methodology with its preferential focus on internal, rather than external validity [49, 51, 68]. They were aware that guideline recommendations were often based on trials that tested therapies using much younger and less complicated patients than those they regularly encountered in their practices [49, 74, 77].

Protocol-driven medicine vs clinical judgement

For these reasons, GPs within and across studies frequently differed in the extent to which they viewed adherence to the tenets of evidence-based medicine feasible, or even desirable, in the context of multimorbidity. For some GPs, awareness of the limitations of existing evidence appears to provide a justification for preferencing their own professional autonomy and clinical judgement: '[Multimorbidity] gives you a lot of freedom to use your experience and own ideas as a doctor to help the patient's problem. Otherwise you'd be much more tied to the evidence….' [49] When this approach didn't result in negative outcomes, a GP's self-confidence could be boosted: 'I think, as you get older, you realize that is not really true because you have done it so many times and they have not had a stroke the next week.' [60]

Other GPs valued guidelines while viewing consistent adherence to them 'an impediment' [49] or 'a kind of hindrance' [51] to patient-centred care: 'Guidelines can only say so much about the disease and nothing about the whole patient.' [66] Some GPs regarded strict adherence to guidelines as a way to 'protect their back' against any professional or legal challenges to their decision making [68]. 'We could always go back to CARPA and say, "Look, this is how we're doing it and that's what's in the book. So leave us alone."' [61] This kind of 'defensive medicine' was also played out when GPs felt it necessary to deviate from guidelines:

> When I deviate from the guidelines, I am careful to write my reasons down in the patient record. For instance, if I take a patient off acetylic acid because he developed a stomach ulcer, I write that I am aware of the increased risk of a blood clot. Good record-keeping helps protect me [68].

A further group of GPs said they generally disregarded guidelines due to the overwhelming volume of evidence coming at them, combined with a lack of time or willingness to consult it [60, 74, 78]. This attitude, largely evident in studies from Australia and New Zealand, contrasts with those of GPs in countries where guideline adherence is mandated despite the fact that 'the map and the terrain simply [do] not match.' [68] In Norway, for example, GPs describe the pressure to conform to all guidelines as '[t]he insecurity that a guideline hell brings,' [68] while in the Netherlands one GP stated 'I have difficulty not following the guidelines if I don't have good reasons to do so.' [51]

Clinical uncertainty and perception of risk

In the absence of adequate evidence, GPs had a strong sense of the risks associated with their decision making, [48, 50–54, 57, 59, 60, 62, 63, 66–69, 71, 72, 74, 79] a situation described as 'doing it without the really significant evidence-based security.' [60] This could lead GPs to feeling nervous, anxious, or fearful of making mistakes and creating negative consequences for their patients [57, 60, 62, 68, 69, 71–74]. As a result, GPs might adopt one of two mindsets: what Anderson [60] describes as a 'risk to be reconciled' or a 'risk to be avoided' frame.

These orientations could be reinforced by positive or negative past experiences.

> Since I've started to look at that more globally, the number of medicines I'm prescribing on average for patients in rest homes is about 50% of what I was prescribing a year ago and they aren't falling off their perch in greater numbers [74].

In avoiding risk, GPs might maintain the status quo or demonstrate 'clinical inertia' in decision making [60, 62, 70, 71], especially in the context of deprescribing. This manifested as a reluctance to 'stir things up', [72] a focus on removing just the 'low hanging fruit,' or waiting for a clear 'trigger event,' such as a patient falling, to know when to cease a therapy [60]. The opposite reaction to a sense of risk was to provide, rather than withhold, treatment to patients [66, 68, 69]. This action might be based on the commonly held perception that health care systems rarely criticised GPs for overtreating patients but would take a hard line against GPs who undertreated.

> We never get criticized for doing too much. You don't get in trouble for having initiated unnecessary examinations even if they lead to complications. But you can be sure you'll get in trouble if you haven't done enough! We're much more vulnerable to the entire health care system's expectation that things must be done. There's an intense 'action imperative' to do more [68].

Theme 2. Confronting patient complexity

GPs reserved the term 'complex' for a subset of patients whose morbidity burden interacted with advanced age, frailty, or non-medical factors such as social, cultural, or economic context [53, 57, 70, 72]. In fact, any difficulties that impaired patient ability to comprehend the problems, participate in decision making, and self-manage were seen as adding to complexity. This included patient memory loss, cognitive impairment [48, 56, 62, 74, 76], low literacy [61, 80], and patient passivity, lack of motivation or initiative [50, 58, 64, 65, 70, 71]. A low expectation of a patient's ability to self-manage might escalate into GP feelings of hopelessness [48, 50, 64, 67, 78], or the perception of a patient as 'difficult.' [50]

> There are a couple of things we encounter such as most patients are 'dead horses'. This does not sound respectful but there are a lot of patients who want to be left alone. We cannot make them understand what we expect from them. Be active, quit smoking, more exercise, loyal to therapy, take their own initiatives [50].

This perception was particularly evident around COPD which some GPs described as a 'self-inflicted disease' with low status and low expectations of adherence [50, 67, 78]. 'You really don't expect adherence to treatment from someone who has smoked himself to COPD. That's probably why you don't refer or treat them.' [78]

Theme 3. Intersectoral failures and problematic policy

GPs described a number of problems in their attempts to share care of patients with multimorbidity with health professionals outside of primary care, chief among them poor communication. This confounded efforts to optimise patient experiences of the health and social care systems and could threaten patient safety. GPs described a sense of professional isolation (the 'lonely game' [70]), even demoralisation, when trying to create coordinated, wholistic care for patients in the face of a fragmented system. They were often unsupported in this by policies dictating consultation times and remuneration.

The primary-secondary divide

GPs reported a crucial disconnect between primary and secondary care prescribers which often resulted in GP reluctance to deprescribe or modify therapies initiated by specialists, even when they were uncertain of the initial indication [60, 62, 66, 70, 73, 74].

> Yeah, look the big doctor in the white coat in the big house on the hill always knows more than the GP especially the house surgeon who might have a brief amount of experience and does what they're told and one of the issues with this process is, experienced GPs still think that the doctor up the road knows more [74].

Patients may also be unwilling to consider reducing or stopping medications when GP advice went against the perceived higher authority of the specialist: 'Doctor X said I must never, ever stop that.' [60] Furthermore, GPs described the information coming to them from specialists as frequently 'delayed, lost or vague'. [62]

The transition point between hospital and the community setting was considered particularly dangerous for the conveyance of information on patients with multiple conditions. GPs may not be informed of why certain drugs had been added to or removed from the patient's list, nor whether this change should be considered permanent or temporary [41, 66].

Across several studies, GPs reported wishing to 'share the onus of responsibility' of multimorbidity care with specialists, 'rather than flying solo on it.' [71] However, endeavours to contact specialists for guidance could be frequently frustrated. According to one GP, this lack of communication had led to '[a] collusion of anonymity, which is, you know, this is not my patient, not my patient....' [72] Not all GPs described a poorly established GP-specialist relationship. GPs in one study regularly contacted renal specialists for advice about CKD and felt buoyed by their availability in the case of a deterioriation [59].

Some GPs perceived specialists as operating in silos with a single disease mindset which could impact significantly on their own workload: 'If we could stop hospital physicians prescribing single issue medicines for compromised older people, we'd reduce our problems by 50% overnight.' [74] Specialist prescribing practices might even interfere with the GP's professional accountability or prescribing autonomy. According to one GP:

> I see how patients go into the hospital and have new medications added because the hospital has followed the guidelines. We often have to take responsibility later for having the patients discontinue some meds and we thereby 'break the rules'. That's no easy job! But we have to try to see the whole patient [68].

As a result, patient care might become disjointed, with little flow of information and continuity of care between settings [65, 75]. Poorly defined individual roles across sectors led many GPs to attempt to assert professional responsibility for counteracting this fragmented, piecemeal approach by providing holistic, coordinated care. When workload pressures often made this hard to achieve in practice, this could lead to 'general inaction on multimorbidity' altogether [62].

Issues within primary and community care

GPs raised several areas of difficulty in providing care to patients with multimorbidity living in the community, especially those within residential aged care. Nursing homes presented GPs with a frustrating range of different computer systems and operational policies and procedures, leading them to label the environment as 'disorganised,' 'chaotic,' 'ad hoc,' and 'deficient in its coordination' [53, 74]. They described inconsistent and unclear documentation practices, as well as the absence of a shared digital patient record system which could provide data continuity between the nursing home and the GP's clinic.

> You try and find the notes, hard to find. You can't find the medicine chart, it could be on the rounds somewhere. It's not computerised, it doesn't link with our technical notes at the medical practice, so quality just goes down. It shouldn't be, but at the practice we've got the computer, we've got light, we don't have a darkened room in a rest home, and we can actually see what's going on [74].

GPs specifically mentioned difficulties in dealing with the anonymity, unavailability, and low skill level of nurses in nursing homes: 'Your first challenge is; you go to the rest home. You try and find a nurse. You can never find one.' [74] The large number of people involved in providing care in this environment was also seen as problematic as it could lead to '… confusion and miscommunication between the staff.' [53] Overall, GPs found the extra workload, stress and inconvenience in trying to work in nursing home visits around their clinic work as a 'juggling act' for which they felt inadequately compensated [74].

Many GPs spoke positively about working with other primary care health professionals, especially pharmacists, to provide team-based care. Pharmacists were seen as particularly important for enabling medication reviews, although a few GPs did not believe pharmacists had sufficient clinical expertise to work independently managing patients with multimorbidity: 'I am not sure that the pharmacist per se is going to be able to make those decisions. I mean they are probably more clinical decisions.' [72] This view also extended to practice nurses: '... that's what we spend years doing, is training to make clinical decisions, you know, so you can't expect nurses to do that, except in a limited way.' [72]

GPs working in areas of social deprivation reported a different set of local challenges. The social problems they encountered daily had broadened their definition of multimorbidity beyond medical considerations to take in unemployment, poor housing, problems with relationships, and poverty [80]. These GPs spoke of feeling 'powerless' to help when they found difficulties in engaging services beyond the clinic in the community to meet their patients' complex needs [79].

Local clinical systems designed to help GPs with care coordination might also impinge on the management of patients with multimorbidity. GPs working with Aboriginal populations in rural, remote Northern Australia described an inflexible electronic data entry template unable to cater for patient complexity, poorly organised patient data in the electronic health record, and burdensome and inadequately coordinated patient recalls [61]. As one GP said: 'If I had the time and took the time, I would usually take about an hour [to piece together the story] for people who had chronic health conditions' [61].

Impact of policy on time and workload

GPs reported struggling with the interrelated concerns of inadequate consultation time, insufficient financial remuneration, and increased workload where multimorbidity was concerned [48, 52, 53, 56, 58, 60, 62, 63, 65, 67, 71, 72, 74, 75, 78–80]. Some of these issues appear to stem from existing national or regional health care policies that still view primary care as oriented towards single disease, rather than multiple disease, management.

The foremost topic across studies and countries was the lack of consultation time afforded by health care systems for GPs to provide adequate care for patients with multimorbidity. The fluctuating nature of multimorbidity requires GPs to monitor patients for adverse biophysiological interactions, changes in psychosocial circumstances or preferences for care, as well as any difficulties in communication and care continuity when moving between different health care sectors. This level of vigilance requires more time that the standard consultation time allows.

> ... [H]ow on earth can you really, in a busy practice, deal with someone with multimorbidity, multi-polypharmacy in a 10-minute consultation? And to be fair to patients you can't, so you spend longer and therefore your day is longer, and you know, that's the nature of the job, but it does contribute to an increased workload [72].

Competing demands in multimorbidity care often left GPs just enough time to focus on acute concerns [71]. They therefore tended to put off tackling more time and resource intensive processes such as medication reviews or deprescribing [62]. Opportunities to discuss non-pharmaceutical or behavioural approaches to prevention such as weight loss or exercise are also deprioritised under time pressures [52, 60, 74]. 'When you see the obese person limping in with a sore throat [you ask]: 'Do you have a sore throat?', [and ignore the limp].' [72]

Dealing with the most pressing medical priorities in the course of a 'standard' appointment also limited the GP's ability to focus on the patient's concerns [67]: 'To be honest, you often get that sense [of opening Pandora's box], and you don't say anything, because you know you're at the beginning of the afternoon or whatever.' [72] This might include their current treatment preferences [62] as well as their longer-term priorities and goals of care [75]. Some GPs believed that this constant '…rationing out [of] time' [80] had a detrimental effect on their performance [67, 72], perhaps even putting patient safety at risk. This concern was evident regardless of GP length of time in practice and clinic location.

Problems with lack of time and extra workload were not helped by remuneration systems which GPs believed provided inadequate compensation for the level of care required by their patients [60, 62, 67, 74, 75]. This view appears to hold sway regardless of whether the primary care model of remuneration is based on fee-for-service, fee-for-performance, capitation, or a mixed model. Any incentives provided were not proportionate to the extra time required for consultation, follow up, and medication review.

Some participants used emotive language in describing the effect of this workload on their resilience, confidence and motivation, especially when patients seemed to make few health gains.

> Not worn down, that's not the right word, but they are difficult to manage because they don't seem to get any better and then obviously that has a psychological impact probably on the doctor and on the patient [57].

Others used terms such as 'burn-out,' [79] 'exhausting,' [80] 'demoralising,' [80] 'draining,' [77] 'overwhelming' [77] and 'soul destroying,' [80] or described feeling like a 'wrung out rag.' [80] Conversely, a few GPs working in more deprived areas felt 'energised rather than de-energised' and emphasized 'the privilege and rewards' of supporting 'complex' multimorbidity patients [80]. For one GP, there was a need 'for me to try and find something positive in it for my own sanity and peace of mind and, if not possible, just accept that there's a group of people whose lives you can't change, so don't try.' [80]

How GPs manage the challenges of multimorbidity

Theme 4. Prioritising a patient-centred approach to care

Across all 33 studies, GPs described the importance of having and maintaining a good relationship or 'partnership' with their patients. Many prioritised this relationship above all other aspects of care, perceiving it to bring benefits to the consultation and treatment outcomes, including the amelioration of certain challenges associated with multimorbidity. Firstly, the GP-patient relationship could provide a solid foundation for garnering better knowledge of patients and their specific life circumstances. This enhanced knowledge might then translate into individually tailored care for each patient based on a richer understanding of patient difficulties, treatment preferences, life goals and personal values.

Building and safeguarding a continuous patient-GP relationship

GPs prioritised building and maintaining a long-term, continuous therapeutic relationship with their patients with multimorbidity, viewing this relationship as a prime facilitating resource in patient care [48, 50, 51, 55, 56, 58, 60, 63–66, 71, 72, 75, 79, 80]. It enabled GPs to see the patient beyond the level of a presenting illness and could provide insights into aspects of the patient's social circumstances and individual psychology which might impact on therapeutic acceptance and success. A long-term partnership was also welcomed as a counter against the short consultation times within which GPs are forced to operate. Seeing a patient over a long period of time allows GPs to work at a slower pace, 'chipping away' at providing better follow up, monitoring the safety of any medication changes, and gradually introducing self-management skills [56].

> So it does make it easier when you do build up that relationship with patients, that you do see the same ones for these conditions, because then you realise, partly you don't have to deal with it all in one go, these are chronic conditions and you are going to be seeing this patient regularly, they build up that trust with you that they can come out with things that are bothering them, and that very, very frequently happens [56].

A GP's knowledge about a particular patient could serve as a frame of reference, adding a sense of security and confidence to assessment and decisions [69]: 'I think, if it is somebody who I know, I know their background, what the plan is and where we are heading, I am involved in the care relationship with them, that gives me confidence.' [60] This knowledge could also provide a dependable 'baseline of well-being' [63] with any deviations from this baseline sending up 'contextual red flags.' [69] GPs might call this their 'intuition' [63, 65] or 'gut feelings' [60].

GPs also valued the trust that often came with relational continuity: 'I think that you need to gain the trust of the patient, and that trust can be gained, I think, by showing interest, by talking with them about the social context.' [48] This trust could extend both ways with GPs trusting the knowledge patients were able to contribute to the decision-making process: 'Which drugs do you think are responsible? Patients are mostly right.' [51]

Preserving the relationship was often deemed so crucial in the management of multimorbidity that GPs might prioritise its safeguarding above communicating difficult information or changing a suboptimal course of therapy [51, 58, 66, 71]. This could lead to trying to please the patient by 'going down the path of least resistance' [66] or avoiding discussing life expectancy versus quality of life for fear of affecting the relationship [51]. Conversations around discontinuing preventative medicines were considered particularly risky as GPs worried that patients might perceive them as 'giving up on the relationship' [51, 71] or 'writing them off' [74].

In those papers describing GP care in socially deprived areas, the therapeutic relationship appeared particularly intense with participants likening the GP role to that of a 'priest' or a 'friend.' [80] However, other GPs working in the same area were reproving of this level of familiarity, particularly with patients perceived as having 'entrenched social problems', 'chaotic lives', or concurrent mental and physical conditions. These GPs felt long term interaction might risk patients becoming too dependent on the relationship [50, 80], consuming the GP's time with little expectation of improvement in situation [50]. These GPs spoke of the need for boundaries or limits between care of the 'medical' and of the 'social' aspects of a patient's life.

Eliciting patient and caregiver values, goals, and preferences for care decisions

GPs appeared to understand the highly individual nature of patient goals and values, accounting for them in the management plan [48, 49, 54, 58, 59, 63, 64, 69, 71, 73, 74, 76]:

> I [need to] get a better complete idea about the background, that is, what's the priority of this old lady, what's the priority of this man…. [If] I get a better idea [of the background] this will solve many problems [67].

Eliciting patient goals and preferences could often be an intuitive, rather than systematic, process that once again rested on the foundation of a GP-patient relationship [65]. GPs were particularly attentive to the goals and preferences of older patients and those with significant multimorbidity, understanding that goals could change quickly with fluctuating conditions and as the end of life approached [54]. Optimising quality of life then became the main medical goal.

Decision making was often described as a somewhat shared process with the GP in the role of an advisor: 'You have to go 'this is your life, your decision' and then give them my advice but they have to make the decision for themselves.' [71] However, not all GPs across the studies expressed the importance of eliciting and prioritising patient goals [51, 59, 62]. Some remained focused on clinical issues—often prevention efforts—stating what they viewed as important without reference to patient preferences. The extent to which GPs involved the patient or family in discussion and decision making was also variable: 'If it is an important decision, then I'll involve the family. But with some decisions, the family don't need to know everything.' [74] Several GPs believed that some patients preferred to be excluded from decision making processes: 'I just worry about it myself … rather than imparting a huge amount of knowledge' [71].

Tailoring care to each patient's unique circumstances and illness experience

GPs described using their knowledge of a patient's unique circumstances to individualise care, even if that meant deviating from the straight application of a guideline recommendation [61]. Having this 'whole picture' at their disposal allowed GPs to be more pragmatic in their approach to management and especially self-care as they weighed up a patient's capacity to meet the financial, emotional, and physical burden imposed by any care strategy: 'When you have known people for so many years then you really do not need to ask very much about self-care, because you know their work situation, who they are married to, their children and all these things' [64].

The understanding that comes with relational continuity led many GPs to express empathy for their patients in their illness experience: 'I worry that what we increasingly ask people to do is something we have got no experience of ourselves... We're telling them to do some impressively horrible things' [80].

Theme 5. Strategies for managing the consultation

In addition to focusing on the patient-GP relationship and utilising the knowledge gained of the patient, some GPs described strategies for the consultation that ensured action rather than passivity but which came with built-in insurance against risk for both patient and GP [52, 56, 60, 63, 69, 71, 75]. One such stategy was to offset some of the uncertainty by 'broadening the loop' to include other health care professionals in the care of a complex patient [71]. '[T]o bounce [ideas] off your colleagues just helps, even if it is just something like 'what in the name of God am I going to do about this', it's really important' [65].

Another common approach across studies was to first prioritise patient problems within a consultation, then manage them sequentially until the consultation time ran out. The patient's remaining problems are then deferred for a subsequent consultation [56, 60, 71, 75]. Bower et al. [56] call this priority-based, sequential method for dealing with the multiple issues thrown up by multimorbidity 'the additive-sequential' approach.

> … If they've got several conditions and several conditions need addressing, then you're limited in what you can do in one consultation slot. You get to know them and maybe next time he might say something like, 'can you make a double appointment next time?' So it gives them that little bit longer. Or ask if they can come back; you do what you can within your time, usually go over time and then get them to come back for the rest if they haven't managed to achieve everything [56].

For GPs, this process could generate a sense of 'having time,' alleviating some of the stress associated with inadequate consultation length for complex problems [63]. It could also buy more time to deal with diagnostic or therapeutic uncertainties as the GP has a longer time span in which to observe patients for adverse reactions or therapeutic benefits. Chiefly, however, it could aid to build greater relational continuity and the trust that can come with it [75]. These benefits were regarded as especially useful for the diagnosis of depression in patients with multimorbidity [63] and when educating patients about self-management, as all information need not be imparted in one go [63].

GPs might also use 'safety netting' as a risk mitigation strategy within the consultation when uncertain of the best course of action but concerned for patient safety. Here GPs prioritise their own agenda for the consultation over that of the patient [75], advising the patient on symptoms to watch for, and building in contingency plans in case the patient's condition worsened between consultations. GPs also employed 'satisficing' in decision making under conditions of uncertainty [60, 71, 75]. Sinnott et al. [71] define this as 'settling for chronic disease management that was satisfactory and sufficient, given the particular circumstances of that patient.' This approach was evident whenever GPs discussed relaxing targets or deviating from guideline recommendations (the 'ideal') in order to base care more on patient goals and preferences. 'I think, not perfectly managed, but managed well enough within that person's individual parameters.' [75] Satisficing might allow GPs to factor in patient self-care ability, as well as life expectancy:

> I'm not aiming for very tight control — I'm happy if his sugars are running a little higher than normal. I mean he has got cardiac failure as well, his life expectancy isn't brilliant — so long term I think, I don't think it's his type 2 diabetes that's going to kill him [71].

A further strategy described by GPs was to look for synergies between patient conditions and focus the management plan on treating a common causal pathway. This plan could then be sold to the patient as a solution to more than one of the patient's problems [75].

Theme 6. GP views on what might help

GPs provided a range of suggestions for improving the experience of multimorbidity for themselves and for patients. These fell within four main categories: More evidence and knowledge; Collaboration with other health professionals; Adequate consultation length; and Changed approach to care planning and coordination.

More evidence and knowledge

GPs expressed the need for evidence and guidelines in both prescribing and deprescribing for patients with multimorbidity [60, 73, 74], especially for the elderly [51]. They believed that current single disease guidelines would only improve their usefulness for patients with multimorbidity if integrated [57], perhaps via cross-referencing [49], if clinical trials involved patients with multimorbidity [49], or if more GPs became involved in guideline development [58]. GPs requested better reporting of guideline external validity [49] and guidance on how to prioritise recommendations, especially for preventative measures [49]. Some saw merit in shifting the focus from disease-specific outcomes towards more generic and global outcomes of value to the patient as these might have applicability across different conditions [49, 56, 79]. GPs also desire readily accessible clinical decision support tools to help their decision making within a number of challenging areas of care [51, 60, 66, 74]. Their suggestions included action cards developed by clinical pharmacologists that could serve as a 'go-to-list' when deprescribing [66] and practical tools for prioritising competing conditions [51, 67].

GPs also stated the need for more and better training and education on delivering patient-centred care for people with multimorbidity [53, 63, 66, 67, 72, 74, 79]. Training could take the form of scheduled 'knowledge exchange' meetings with other health professionals such as pharmacists and specialists [71], regular refresher courses, or post-academic courses focused on multimorbidity [49].

Collaboration with other health professionals

GPs spoke positively about working in closer collaboration with pharmacists in the planning and delivery of medication reviews and for deprescribing [51, 52, 60, 62, 66, 72, 74].

> I think we need to carry out medication reviews, and not miss people out. Sometimes its good to have somebody else look at it, so working together with a pharmacist is a good idea. Because I think two pairs of eyes looking at the same page, often gets better results than one person looking at a patient [74].

They also desired better cross-sectoral collaboration, envisaging better communication and support for both themselves and patients through a multidisciplinary team approach [52, 66, 72, 79].

Adequate consultation length

GPs argued the need to 'create a distinct consultation for multimorbid patients' [79] by extending appointment length by a reasonable amount to afford more time to spend with patients [72, 80]: '... [G]ive at least 30 min consultations for these patients;' [79] '... if we had time to have longer consultations with them they would consult us less;' [72] '... you know, the ideal thing if you could set aside a 40, 45-min slot for each of your multimorbidity patients, and just you know, do a clinic.' [72] Beyond this, GPs did not suggest how existing systems, policies, and remuneration models could be modified to make extended consultation times a reality.

Changed approach to care planning and coordination

GPs raised the need for care plans borne out of a process 'sensitized to multimorbidity.' [56] Such a plan would include patient goals and concerns, as well as individualised management strategies, and serve as a formalised, negotiated, and explicit agreement between the patient and the GP [54, 56, 76]. Ideally it would be available digitally [53]. A further idea was to increase the use of care coordinators in supporting patients to navigate multiple health care sectors and providers [62]. This role, which might be taken by a single GP [72], would work on optimising care plans and creating practical measures for improving care coordination [53].

Discussion

This review synthesised the first-hand accounts of 593 GPs from 14 countries. It confirms the findings of an earlier systematic review that GPs are challenged by inadequate guidelines and fragmented health care systems built around single disease states [25]. It also builds on these findings by identifying additional themes around GPs' pragmatic strategies for circumventing or managing these challenges and presenting their own suggestions for change.

The data makes clear that GP views are framed by specific national or regional policy levers impacting at the level of their own practice. These levers might dictate if and how patients are to be referred to services such as Disease Management Programs in Denmark [65] or nephrologists in the United Kingdom [55]. They might stipulate how care provided to nursing home patients will be reimbursed [74] while regulating the evaluation of care quality by linking it to clinician performance incentives [56, 68]. Yet despite important local differences, this synthesis identified commonalities between countries in terms of problems faced and approaches for dealing with them.

GPs continue to perceive the evidence base for multimorbidity care as insufficient and incapable of providing guidance for the clinical questions they most need answering. While uncertainty in the face of undifferentiated clinical and psychosocial problems is not uncommon to the GP [81], manifold knowledge gaps around multimorbidity persist [1]. These start with questions at the micro level of biophysiological mechanisms [82] and extend through to macro considerations of the best interventions [83] or care models [84, 85] for improving patient outcomes. Multiple chronic conditions can also present in unique permutations across individuals, challenging diagnostic certainty, limiting management options and altering the treatment benefit/risk profile [86].

It has been known for some time that clinical practice guidelines which prioritise evidence from randomised controlled trials may lack external validity for patients with multimorbidity, being based on younger and relatively healthier populations [87, 88]. The risks of applying a range of recommendations from single condition guidelines to any individual patient were first raised in 2005 [89] and continue to be reported [90–94]. Furthermore, published guidelines continue to inadequately acknowledge comorbidities [95–98]. It is not surprising, therefore, that GPs across the studies in this review demonstrated a cautiousness in strictly adhering to guideline evidence for patients with multimorbidity. They were not insensitive to the potential for iatrogenic harm, overtreatment with little tangible benefit, and increased patient burden of care [18], using terms such as 'risk', 'insecurity', 'anxiety', and 'fear' to describe their decision-making experiences. This insecurity appears to affect both prescribing decisions and questions of when to cease unnecessary or harmful therapies. This perception of a lack of safe deprescribing guidance is confirmed in the research literature [99].

Although GPs may be aware of these evidential limitations, some GPs expressed a preference for adhering to guidelines based on the security they represent, viewing decisions based on one's own clinical judgement as a riskier enterprise. This tension was particularly notable in places where regulatory bodies have linked remuneration or professional accreditation to the attainment of a range of evidence-based quality indicators. It has been widely suggested that these indicators may be less appropriate for patients with multiple conditions as they do not capture the complexity and dynamism of the multimorbidity experience [100]. Furthermore, the outcomes captured by the indicators may not reflect the priorities of patients themselves [101]. For these reasons, alternative evidence-based quality assessment frameworks for complex patients have been proposed or are in development. These might measure and incentivise continuity of care [102], patient preferences and values [100], or use patient-reported indicators to capture the patient's care experience and outcomes [103].

Gaps or delays in communication from specialists to GPs and specialist inaccessibility to GPs are important system failures which persist despite technological advances such as the Shared Health Record. These interprofessional communication failures provide the GP with an additional, but avertible source of uncertainty as the specialist's intentions for a patient must be interpreted to minimise treatment conflicts [104, 105]. The problem is not only felt by GPs. It can also impact negatively on patient self-reported perceptions of their care [21, 106–108].

Policies shaping the organisation of care delivery are also shown to have a disruptive impact on the patient consultation by creating a care context 'structured and incentivized to support short clinical interactions and disease focused care' [109]. This approach is not only at odds with the principles of patient-centred care endorsed by health systems (even at the national level), but also with the everyday reality of clinical practice where increased patient complexity requires more, not less time and interaction with the GP. Adopting an approach such as the 'additive-sequential' model suggested by Bower [56] could, therefore, be considered a deferment tactic indicative of a workload problem, rather than an effective approach to patient care. Currently GPs in the United Kingdom are facing increasing workloads [42] and the strain of trying to meet the higher volume and intensity of work is said to portend a crisis of GP retention [110]. GPs have attributed their widespread low morale and exhaustion to limited time and resources for dealing with increased patient complexity, together with non-commensurate financial rewards [111]. Lack of time to deal with the problems faced in general practice and high rates of GP psychological stress were recently highlighted as concerns in Australia as well [112, 113]. Together, the many negative terms used to describe multimorbidity across included studies in this review may be telling of more extensive morale and stress issues in this context. Without correction, increasing workloads and rising societal expectations of GPs may threaten the goals of both the Triple and Quadruple Aims [114].

Considering the strong association of multimorbidity with aging populations, we were surprised to identify only two studies focused on GP care provision for residential aged care patients with multimorbidity [53, 74]. Here again GPs conveyed a sense of hopelessness in achieving a reasonable standard of care for their patients due to time pressures, poor communication between care providers, inefficient local systems and policies, and a perception of multimorbidity care as being beyond the skill level of some nurses. Models of primary care and their associated financial incentives also appear to impact on GP satisfaction with their residential aged care duties.

How GPs perceive their role

Despite the many challenges they confront, GPs see themselves as having an important role in managing patients with multimorbidity. The views conveyed within the data strongly support the general practice ethos of providing holistic care with an emphasis on the biopsychosocial context, including family and community. GP concerns for patient safety and wellbeing were expressed in terms that align well with the concept of the 'patient-centred consultation' as operationalised by Stewart [115]. GPs strove to understand the patient's illness experience; see the whole person in context; find common ground; and enhance the doctor-patient relationship through, for example, compassion and the gaining of trust [115]. The approach described by many GPs in the study also resonates with the Sage Consultation Model of the 'expert generalist' which takes an inductive, data driven approach to decision making by combining information from research, patient, and professional to 'co-create an individualised account of illness' [116].

Most strikingly, GPs' attitudes aligned strongly with the WONCA statement that GPs work by 'utilising the knowledge and trust engendered by repeated contacts' [22]. This was clear from the importance GP participants placed on relational continuity, appearing to safeguard it in the face of protocolised targets and guidelines. GPs might value the longitudinal interpersonal relationship with a patient for quite pragmatic reasons, including its usefulness as a 'simple and powerful tool' for addressing multimorbidity [117]. It could be relied on as an important source of accumulated knowledge of the patient—one existing beyond the limitations of an inflexible or sparsely populated electronic patient record [118]. This knowledge might impart a perceived security to difficult diagnostic decisions by giving some context to any signs of change or deterioration. As Sturmberg states: 'The ongoing doctor-patient relationship is a necessary a priori to the creation of shared memories, stored as tacit knowledge…' for this knowledge grants the GP the ability to 'discriminate between information and noise' in a patient's narrative [119]. In addition to this accumulative knowledge benefit, the research evidence supports the importance of interpersonal continuity of care for downstream effects such as decreased mortality [120, 121], reduced emergency visits [122], and hospitalisations [123], and a greater sense of patient satisfaction with care provision [124, 125]. Despite this positive association, there is growing evidence that relational continuity is on the decline [126] or under threat [127]. Prime reasons given for this erosion include a GP workforce shortage, more GPs working part-time, government policies that prioritise access to care over its continuity, and the widening of teams in primary care into 'super practices' [128].

Solutions from GPs

The GP participants offered some solutions for the problems they encountered when asked to do so. Firstly, they desired closer working ties with pharmacists for the purpose of medication reviews. This was seen as a positive way to resolve the dual issues of uncertainty around (de)prescribing and lack of adequate consultation time. Although recent systematic reviews have highlighted the benefits to patients and GPs of integrating pharmacists into general practices [129, 130], the rate of uptake varies across countries. For example, NHS England recently committed resources towards increasing the numbers of clinical pharmacists working in general practices after a successful pilot project [131]. Meanwhile the Australian government funds community pharmacists to conduct medication reviews but pharmacist integration into general practices remains uncommon, despite some small-scale commissioned trials [132, 133] and a Pharmaceutical Society of Australia action plan for 2023 [134]. In comparison to the pharmacist role, the role of the practice nurse/nurse practitioner in supporting general practice was not mentioned. This may be due to the relative ubiquity of the role in the countries studied.

GPs also emphasised the need for longer appointment times for complex patients. Without adequate time, medication reviews, conversations around goals and priorities, and shared decision making remain 'nice-to-have extras' [135]. Concerns over lack of adequate consultation time for patients with multimorbidity have been raised elsewhere [111, 136–138], with one study finding 70% of GPs believed longer appointments enhanced patient enablement and reduced their own workload stress [139]. However, appointment length often goes hand-in-hand with models of remuneration to the extent that changing one requires restructuring the other. In Australia, for example, the fee-for-service model rewards GPs more for giving shorter, rather than longer consultations [140], inevitably creating a consultation culture quite different to that of the salaried or capitation general practices. Furthermore, despite GPs wanting more time with complex patients, the evidence supporting longer consultations remains mixed. One Cochrane systematic review of low quality studies found no relationship between length of consultation time and patient satisfaction or health outcomes [141]. Conversely, the 2016 CARE Plus trial could demonstrate a positive impact of longer consultations on patient quality of life and enablement [142].

Finally, GPs proposed a raft of small, somewhat disconnected ideas relating to their current problems with evidence. There was some benefit seen in addressing common risk factors such as obesity, smoking, lack of activity, as well as prioritising the most debilitating disease clusters. More commonly, however, GPs expressed a need for more training and education in how to manage multimorbidity. Although this may be one of the easier multimorbidity challenges to address, the question of how to adequately provide such training to general practitioners remains unresolved [143].

Implications of these findings

Multimorbidity is ubiquitous and its prevalence is expected to rise as populations age. GPs are at the forefront of care for these patients but there is evidence that they are finding this responsibility a strain. If GPs are struggling to manage these patients, they are at risk of poor personal outcomes such as burnout or loss to the profession which raises concerns for patient safety issues and the sustainability of general practice as a whole. We know that patients have better outcomes in countries with strong primary care [4, 144], and that this may be especially true for patients with multimorbidity [145]. Therefore, as stated by the Royal Australian College of General Practitioners, 'it is more important than ever to support GPs in their role as health stewards of coordinated patient health care and enhance their ability to provide holistic patient-centred care' [112].

This study used a qualitative design to focus in on the GP voice to hear what they are telling us works and what doesn't work. These findings therefore provide some insight into the nature of the problems GPs are facing. Most pressingly, GPs have expressed a need for greater support in providing the generalist care required. This means support from generalisable evidence and from other health professionals, especially those working in other parts of what they consider a fragmented health care system. GPs also require remuneration schemes commensurate with the workload of multimorbidity and the removal of any structural impediments to their ability to forge ongoing relationships with their patients. These concerns may require significant reform of overarching yet antiquated models with considerable system-level support from governments.

Study strengths and limitations

This synthesis was conducted according to a rigorous methodology that included investigator triangulation for coding and theme derivation and the involvement of researchers from different discipline backgrounds and varied levels of experience with qualitative research. Furthermore, we believe the purposely broad nature of the inclusion criteria and search strategy has ensured that a range of GP perspectives informed the themes.

Restricting the results to countries with similar models of general practice may be seen as both strength and limitation. While it made it easier to meaningfully compare and contrast studies, a future study might involve a cross-country comparison using the included versus the excluded country studies. Furthermore, our included countries may have cultural and socioeconomic differences that influenced findings in unforeseen ways. We were also aware that the primary data sources on which we base our own findings have already been selected and interpreted by other researchers. We do not have access to the full data originally obtained from participants, therefore have no way of knowing if other quotes exist that better support our findings or ably refute them [146]. That said, the richer the data provided in the original papers and the stronger the methodology used, the more confidence we have that authors' findings (also included in the synthesis) are based on the totality of the data. The quality appraisal process found most of the studies in this review strong on both these attributes.

Similarly, we could only work with what GPs said they do. This means some self-reflections may describe aspirations rather than actual behaviours. The close focus on the topic of multimorbidity may have also led GPs to overestimate the problems or underestimate their own handling of them. Further research may be warranted to determine how generalisable these findings are to a larger number of GPs within the individual health care systems represented here. This might take the form of country-specific cross-sectional studies to verify findings on a larger scale. It might also be useful to ask similar questions of specialists in order to compare their views and experiences of managing patients with multimorbidity to that of general practitioners.

Conclusions

This paper adds to an understanding of the problems GPs experience in providing frontline care to patients with multimorbidity. The currency of the earliest papers highlights the slow pace at which necessary reforms are being made to health care systems to improve the workplace experiences of GPs and the quality of care received by more complex patients. If we value strong primary care systems we must listen to its practitioners, understand their issues and make concerted efforts to remove barriers to their provision of tailored and patient-centred care. This might also require changes to models of primary care and their systems of remuneration, processes of communication between health sectors, and a focus on multimorbidity education opportunities for GPs and their primary care teams. However, as Salisbury said back in 2013: '(T)he time has come to stop just describing the problem of multimorbidity, but to do something about it' [101].

Supplementary information

Supplementary information accompanies this paper at https://doi.org/10.1186/s12875-020-01197-8.

Additional file 1. Ovid Medline search strategy.

Additional file 2. Appraisal of primary studies according to CASP Qualitative Appraisal tool.

Additional file 3. Illustrative quotes supporting derived themes.

Abbreviations

AGS: American Geriatrics Society; CARPA: Central Australian Rural Practitioners Association; CASP: Critical Appraisal Skills Programme; CKD: Chronic Kidney Disease; COPD: Chronic Obstructive Pulmonary Disease; CVA: Cerebrovascular accident; ENTREQ: Enhancing transparency in the reporting of qualitative health research; GP(s): General practitioner(s); MCC: Multiple chronic conditions; NICE: National Institute for Health and Care Excellence; NZD: New Zealand Dollars; PHO(s): Primary *Health* Organisation(s); PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses; QOF: Quality and Outcomes Framework; TIA: Transient Ischaemic Attack; WONCA: World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians

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Authors' contributions

RD conceived the study, designed and conducted the search for studies, screened citations against eligibility criteria, conducted the quality appraisal, coded and extracted the data, and drafted the manuscript. DM and JT analysed the coding, contributed to the development of analytic themes, and made important contributions to the drafting of the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets analysed during the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Publisher's Note

A1.2 Ovid Medline search strategy

Datasets included: Ovid Medline, Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions, 1946 to September 14, 2018.

#	**Searches**
1	Comorbidity/ or Multimorbidity/ or Multiple Chronic Conditions/
2	(multimorbid* or "multi-morbid*" or comorbid* or "co-morbid*").tw,kf.
3	(polymorbid* or poly-morbid* or multipathology or multi-pathology or polipathology or polypathology or pluripathology or poli-pathology or poly-pathology or pluri-pathology).tw,kf.
4	((multipl* or "more than" or several or co-occur* or cooccur* or coexist* or co-exist* or concurrent*) adj3 (long-term or longterm or chronic)).tw,kf.
5	(multidisease* or multi-disease* or multicondition* or multi-condition* or (multiple adj (ill* or disease* or condition* or syndrom* or disorder*))).tw,kf.
6	Polypharmacy/
7	(polypharmac* or poly-pharmac* or polymedicat* or poly-medicat*).tw,kf.
8	or/1-7
9	Primary Health Care/ or General Practice/ or Family Practice/ or General Practitioners/ or Physicians, Family/ or Physicians, Primary Care/
10	(primary care or primary healthcare or primary health care or general practice* or general medicine or general practitioner* or GP or GPs or family practice* or family medicine or family practitioner* or family physician*).tw,kf.
11	or/9-10
12	Decision Making/ or Clinical Decision Making/ or Uncertainty/ or Heuristics/ or Judgment/ or Problem Solving/
13	Evidence-Based Practice/ or Evidence-Based Medicine/ or Guidelines as Topic/ or Practice Guidelines as Topic/ or Guideline Adherence/ or Clinical Protocols/ or Critical Pathways/ or Algorithms/ or Decision Support Systems, Clinical/ or Decision Support Techniques/
14	Health Knowledge, Attitudes, Practice/ or Knowledge/ or Professional Practice/ or Physician's Practice Patterns/ or Professional Competence/ or Clinical Competence/
15	Negotiating/ or Consensus/ or Watchful Waiting/
16	Patient Care Planning/ or Patient Care Management/ or Patient-Centered Care/ or Patient Preference/
17	Inappropriate Prescribing/ or Deprescriptions/ or (deprescrib* or de-prescrib* or ((discontinuing or stopping or ceasing) adj2 medic*)).tw,kf.
18	(decision* or uncertain* or heuristic* or judg?ment* or problem solv* or reason* or intuit* or gut feeling*).tw,kf.
19	(evidence based or best evidence or best practice or guideline* or clinical protocol* or critical pathway* or algorithm*).tw,kf.
20	(knowledg* or competenc*).tw,kf.
21	(negotiat* or consensus or watchful waiting).tw,kf.
22	((patient or multimorbid* or multi-morbid* or comorbid* or co-morbid*) adj1 (manag* or treat* or therap* or prescrib* or prescrip*)).tw,kf.
23	or/12-22

24	"Attitude of Health Personnel"/ or Focus Groups/ or Interviews as Topic/ or Narration/ or "Surveys and Questionnaires"/ or Self Report/ or Grounded Theory/ or Qualitative Research/ or Hermeneutics/ or px.fs.
25	((semi-structured or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide? or group*) adj3 (discussion* or questionnaire*)).tw,kf.
26	(interview* or focus group* or diary or diaries or transcrib* or verbatim or field not* or memo? or memoing).tw,kf.
27	(audiotap* or audio-tap* or audio record* or audiorecord* or tape record* or taperecord* or video*).tw,kf.
28	((context* or semantic or content or conversation or discourse* or discurs*) adj2 analys*).tw,kf.
29	((narrat* not narrative review) or qualitative* or ethnograph* or fieldwork or (field adj (work or research* or study or studies)) or informant* or phenomenolog* or hermeneutic* or grounded or interpretive* or participant observ* or background observ* or reflective* or reflection* or textual* or open-ended or theme? or thematic* or triangulat* or mixed method*).tw,kf.
30	((theoretical or purpos* or cluster) adj2 sampl*).tw,kf.
31	((primary care or primary healthcare or primary health care or general practice* or general medicine or general practitioner* or GP or GPs or Family practice* or Family medicine or Family practitioner* or Family physician* or clinician* or provider* or professional*) adj5 (experience or experiences or opinion* or perception* or insight* or perspective* or attitude* or belief* or considerations or awareness or view or views or reflection* or value*)).tw,kf.
32	or/24-31
33	8 and 11 and 23 and 32

Notes: / = search on Medical Subject Headings (MeSH) ; tw,kf = search on title and abstract (tw) fields as well as author-assigned keywords field (kf); px.fs = search on "Psychology" (px) MeSH subheading (fs); * = search for variant word endings; ? = allows for zero or one character replacement within a specified word; Adj finds terms next to each other in specified order; Adj1 finds terms next to each but in any order; Adj2 finds terms in any order with one word or less between them; Adj3 finds terms in any order with two words or less between them.

A1.3 CASP critical appraisal checklist for qualitative studies

CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference: ....

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?	Yes ☐ Can't Tell ☐ No ☐	HINT: Consider • what was the goal of the research • why it was thought important • its relevance

Comments:

2. Is a qualitative methodology appropriate?	Yes ☐ Can't Tell ☐ No ☐	HINT: Consider • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants • Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?	Yes ☐ Can't Tell ☐ No ☐	HINT: Consider • if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

A1.4 Critical appraisal of included qualitative primary studies using CASP Qualitative Checklist

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Ailabouni 2016a	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ailabouni 2016b	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Anderson 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Austad 2016	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Blakeman 2012	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Bower 2011	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Clyne 2016	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Jones 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Kenning 2013	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Kristensen 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Kuluski 2013	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Laue 2016	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Laursen 2018	Y	Y	CT	Y	Y	CT	Y	CT	Y	Y
Luijks 2012	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Luijks 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
McNamara 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
O'Brien 2011	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Ploeg 2017	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Prazeres 2016	Y	Y	Y	Y	Y	NA	Y	Y	Y	Y
Risor 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Sandelowsky 2016	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Sinnige 2016	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Sinnott 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Smith 2010	Y	Y	Y	Y	Y	Y	CT	Y	Y	Y
Solomon 2012	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Sondergaard 2015	Y	Y	Y	Y	Y	CT	CT	Y	Y	Y
Stanners 2012	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Stokes 2017	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Tonkin-Crine 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Van de Pol 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Vermunt 2018	Y	Y	Y	Y	Y	Y	CT	Y	Y	Y

Legend: Y=Yes, N=No, CT=Cannot tell, NA=Not applicable

A1.5. Differences between the thesis and the Sinnott et al.[1] systematic reviews

	Sinnott (2013)	**Damarell (2021)**
Aim 1	To determine the perceptions of GPs (or their equivalent) on the clinical management of multimorbidity.	To determine which aspects of patient care are considered challenging for GPs in the therapeutic management of patients. with multimorbidity
Aim 2	To determine targets for future research that aims to improve clinical care in multimorbidity.	To determine the strategies GPs engage to handle these challenges in order to provide satisfactory patient care.
Method of synthesis	Meta ethnographic synthesis[2] of qualitative studies.	Thematic synthesis[3] of qualitative studies.
Differences in eligibility criteria	Studies were excluded if the focus was on an index condition No limits on country of study. Not limited to English language	Studies were not excluded if the focus was on an index condition, provided multimorbidity was explored as an issue in questions or findings Limited to countries with similar primary healthcare systems (i.e., excluded the United States) Limited to English language
***Unique* databases searched**	• Academic Search Complete • SocIndex • Social Sciences Full Text	• Ageline (EBSCOhost) • Scopus • Web of Science • ProQuest
Differences in search strategies	Concepts: Primary care, multimorbidity, domains of interest, qualitative studies Searches for each concept used either database subject headings OR textwords. Qualitative search component used very few terms.	Concepts: Primary care, multimorbidity, domains of interest, qualitative studies Searches for each concept used a combination of both database subject headings AND textwords. Textword synonyms were employed to a much greater extent, especially in the qualitative search component.
Number of included studies	1805 unique citations screened 10 included studies	4214 unique citations screened 33 included studies including 6 of the Sinnott review.
Countries covered	7	14
Years covered by	2009-2012	2010-2018

included studies		
No. of individual participant voices	275	593
Critical appraisal tool	CASP (qualitative)	CASP (qualitative)
Side-by-side themes comparison	**Challenges** 1. Disorganisation and fragmentation of healthcare • Multiple specialist involvement ‘antagonistic to GPs’ ‘holistic’ goals • Poor coordination and communication between providers • *Role uncertainty* 2. Inadequacy of guidelines and evidence-based medicine • Evidence considered non-generalisable to unique patients • Conflict between following and deviating from guidelines *3. Challenges in delivering patient-centred care* • Trying to factor in psychosocial issues increased the complexity of management • A patient-centred approach could offset uncertainty • Patient-centred care could also put GPs in conflict with evidence-based medicine. • Burden of treatment *4. Challenges in shared decision-making* • *Patients limited in their ability to share decisions* • Challenging to communicate complex or unknown risks and benefits associated with various options.	**Challenges** 1. Intersectoral failures and problematic policy • Disconnect between GPs and specialists outside primary care raises *patient safety concerns (prescribing, transitions of care)* • Poor coordination and communication between providers • *Dissatisfaction with residential aged care working conditions* • *Inadequate consultation time linked with insufficient remuneration for heavy workload.* 2. Practicing at the bounds of evidence • Evidence considered non-generalisable to unique patients • *Awareness of impact on patient safety and self-management* • *Experiences of uncertainty and discomforting perception of risk* • Conflict between following and deviating from guidelines. *3. Confronting patient complexity* • Many patients limited in their ability to comprehend problems and self-manage ***Strategies*** *4. Prioritising a patient-centred approach to care* • *Building and safeguarding longitudinal relationship* • *Focus on patient values, goals, and preferences* • *Tailoring care to*

		circumstances 5. *Strategies for managing the consultation* - *Involving colleagues, additive sequential approach, safety netting, satisficing.*
Reporting	Informed by ENTREQ (cite)	Informed by ENTREQ

Note: Unique themes and subthemes (or their unique expression) are italicised.

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APPENDIX 2

Chapter 5. Multimorbidity through the lens of life-limiting illness: how helpful are Australian clinical practice guidelines to its management in general practice?

A2.1 Published journal articles based on the Chapter 5 content analysis

1. Damarell RA, Morgan DD, Tieman JJ, Healey DF. Multimorbidity through the lens of life-limiting illness: How helpful are Australian clinical practice guidelines to its management in primary care? Aust J Prim Health. 2021 Jan 19;27(2):122-9. doi: 10.1071/PY20164
2. Damarell RA, Morgan DD, Tieman JJ, Healey D. Bolstering general practitioner palliative care: a critical review of support provided by Australian guidelines for life-limiting chronic conditions. Healthcare. 2020 Dec;8(4):553. doi: 10.3390/healthcare8040553.

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Australian Journal of Primary Health **Manuscript No.** PY20164

Title of the paper (the 'Work') Life-limiting illness and multimorbidity: how helpful are Australian clinical practice guidelines to their management in primary care?

Author(s) Damarell, Raechel; Morgan, Deidre; Tieman, Jennifer; Healey, David

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Research

Multimorbidity through the lens of life-limiting illness: how helpful are Australian clinical practice guidelines to its management in primary care?

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Abstract. This study assessed Australian clinical practice guidelines for life-limiting index conditions for the extent to which they acknowledged comorbidities and framed management recommendations within the context of older age and reduced life expectancy. A comprehensive search identified current, evidence-based Australian guidelines for chronic life-limiting conditions directed at general practitioners. Guideline content was analysed qualitatively before comorbidity acknowledgements were quantified using a 17-item checklist. Full guidelines were quality appraised using AGREE-II. Ten documents covering chronic obstructive pulmonary disease, heart failure, cancer pain, dementia and palliative care in aged care were identified. Most guidelines addressed one 'comorbid' condition and prompted clinicians to consider patient quality of life and personal preferences. Fewer addressed burden of treatment and half suggested modifying treatments to account for limited life expectancy, age or time horizon to benefit. Half warned of potential adverse drug interactions. Guidelines were of moderate to very high quality. Guidelines naturally prioritised their index condition, directing attention to only the most common comorbidities. However, there may be scope to include more condition-agnostic guidance on multimorbidity management. This might be modelled on the 'guiding principles' approach now emerging internationally from organisations such as the American Geriatrics Society in response to increasing multimorbidity prevalence and evidence limitations.

Keywords: general practitioners, multimorbidity, life expectancy, practice guidelines, evidence-based medicine, Australia.

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Introduction

Ageing populations in high income countries such as Australia are increasingly burdened by multimorbidity – the presence of two or more chronic conditions in the one person (Nguyen *et al.* 2019). Multimorbidity reduces life expectancy, quality of life and function, while increasing health service use (Academy of Medical Sciences 2018). Australian general practice data puts multimorbidity prevalence at 51.6% for two or more conditions and 30.4% for complex multimorbidity (Harrison *et al.* 2017). Moreover, multimorbidity prevalence increases with age, reaching 93% and a median number of four conditions in Australians over 85 years (Collerton *et al.* 2016).

Despite clear familiarity with multimorbidity, general practitioners (GPs) report challenges providing care for this population. Primarily, they question the relevance of single condition clinical practice guidelines that continue to draw on research involving younger, fitter patients (Sinnott *et al.* 2013; Damarell *et al.* 2020). Negotiating a balance between benefits and harms for competing conditions using guidelines requires cautious extrapolation of evidence, adjusting for different baseline risks and effect sizes on the ageing physiology. Furthermore, applying recommendations across guidelines puts patients at risk of drug–drug and drug–condition interactions and may impose a heavy burden of treatment (Dumbreck *et al.* 2015).

Multimorbidity is heterogeneous in that a chronic 'index' condition might be accompanied by any number of concordant or discordant comorbidities, both physical and mental. It would be unrealistic, therefore, to expect guidelines to anticipate and address each potential adverse outcome. However, chronic life-limiting conditions might invite special consideration as a group of illnesses expected to lead directly to death (Palliative Care Australia 2018). Conditions such as chronic cancer, heart failure and dementia are prevalent in older adults and are often associated with significant and disabling comorbidities. In Australia, the prevalence of chronic conditions in addition to a life-limiting condition ranges from 82% for cancer and 90% for chronic obstructive pulmonary disease (COPD) (Australian Bureau of Statistics 2015). This rises to 99.1% for heart failure (Taylor *et al.* 2017). Unlike other conditions of increasing age such as arthritis, osteoporosis, perhaps even diabetes, the management of these progressive conditions is likely to be framed by considerations of life expectancy, quality of life, and an inevitable, but perhaps hard to time, transition phase from active management to end-of-life care.

Clinical guidelines for life-limiting conditions might therefore have leeway to approach the management of multimorbidity through more general considerations of treatment burden and maximising quality of life. They might address cessation of unnecessary therapies, such as those with a long ‘time horizon to benefit’ or large ‘number needed to treat’, while highlighting the importance of determining patient and family’s preferences for care and creating an advance care plan (American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity 2012). This approach would support the holistic mission of general practitioners who view their role as one of coordinating the care each patient receives across all body systems and sectors of the health care system.

Multiple systematic assessments of clinical guidelines have examined the degree to which they acknowledge comorbid conditions in addition to an index condition. Each assessment has focussed on a specific subset of chronic condition guidelines such as those for an individual condition, by an organisation, or originating from a certain country. This study adds to this research by examining how Australian clinical practice guidelines acknowledge, address, or prompt the management of multimorbidity in the contexts of life-limiting illness and general practice.

Methods

Ethics approval

This study is a document analysis and, as such, did not require ethics approval.

Guideline eligibility criteria

Guidelines and evidence summaries were eligible if they met both the production and content criteria outlined. Summarised versions of guidelines, such as those published in journals, were excluded.

Production criteria

Australian guidelines and evidence summaries produced for a national audience during or since 2012 and providing an explicit report of their methodology, including the basis on which recommendations were formed. This might include ‘expert consensus’ in instances where there is little or no evidence available, or ‘evidence-based recommendation’ where evidence has been weighed for its quality and strength. This criterion ensures all included resources are comparable in meeting a minimum standard of reporting quality for gauging trustworthiness. It also aligns with the expectations of critical appraisal tools such as AGREE II and national agencies responsible for endorsing guidelines (e.g. National Medical Research Council Australia).

Content criteria

Resources relevant to a primary care, rather than solely specialist, audience and focussed on the therapeutic management of a chronic, life-limiting condition in adults. Conditions might include cancer, organ failure, and neurodegenerative conditions. Guidelines for the care of frail elderly or palliative populations where a high prevalence of multimorbidity is expected were also eligible. We excluded acute stroke and chronic conditions, such as diabetes, which may contribute to mortality without being the direct cause.

Search strategy

Resources were identified via databases (OVID Medline, Embase, Joanna Briggs Institute EBP Database, PubMed, Scopus, and Web of Science), guideline repositories, organisational websites, and a Google search. The Ovid Medline search strategy and a list of websites targeted by the search are provided as Supplementary Material S1.

Guideline selection

Resource selection proceeded in three stages: (1) One author (RD) screened titles and abstracts to determine broad relevance; (2) retained items were assessed against the production criteria (RD); and (3) a GP author (DH) reviewed the short list against the content criteria.

Assessment of comorbidity acknowledgement

Two authors (RD and DH) independently rated resources for their acknowledgement of comorbid conditions. This was conducted using an existing, validated 17-item yes/no checklist that focuses on a broad range of concerns relevant to the care needs of multimorbid patients (Fortin *et al.* 2011). Checklist items are organised into six domains, which quantify acknowledgement of: (1) older populations with and without multiple conditions; (2) the quality of evidence relating to these populations; (3) accumulating comorbidity, (4) burden of treatment; (5) patient preferences; and (6) medication side-effects and interactions. Resource content was read in its entirety and potentially relevant text was coded against checklist domains using the NVivo software (12 Pro). Checklist ‘yes’ answers scored a point to a maximum total of 17 points per guideline. Scoring differences were discussed until reviewers reached consensus.

Assessment of guideline quality

Guidelines were quality appraised by two authors independently (RD and DM) using the validated Appraisal of Guidelines Research and Evaluation (AGREE II) critical appraisal instrument (Brouwers *et al.* 2010). When appraiser scores varied more than three points per item, authors discussed their decisions with the goal of reducing the gap in scores. Final domain scores were calculated according to the tool’s instructions. Evidence summaries were not appraised as these were not expected to be

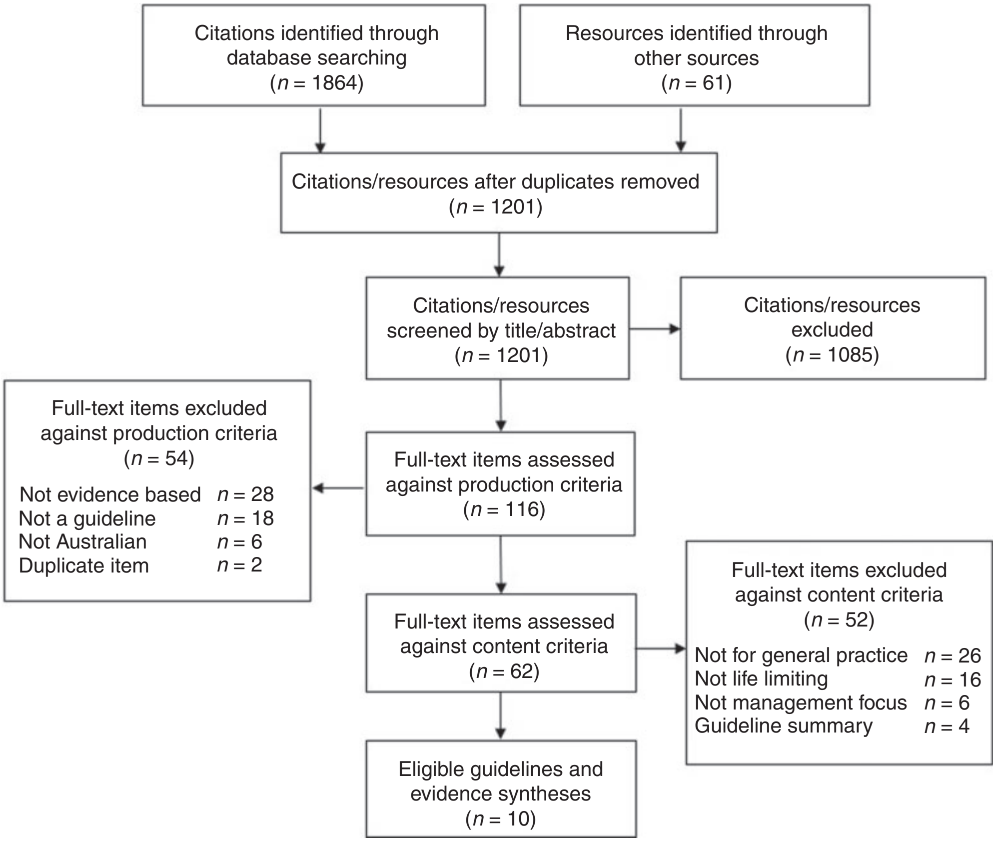

Fig. 1. PRISMA flow diagram of guidance screening process.

produced or reported to the same level of detail as clinical practice guidelines.

Results

Searches were conducted between 15–22 August 2018. Screening against eligibility criteria resulted in a total of 10 items. The full selection process is documented in a PRISMA flow diagram (Fig. 1).

Characteristics of included guidance

Documents for analysis included six guidelines and four evidence summaries covering management of:

- Heart failure (Royal Australian College of General Practitioners 2016*a*; National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand Heart Failure Guidelines Working Group *et al.* 2018)
- Chronic obstructive pulmonary disease (COPD) (Alison *et al.* 2017; Yang *et al.* 2018)
- Dementia (Guideline Adaptation Committee 2016; Reeve *et al.* 2018)
- Cancer (Australian Adult Cancer Pain Management Guideline Working Party and Cancer Council Australia 2013; Royal Australian College of General Practitioners 2016*b*; Jayasekara 2017)
- Palliative care patients in aged care (PalliAGED Evidence Advisory Group 2017)

Table 1 provides characteristics of included resources.

Findings across resources

Table 2 gives the total scores across resources for each of the 17 checklist items.

Acknowledgement of comorbidity

Most resources (8/10) acknowledged comorbidity as an issue for treatment. Recognition ranged from broad, general statements ('comorbidities are common in people with …') to practical management guidance. Treatment concerns for older people were raised by 5/10 resources; however, only three of these specifically referred to multimorbidity. Quality of evidence presented for comorbid conditions was discussed in 7/10 resources, although less in association with older patients (2/10). Most resources (7/10) provided at least one recommendation addressing a single comorbidity. Only one guideline addressed the management of two (Yang *et al.* 2018). No resource discussed the implications of managing more than two comorbid conditions.

Patient/carer preferences and burden of treatment

More than half of the resources (6/10) acknowledged the potential for treatment burden while half (5/10) addressed time needed to treat to benefit in the context of life expectancy. Personal out-of-pocket treatment costs for patients were noted (6/10), although costs to the health system were a more common concern. All guidance referred to patient quality of life, outlining factors serving to jeopardise or improve it. Most resources (9/10)

Table 1. General characteristics and checklist scores of included resources
RACGP, Royal Australian College of General Practitioners

Title (author date)	Development organisation	Description	Availability	No. checklist criteria satisfied
Guidelines for the prevention, detection, and management of heart failure in Australia (National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand Heart Failure Guidelines Working Group *et al.* 2018)	National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand	Full guideline (update)	Open access journal article	14/17
Exercise based rehabilitation: heart failure (RACGP 2016*a*)	RACGP	Evidence summary	Freely available via Handbook of Non-Drug Interventions (HANDI)	6/14[A]
Australian and New Zealand pulmonary rehabilitation guidelines (Alison *et al.* 2017)	Lung Foundation Australia and the Thoracic Society of Australia and New Zealand	Full guideline (new)	Open access journal article	3/14[A]
The COPD-X Plan: Australian and New Zealand guidelines for the management of chronic obstructive pulmonary disease (Yang *et al.* 2018)	Lung Foundation Australia and the Thoracic Society of Australia and New Zealand	Full guideline (update)	Freely available online	15/17
Evidence-based clinical practice guideline for deprescribing cholinesterase inhibitors and memantine in people with dementia[B] (Reeve *et al.* 2018)	University of Sydney, Cognitive Decline Partnership Centre, and Bruyère Research Institute	Full guideline (new)	Freely available online	12/17
Clinical practice guidelines and principles of care for people with dementia[B] (Guideline Adaptation Committee 2016)	Cognitive Decline Partnership Centre. Guideline Adaptation Committee	Full guideline (adapted)	Freely available online	12/17
Cancer pain management in adults (Australian Adult Cancer Pain Management Guideline Working Party 2013)	Australian Adult Cancer Pain Management Guideline Working Party and Cancer Council Australia	Full guideline (adapted)	Freely available online	6/17
Cancer survivor: exercise and physical activity (Jayasekara 2017)	Joanna Briggs Institute (JBI)	Evidence summary	Requires subscription to JBI EBP Database	5/14[A]
Exercise: cancer fatigue (RACGP 2016*b*)	RACGP	Evidence summary	Freely available via Handbook of Non-Drug Interventions (HANDI)	1/14[A]
PalliAGED: palliative care aged care evidence. Evidence summaries (PalliAGED Evidence Advisory Group 2017)	PalliAGED	Evidence summary	Freely available online	12/17

[A] Non-pharmacological management resources excluded from medications scoring (i.e. maximum possible score is 14, not 17).
[B] Guidelines endorsed by the National Health and Medical Research Council (NHMRC).

stated the importance of considering patient preferences in decision-making.

Advice on medications

Four resources focussed solely on non-pharmacological management (Royal Australian College of General Practitioners 2016*a*, 2016*b*; Alison *et al.* 2017; Jayasekara 2017). These were excluded from consideration within the medication section of the checklist. Of the six remaining resources, three addressed potential adverse interactions between medications in the context of comorbidity (National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand Heart Failure Guidelines Working Group *et al.* 2018; Reeve *et al.* 2018; Yang *et al.* 2018).

Findings for individual resources

The final column of Table 1 provides totalled checklist scores for individual resources.

Acknowledgement of comorbidity

Individual resource scores ranged from 1/14 to 15/17. The COPD guidelines met most checklist criteria (15/17) followed by guidelines for heart failure (14/17). While references to comorbidity were often diffuse throughout resources, the heart failure and COPD guidelines provided separate sections addressing comorbidities.

The nature, strength, and quality of the evidence

Most references to comorbidity occurred as statements outside of key guideline recommendations, or as ‘practice points’, without an accompanying evidence level or strength grading. However, three guidelines provided graded or ranked recommendations for a comorbidity issue. These were the guidelines for heart failure ($n = 11$ recommendations), COPD ($n = 10$), and dementia ($n = 3$). These recommendations varied in their specificity and directiveness. The COPD guideline, for example, provided general, non-directive graded recommendations such as '[c]omorbid conditions are common in patients with COPD' (NHMRC: III-2, GRADE: Strong), or '[t]he combination of COPD and obstructive sleep apnoea (OSA) is known as the 'overlap syndrome' (NHMRC: III-2)'. Heart failure guidelines were more directive: '[t]hiazolidinediones (glitazones) are not recommended in patients with heart failure due to the risk that they will lead to worsening of heart failure (GRADE: Weak AGAINST; Quality: Moderate)'. Supplementary Material S2 provides further examples of graded recommendations from relevant guidelines.

Patient/carer preferences and burden of treatment

Four resources met all patient preferences and burden of treatment criteria (Guideline Adaptation Committee 2016; PalliAGED Evidence Advisory Group 2017; Reeve *et al.* 2018; Yang *et al.* 2018). Dementia and deprescribing guidelines were especially strong in their consideration of carers, frequently urging clinicians to consider the social and health care needs of the patient-carer dyad (Guideline Adaptation Committee 2016; Reeve *et al.* 2018). Supplementary Material S2 provides a selection of illustrative statements on patient and carer preferences, quality of life, financial costs, and overall burden of treatment.

Advice on medications

Three of the six resources that included pharmacological recommendations addressed the issue of adverse interactions between medications (National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand Heart Failure Guidelines Working Group *et al.* 2018; Reeve *et al.* 2018; Yang *et al.* 2018). Only two of these used the term 'polypharmacy' in referring to drugs prescribed for other, competing conditions (Reeve *et al.* 2018; Yang *et al.* 2018).

Guideline quality assessment

The six guidelines were assessed for quality (Australian Adult Cancer Pain Management Guideline Working Party and Cancer Council Australia 2013; Guideline Adaptation Committee 2016; Alison *et al.* 2017; National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand Heart Failure Guidelines Working Group *et al.* 2018; Reeve *et al.* 2018; Yang *et al.* 2018). The results of this assessment are shown in Table 3.

The two guidelines relating to dementia management—both endorsed by Australia's National Health and Medical Research Council (NHMRC)—achieved near perfect quality scores (95.7% and 96.5%). Pulmonary rehabilitation guidance also scored highly (87.2%), while the remaining three guidelines scored between 70–78% (Australian Adult Cancer Pain Management Guideline Working Party and Cancer Council Australia 2013; National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand Heart Failure Guidelines Working Group *et al.* 2018; Yang *et al.* 2018).

Discussion

Most current Australian guidelines and evidence summaries for life-limiting chronic conditions acknowledge the likelihood of one or two comorbid conditions. Perhaps unsurprisingly, none look beyond this to address the cumulative, chronic comorbidity that often confronts GPs in daily practice. There may be several explanations for this. First, guideline developers are charged with examining patient management from the perspective of an index condition. Other conditions and treatments are therefore only interesting insofar as they impact on that condition. However, with patient heterogeneity in multimorbidity the list of potential confounding conditions is longer than what can be reasonably expected to be accommodated in a single guideline, let alone an evidence summary. Second, the evidence base for what works in managing even comorbid conditions that tend to cluster together remains scarce as clinical trials of therapeutic effectiveness continue to use comorbidities and older age as part of their exclusion criteria (Academy of Medical Sciences 2018). An insufficient evidence base may explain why we found references to comorbidity to be general in nature, comparatively lacking in directiveness, and largely located outside of the key recommendations, often as practice points rather than graded evidence.

The guidelines for COPD and heart failure afforded comorbidity/multimorbidity management a separate chapter of its own. These guidelines met nearly all the comorbidity checklist

Table 2. Number of resources addressing checklist criteria

Criteria	No. guidelines addressing criteria
Issues addressed	
Guideline addressed treatment for older patients	5/10
Guideline addressed treatment for patients with multiple comorbid conditions	8/10
Guideline addressed treatment for older patients with multiple comorbid conditions	3/10
Quality of evidence	
Quality of evidence discussed for older patients	4/10
Quality of evidence discussed for patients with multiple comorbid conditions	7/10
Quality of evidence discussed for older patients with multiple comorbid conditions	2/10
Recommendations	
Specific recommendations for patients with one comorbid condition	7/10
Specific recommendations for patients with two comorbid conditions	1/10
Specific recommendations for patients with more than two comorbid conditions	0/14
Burden of treatment	
Time needed to treat to benefit from treatment in the context of life expectancy discussed	5/10
Guideline discussed burden of comprehensive treatment on patients or caregivers	6/10
Guideline discussed patients' financial burden	6/10
Guideline discussed patients' quality of life	10/10
Patient preferences	
Guideline discussed patient preferences	9/10
Medications[A]	
Guideline discussed medications' side-effects	5/6
Guideline is adapted to possible medications' side-effects	5/6
Guideline discussed possible medications' interactions related to comorbidities	3/6

[A] This section excludes $n = 4$ resources focussed solely on non-pharmacological management.

Table 3. AGREE II scores per domain for individual guidelines

Guideline	Scope and purpose (%)	Stakeholder involvement (%)	Rigor of development (%)	Clarity and presentation (%)	Applicability (%)	Editorial independence (%)	Average score (%)
Heart failure							
Full guideline	86.1	47.2	72.9	100	68.8	50.0	70.8
Chronic obstructive pulmonary disease (COPD)							
Full guideline	80.6	88.9	69.8	88.9	37.5	100	77.6
Pulmonary rehabilitation	94.4	83.3	93.8	97.2	75.0	79.2	87.2
Dementia							
Full guideline	100.0	100.0	100.0	100.0	79.2	100.0	96.5
Deprescribing cholinesterase inhibitors and memantine	97.2	100.0	96.9	91.7	88.3	100.0	95.7
Cancer							
Cancer pain management in adults	75.0	75.0	78.0	97.0	37.5	61.9	70.7
Average standardised domain score	88.9	82.4	85.2	95.8	64.4	81.9	83.1

criteria and contained most of the graded comorbidity references between them. We suggest that other guideline developers might want to grant comorbidities separate chapter status as this appears to sharpen the focus on the issues associated with it.

The resources examined were of high quality in terms of their patient-centred approach in acknowledging the importance of patient preferences and quality of life. The two dementia guidelines were also especially strong in their concern for carers. This strength across the resources possibly reflects the life-limiting nature of the index condition under examination, rather than a concern for comorbidities, otherwise more resources might have acknowledged the potential for burden of treatment arising from multiple co-existing conditions.

Implications for clinical practice

While there are clear challenges for guideline developers in accommodating comorbidity/multimorbidity recommendations in single condition guidelines, some omissions with potential patient safety concerns merit attention. First, the guidelines examined provided few statements on drug–drug interactions, even for commonly co-occurring conditions. While GPs might not expect explicit guidance on interactions between a range of specific medications, there may be scope for alerting GPs to the potential for such interactions and factors, such as advanced age, that could elevate risk.

Problematic polypharmacy might also be mentioned as an issue that, in the context of life-limiting illness, could be addressed through promotion of pharmacist or GP medication review or the deprescribing of preventative drugs with high numbers needed to treat and a long time horizon to benefit. These aspects of prescribing were rarely acknowledged within the guidelines although the limited life expectancy associated with each condition arguably provided a warrant for their discussion, alongside related issues of patient burden of treatment and quality of life.

It might also benefit clinicians to know where the evidence on multimorbidity management is currently weak or lacking by having clear and informative statements accompanying comorbidity acknowledgements. Guidelines might also prompt awareness of generalisability issues for specific recommendations, giving clinicians scope to prioritise patient values and preferences as they would for preference-sensitive decisions.

Implications for guideline development

The American Geriatrics Society and National Institute for Health and Care Excellence (UK) have confronted these issues by producing patient-centred, guiding principles of care (American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity 2012; National Guideline Centre 2016). These general principles elevate the importance of comprehensive assessment, communication, and clinician awareness of patient needs, concerns, and priorities. This approach has been applied to the RACGP's latest edition of the Aged Care Clinical Guide, the 'Silver Book' (Royal Australian College of General Practitioners 2019). While this is a good step forward, guidance on multimorbidity is also needed outside the aged care context as multimorbidity also affects younger populations (Barnett *et al.* 2012). The alternative to standalone generic guidelines is to persevere with single chronic disease guidelines, perhaps pressuring for greater involvement of GPs in their production, as well as dedicating a complete chapter to guiding principles of multimorbidity care.

Strengths and limitations

This analysis relied on a comprehensive search to identify guidelines and evidence summaries and employed non-clinician/clinician combinations to screen and appraise the data, providing for diverse viewpoints. Data were analysed using validated tools and both qualitative and quantitative methods.

However, we note some potential limitations in the present study. First, the term 'life-limiting conditions' is not precisely defined, and we acknowledge that there may be different views on what conditions should be included. Second, we only included 'evidence-based' resources that documented their development processes and the decisional basis of their recommendations. In this, we deliberately eliminated low quality, opinion-based resources in favour of those meeting universally accepted standards for reporting quality. We acknowledge that this may have led to the exclusion of guidelines commonly used and valued by general practitioners. However, it is not clear why guidelines originating from highly reputable organisations and respected authors did not produce evidence of their methodology to satisfy appraisal processes. This may reflect a tension between the timely production of guidelines in formats GPs appreciate and investing further resources to meet external quality directives. However, the guidelines that met our inclusion criteria found ways to do both. A future study might investigate the perception of guideline quality from the viewpoint of developers, endorsement agencies such as NHMRC, and clinicians.

We may have interpreted some of the items in the comorbidity checklist in unintended ways. Unlike the AGREE II tool that provides ample directions for use, we found some checklist items ambiguous and not served by definitions in the original papers. We therefore developed our own definitions for some items that may render problematic comparisons between this analysis and others based on the same checklist. However, we note that the checklist quantifies comorbidity acknowledgement, but cannot capture the quality, context, and comprehensiveness of any acknowledgement. We had to complement the checklist with qualitative analysis. Further development of the checklist to incorporate elements of quality analysis could facilitate more nuanced judgements of practical applicability.

We also note as interesting the lack of correlation between the comorbidity checklist results and the quality appraisal process. The higher scoring guidelines against the AGREE criteria (dementia and deprescribing) were not those that scored highest on comorbidity acknowledgement (COPD and heart failure), despite the inclusion of ‘quality’ items in the checklist. More importantly, AGREE scores, no matter how objectively calculated, cannot account for how GPs interact with guidelines in clinical practice (or if they do) and their own real-world views on issues of format, accessibility, and applicability.

Conclusion

Australian clinical guidelines and evidence summaries for life-limiting chronic conditions provide some acknowledgement of comorbid conditions and are strong on person-centred considerations such as patient preferences and quality of life. However, there may be scope for more general advice within guidelines on the potential for drug–drug interactions and the cumulative effects of multimorbidity. Guidelines might also suggest where treatments should be modified based on limited life expectancy or advanced age. Standalone guiding principles of care or complete chapters for addressing comorbidity issues may offer a better approach for GPs working to manage multiple conditions.

Conflicts of interest

The authors declare no conflicts of interest.

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A2.2 Ovid Medline search strategy for guidelines

Datasets included: Ovid Medline, Epub Ahead of Print, In-Process & Other Non-Indexed Citations; Daily and Versions, 1946 to August 03, 2018.

#	**Searches**
1	Critical Pathways/
2	Clinical Protocols/
3	Consensus/
4	consensus development conference/ or consensus development conference, nih/
5	consensus development conferences as topic/ or consensus development conferences, nih as topic/
6	guideline/ or practice guideline/
7	guidelines as topic/ or practice guidelines as topic/
8	Health Planning Guidelines/
9	(consensus development conference or consensus development conference, nih or guideline or practice guideline).pt.
10	(position statement* or policy statement* or practice parameter* or best practice*).ti,kf,kw.
11	(standards or guideline or guidelines).ti,kf,kw.
12	((practice or treatment* or clinical) adj guideline*).ab.
13	(CPG or CPGs).ti.
14	consensus*.ti,kf,kw.
15	consensus*.ab. /freq=2
16	((critical or clinical or practice) adj2 (path or paths or pathway or pathways or protocol*)).ti,kf,kw.
17	recommendat*.ti,kf,kw.
18	(care adj2 (standard or path or paths or pathway or pathways or map or maps or plan or plans)).ti,kf,kw.
19	(algorithm* adj2 (pharmacotherap* or therap* or treatment* or intervention*)).ti,kf,kw.
20	or/1-19
21	exp *neoplasms/
22	(Cancer* or melanoma* or myeloma* or sarcoma* or lymphoma* or neuroblastoma* or retinoblastoma* or osteosarcoma* or tumor* or tumour* or malignan* or neoplas* or leukemi* or leukaemi* or carcinoma* or adenocarcinoma*).ti.
23	exp *Coronary Disease/
24	((Coronary or ischemi* or ischaemi*) adj2 disease*).ti.
25	exp *Dementia/ or (dementia* or Alzheimer* or frontotemporal lobar degeneration* or pick disease* or picks disease*).ti.
26	*cardiovascular diseases/ or cardiovascular disease*.ti.
27	*Myocardial Ischemia/ or *Heart diseases/
28	((myocardial or heart) adj (disease* or ischemi* or ischaemi*)).ti.
29	exp *cardiomyopathies/ or exp *heart failure/
30	(cardiomyopath* or heart failure).ti.

31	*Pulmonary Disease, Chronic Obstructive/ or (chronic obstructive pulmonary disease* or COPD).ti.
32	*renal insufficiency, chronic/ or *kidney failure, chronic/
33	(Chronic adj (renal or kidney)).ti.
34	*liver failure/ or *end stage liver disease/
35	((liver or hepatic) adj (failure or disease*)).ti.
36	(chronic adj (liver or hepatic)).ti.
37	*neurodegenerative diseases/ or *lewy body disease/ or *motor neuron disease/ or *amyotrophic lateral sclerosis/ or *bulbar palsy, progressive/ or *muscular atrophy, spinal/ or *parkinson disease/
38	(neurodegenerative or lewy body or motor neuron* or amyotrophic lateral sclerosis or progressive bulbar palsy or parkinson* or (MND or ALS)).ti.
39	*multiple sclerosis/ or *multiple sclerosis, chronic progressive/ or *multiple sclerosis, relapsing-remitting/
40	multiple sclerosis.ti.
41	or/21-40
42	exp Australia/ or (australia* or australasia* or new south wales* or victoria* or queensland* or tasmania* or northern territory*).ti,ab,kw,kf.
43	20 and 41 and 42
44	limit 43 to yr="2012 -Current"
45	limit 44 to english language

Notes: Lines 1-19 represent the ‘guidelines’ part of the search. This is based on an existing search by Canadian Agency for Drugs and Technologies in Health (CADTH). / = Medical Subject Heading (MeSH) search; ti = title field search; ab = abstract field search; kw = exact author keyword field search; kf = author keyword field search; pt = publication type field search; adj2 = search words can occur within two spaces of each other, in either order; ab. /freq=2 = words must appear with a frequency of 2 (i.e. twice) within the abstract field.

A2.3 Sources used to identify Australian clinical practice guidelines

Guideline repositories and sources of evidence summaries

- Clinical Practice Guidelines Portal (Australia): https://www.clinicalguidelines.gov.au/portal
- Guidelines International Network (GIN): http://www.g-i-n.net/
  MJA's 'Guidelines and Statements' section: https://www.mja.com.au/journal/guidelines
- eTG Complete (subscription resource)
- Australian Medicines Handbook (subscription resource)
- Handbook of Non-Drug Interventions: HANDI: https://www.racgp.org.au/clinical-resources/clinical-guidelines/handi

Medical speciality colleges or societies, or organisations

- Royal Australian College of General Practitioners (RACGP): https://www.racgp.org.au/
- Royal Australian College of Physicians (RACP): https://www.racp.edu.au/
- Centre for Remote Health: https://www.crh.org.au/remote-phc-manuals-overview
    - CARPA Standard Treatment Manual
    - Minymaku Kutju Tjukurpa: Women's Business Manual
- Australian Primary Health Care Research Institute: https://rsph.anu.edu.au/research/centres-departments/australian-primary-health-care-research-institute
- AusDoc.Plus 'Guide to Guidelines': https://www.ausdoc.com.au/guidetoguidelines

Palliative care organisational websites

- Palliative Care Australia (PCA): https://palliativecare.org.au/
- CareSearch: https://www.caresearch.com.au/Caresearch/Default.aspx
- End of Life Directions for Aged Care (ELDAC): https://www.eldac.com.au/
- PalliAGED: https://www.palliaged.com.au/

Condition-specific organisational websites

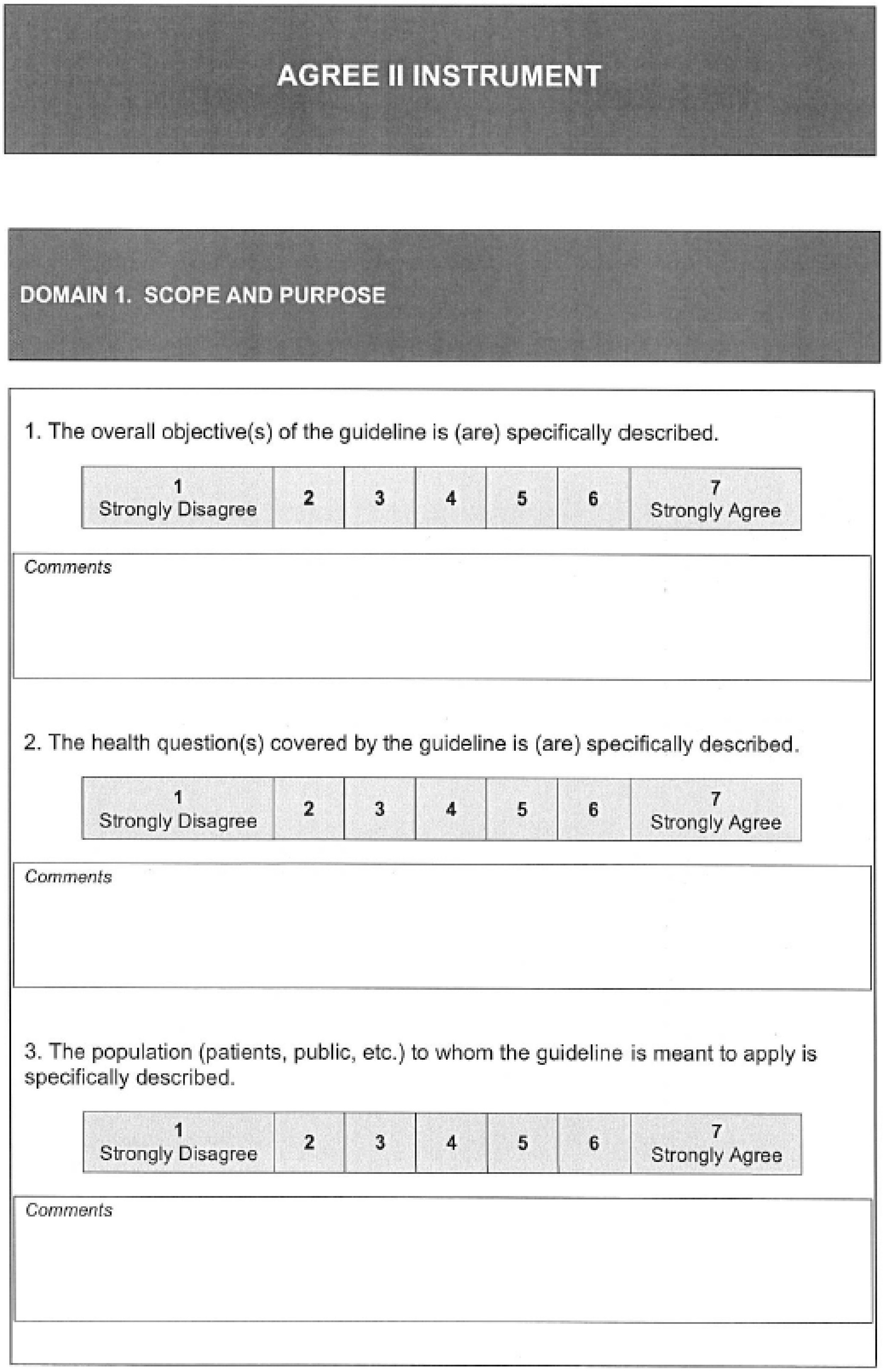
- Cancer Council Australia (CCA): https://wiki.cancer.org.au/australia/Guidelines
- Cancer Australia: https://canceraustralia.gov.au/
- Clinical Oncological Society of Australia (COSA): https://www.cosa.org.au/
- Australian Heart Foundation: https://www.heartfoundation.org.au/
- Cardiac Society of Australia and New Zealand: http://www.csanz.edu.au/
- Lung Foundation Australia: https://lungfoundation.com.au/
- Thoracic Society of Australia and New Zealand: https://www.thoracic.org.au/
- Kidney Health Australia: http://kidney.org.au/
- Gastroenterological Society of Australia (GESA): http://www.gesa.org.au/
- Australian Liver Foundation: http://liver.org.au/
- Dementia Australia: https://www.dementia.org.au/

- MND Australia: https://www.mndaust.asn.au/
- Parkinson’s Australia: https://www.parkinsons.org.au/
- MS Australia: https://www.msaustralia.org.au/

Government sites

- Australian Government Department of Health: https://www.health.gov.au/
- National Health and Medical Research Committee (NHMRC): https://www.nhmrc.gov.au/

A2.4 AGREE-II guideline critical appraisal tool



AGREE II INSTRUMENT

DOMAIN 1. SCOPE AND PURPOSE

1. The overall objective(s) of the guideline is (are) specifically described.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

2. The health question(s) covered by the guideline is (are) specifically described.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

3. The population (patients, public, etc.) to whom the guideline is meant to apply is specifically described.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

DOMAIN 2. STAKEHOLDER INVOLVEMENT

4. The guideline development group includes individuals from all relevant professional groups.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

5. The views and preferences of the target population (patients, public, etc.) have been sought.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

6. The target users of the guideline are clearly defined.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

DOMAIN 3. RIGOUR OF DEVELOPMENT

7. Systematic methods were used to search for evidence.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

8. The criteria for selecting the evidence are clearly described.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

9. The strengths and limitations of the body of evidence are clearly described.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

DOMAIN 3. RIGOUR OF DEVELOPMENT continued

10. The methods for formulating the recommendations are clearly described.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

11. The health benefits, side effects, and risks have been considered in formulating the recommendations.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

12. There is an explicit link between the recommendations and the supporting evidence.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

DOMAIN 3. RIGOUR OF DEVELOPMENT continued

13. The guideline has been externally reviewed by experts prior to its publication.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

14. A procedure for updating the guideline is provided.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

DOMAIN 4. CLARITY OF PRESENTATION

15. The recommendations are specific and unambiguous.

1 Strongly Disagree	**2**	**3**	**4**	**5**	**6**	**7** Strongly Agree

Comments

16. The different options for management of the condition or health issue are clearly presented.

1 Strongly Disagree	**2**	**3**	**4**	**5**	**6**	**7** Strongly Agree

Comments

17. Key recommendations are easily identifiable.

1 Strongly Disagree	**2**	**3**	**4**	**5**	**6**	**7** Strongly Agree

Comments

DOMAIN 5. APPLICABILITY

18. The guideline describes facilitators and barriers to its application.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

19. The guideline provides advice and/or tools on how the recommendations can be put into practice.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

20. The potential resource implications of applying the recommendations have been considered.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

DOMAIN 5. APPLICABILITY continued

21. The guideline presents monitoring and/or auditing criteria.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

DOMAIN 6. EDITORIAL INDEPENDENCE

22. The views of the funding body have not influenced the content of the guideline.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

23. Competing interests of guideline development group members have been recorded and addressed.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments

OVERALL GUIDELINE ASSESSMENT

For each question, please choose the response which best characterizes the guideline assessed:

1. Rate the overall quality of this guideline.

1 Lowest possible quality	2	3	4	5	6	7 Highest possible quality

2. I would recommend this guideline for use.

Yes	
Yes, with modifications	
No	

A2.5 Completed Boyd/Fortin checklist criteria

Resource name: **Cancer and exercise (evidence summary)**

Total score: 5/14

Issues addressed	**Yes/No**
Guideline addressed treatment for older patients	No
Guideline addressed treatment for patients with multiple comorbid conditions	Yes
Guideline addressed treatment for older patients with multiple comorbid conditions	No
Quality of evidence	
Quality of evidence discussed for older patients	No
Quality of evidence discussed for patients with multiple comorbid conditions	Yes
Quality of evidence discussed for older patients with multiple comorbid conditions	No
Recommendations	
Specific recommendations for patients with one comorbid condition	Yes
Specific recommendations for patients with two comorbid conditions	No
Specific recommendations for patients with more than two comorbid conditions	No
Burden of treatment	
Time needed to treat to benefit from treatment in the context of life expectancy discussed	No
Guideline discussed burden of comprehensive treatment on patients or caregivers	No
Guideline discussed patients' financial burden	No
Guideline discussed patients' quality of life	Yes
Patient preferences	
Guideline discussed patient preferences	Yes
Medications	
Guideline discussed medications' side effects	NA
Guideline is adapted to possible medications' side effects	NA
Guideline discussed possible medications' interactions related to comorbidities	NA

Resource name: **Exercise for cancer fatigue (evidence summary)**

Total score: 1/14

Issues addressed		**Yes/No**
	Guideline addressed treatment for older patients	No
	Guideline addressed treatment for patients with multiple comorbid conditions	No
	Guideline addressed treatment for older patients with multiple comorbid conditions	No
Quality of evidence		
	Quality of evidence discussed for older patients	No
	Quality of evidence discussed for patients with multiple comorbid conditions	No
	Quality of evidence discussed for older patients with multiple comorbid conditions	No
Recommendations		
	Specific recommendations for patients with one comorbid condition	No
	Specific recommendations for patients with two comorbid conditions	No
	Specific recommendations for patients with more than two comorbid conditions	No
Burden of treatment		
	Time needed to treat to benefit from treatment in the context of life expectancy discussed	No
	Guideline discussed burden of comprehensive treatment on patients or caregivers	No
	Guideline discussed patients' financial burden	No
	Guideline discussed patients' quality of life	Yes
Patient preferences		
	Guideline discussed patient preferences	No
Medications		
	Guideline discussed medications' side effects	NA
	Guideline is adapted to possible medications' side effects	NA
	Guideline discussed possible medications' interactions related to comorbidities	NA

Resource name: **Cancer pain management in adults (full guideline)**

Total score: 6/17

Issues addressed	**Yes/No**
Guideline addressed treatment for older patients	No
Guideline addressed treatment for patients with multiple comorbid conditions	Yes
Guideline addressed treatment for older patients with multiple comorbid conditions	No
Quality of evidence	
Quality of evidence discussed for older patients	No
Quality of evidence discussed for patients with multiple comorbid conditions	No
Quality of evidence discussed for older patients with multiple comorbid conditions	No
Recommendations	
Specific recommendations for patients with one comorbid condition	No
Specific recommendations for patients with two comorbid conditions	No
Specific recommendations for patients with more than two comorbid conditions	No
Burden of treatment	
Time needed to treat to benefit from treatment in the context of life expectancy discussed	No
Guideline discussed burden of comprehensive treatment on patients or caregivers	Yes
Guideline discussed patients' financial burden	No
Guideline discussed patients' quality of life	Yes
Patient preferences	
Guideline discussed patient preferences	Yes
Medications	
Guideline discussed medications' side effects	Yes
Guideline is adapted to possible medications' side effects	Yes
Guideline discussed possible medications' interactions related to comorbidities	No

Resource name: **COPD (full guideline)**

Total score: 15/17

Issues addressed	**Yes/No**
Guideline addressed treatment for older patients	Yes
Guideline addressed treatment for patients with multiple comorbid conditions	Yes
Guideline addressed treatment for older patients with multiple comorbid conditions	Yes
Quality of evidence	
Quality of evidence discussed for older patients	Yes
Quality of evidence discussed for patients with multiple comorbid conditions	Yes
Quality of evidence discussed for older patients with multiple comorbid conditions	No
Recommendations	
Specific recommendations for patients with one comorbid condition	Yes
Specific recommendations for patients with two comorbid conditions	Yes
Specific recommendations for patients with more than two comorbid conditions	No
Burden of treatment	
Time needed to treat to benefit from treatment in the context of life expectancy discussed	Yes
Guideline discussed burden of comprehensive treatment on patients or caregivers	Yes
Guideline discussed patients' financial burden	Yes
Guideline discussed patients' quality of life	Yes
Patient preferences	
Guideline discussed patient preferences	Yes
Medications	
Guideline discussed medications' side effects	Yes
Guideline is adapted to possible medications' side effects	Yes
Guideline discussed possible medications' interactions related to comorbidities	Yes

Resource name: **COPD (concise version for primary care)**

Total score: 9/17

Issues addressed	**Yes/No**
Guideline addressed treatment for older patients	Yes
Guideline addressed treatment for patients with multiple comorbid conditions	Yes
Guideline addressed treatment for older patients with multiple comorbid conditions	No
Quality of evidence	
Quality of evidence discussed for older patients	Yes
Quality of evidence discussed for patients with multiple comorbid conditions	No
Quality of evidence discussed for older patients with multiple comorbid conditions	No
Recommendations	
Specific recommendations for patients with one comorbid condition	Yes
Specific recommendations for patients with two comorbid conditions	No
Specific recommendations for patients with more than two comorbid conditions	No
Burden of treatment	
Time needed to treat to benefit from treatment in the context of life expectancy discussed	No
Guideline discussed burden of comprehensive treatment on patients or caregivers	No
Guideline discussed patients' financial burden	Yes
Guideline discussed patients' quality of life	Yes
Patient preferences	
Guideline discussed patient preferences	Yes
Medications	
Guideline discussed medications' side effects	Yes
Guideline is adapted to possible medications' side effects	Yes
Guideline discussed possible medications' interactions related to comorbidities	No

Resource name: **Pulmonary rehabilitation (full guideline)**

Total score: 3/14

Issues addressed	**Yes/No**
Guideline addressed treatment for older patients	No
Guideline addressed treatment for patients with multiple comorbid conditions	No
Guideline addressed treatment for older patients with multiple comorbid conditions	No
Quality of evidence	
Quality of evidence discussed for older patients	No
Quality of evidence discussed for patients with multiple comorbid conditions	No
Quality of evidence discussed for older patients with multiple comorbid conditions	No
Recommendations	
Specific recommendations for patients with one comorbid condition	No
Specific recommendations for patients with two comorbid conditions	No
Specific recommendations for patients with more than two comorbid conditions	No
Burden of treatment	
Time needed to treat to benefit from treatment in the context of life expectancy discussed	No
Guideline discussed burden of comprehensive treatment on patients or caregivers	No
Guideline discussed patients' financial burden	Yes
Guideline discussed patients' quality of life	Yes
Patient preferences	
Guideline discussed patient preferences	Yes
Medications	
Guideline discussed medications' side effects	NA
Guideline is adapted to possible medications' side effects	NA
Guideline discussed possible medications' interactions related to comorbidities	NA

Resource name: **Dementia (full guideline)**

Total score: 12/17

Issues addressed	**Yes/No**
Guideline addressed treatment for older patients	Yes
Guideline addressed treatment for patients with multiple comorbid conditions	Yes
Guideline addressed treatment for older patients with multiple comorbid conditions	No
Quality of evidence	
Quality of evidence discussed for older patients	Yes
Quality of evidence discussed for patients with multiple comorbid conditions	Yes
Quality of evidence discussed for older patients with multiple comorbid conditions	No
Recommendations	
Specific recommendations for patients with one comorbid condition	Yes
Specific recommendations for patients with two comorbid conditions	No
Specific recommendations for patients with more than two comorbid conditions	No
Burden of treatment	
Time needed to treat to benefit from treatment in the context of life expectancy discussed	Yes
Guideline discussed burden of comprehensive treatment on patients or caregivers	Yes
Guideline discussed patients’ financial burden	Yes
Guideline discussed patients’ quality of life	Yes
Patient preferences	
Guideline discussed patient preferences	Yes
Medications	
Guideline discussed medications’ side effects	Yes
Guideline is adapted to possible medications’ side effects	Yes
Guideline discussed possible medications’ interactions related to comorbidities	No

Resource name: **Deprescribing cholinesterase inhibitors and memantine (full guideline)**

Total score: 12/17

Issues addressed	**Yes/No**
Guideline addressed treatment for older patients	Yes
Guideline addressed treatment for patients with multiple comorbid conditions	Yes
Guideline addressed treatment for older patients with multiple comorbid conditions	No
Quality of evidence	
Quality of evidence discussed for older patients	No
Quality of evidence discussed for patients with multiple comorbid conditions	Yes
Quality of evidence discussed for older patients with multiple comorbid conditions	No
Recommendations	
Specific recommendations for patients with one comorbid condition	Yes
Specific recommendations for patients with two comorbid conditions	No
Specific recommendations for patients with more than two comorbid conditions	No
Burden of treatment	
Time needed to treat to benefit from treatment in the context of life expectancy discussed	Yes
Guideline discussed burden of comprehensive treatment on patients or caregivers	Yes
Guideline discussed patients' financial burden	Yes
Guideline discussed patients' quality of life	Yes
Patient preferences	
Guideline discussed patient preferences	Yes
Medications	
Guideline discussed medications' side effects	Yes
Guideline is adapted to possible medications' side effects	Yes
Guideline discussed possible medications' interactions related to comorbidities	Yes

Resource name: **Heart failure (full guideline)**

Total score: 14/17

Issues addressed	**Yes/No**
Guideline addressed treatment for older patients	Yes
Guideline addressed treatment for patients with multiple comorbid conditions	Yes
Guideline addressed treatment for older patients with multiple comorbid conditions	Yes
Quality of evidence	
Quality of evidence discussed for older patients	Yes
Quality of evidence discussed for patients with multiple comorbid conditions	Yes
Quality of evidence discussed for older patients with multiple comorbid conditions	Yes
Recommendations	
Specific recommendations for patients with one comorbid condition	Yes
Specific recommendations for patients with two comorbid conditions	No
Specific recommendations for patients with more than two comorbid conditions	No
Burden of treatment	
Time needed to treat to benefit from treatment in the context of life expectancy discussed	Yes
Guideline discussed burden of comprehensive treatment on patients or caregivers	Yes
Guideline discussed patients' financial burden	No
Guideline discussed patients' quality of life	Yes
Patient preferences	
Guideline discussed patient preferences	Yes
Medications	
Guideline discussed medications' side effects	Yes
Guideline is adapted to possible medications' side effects	Yes
Guideline discussed possible medications' interactions related to comorbidities	Yes

Resource name: **Exercise-based rehabilitation for heart failure (evidence summary)**

Total score: 6/14

Issues addressed	**Yes/No**
Guideline addressed treatment for older patients	No
Guideline addressed treatment for patients with multiple comorbid conditions	Yes
Guideline addressed treatment for older patients with multiple comorbid conditions	No
Quality of evidence	
Quality of evidence discussed for older patients	No
Quality of evidence discussed for patients with multiple comorbid conditions	Yes
Quality of evidence discussed for older patients with multiple comorbid conditions	No
Recommendations	
Specific recommendations for patients with one comorbid condition	Yes
Specific recommendations for patients with two comorbid conditions	No
Specific recommendations for patients with more than two comorbid conditions	No
Burden of treatment	
Time needed to treat to benefit from treatment in the context of life expectancy discussed	No
Guideline discussed burden of comprehensive treatment on patients or caregivers	No
Guideline discussed patients’ financial burden	Yes
Guideline discussed patients’ quality of life	Yes
Patient preferences	
Guideline discussed patient preferences	Yes
Medications	
Guideline discussed medications’ side effects	NA
Guideline is adapted to possible medications’ side effects	NA
Guideline discussed possible medications’ interactions related to comorbidities	NA

Resource name: **PalliAGED (evidence summary)**

Total score: 12/17

Issues addressed	**Yes/No**
Guideline addressed treatment for older patients	Yes
Guideline addressed treatment for patients with multiple comorbid conditions	Yes
Guideline addressed treatment for older patients with multiple comorbid conditions	Yes
Quality of evidence	
Quality of evidence discussed for older patients	Yes
Quality of evidence discussed for patients with multiple comorbid conditions	Yes
Quality of evidence discussed for older patients with multiple comorbid conditions	Yes
Recommendations	
Specific recommendations for patients with one comorbid condition	Yes
Specific recommendations for patients with two comorbid conditions	No
Specific recommendations for patients with more than two comorbid conditions	No
Burden of treatment	
Time needed to treat to benefit from treatment in the context of life expectancy discussed	Yes
Guideline discussed burden of comprehensive treatment on patients or caregivers	Yes
Guideline discussed patients' financial burden	Yes
Guideline discussed patients' quality of life	Yes
Patient preferences	
Guideline discussed patient preferences	Yes
Medications	
Guideline discussed medications' side effects	No
Guideline is adapted to possible medications' side effects	No
Guideline discussed possible medications' interactions related to comorbidities	No

A2.6 Examples of graded guideline recommendations

Guideline or summary	No. and type of comorbidity evidence ratings/gradings	Example recommendation	Level and/or grade of recommendation
The COPD-X Plan: Australian and New Zealand guidelines for the management of chronic obstructive pulmonary disease	10 x NHMRC ranked statements	Anxious and depressive symptoms and disorders are common comorbidities in people with COPD … and have a range of negative impacts (D5 p.121)	*NHMRC: level I* (i.e., evidence obtained from a systematic review of all relevant randomised controlled trials)
Clinical practice guidelines and principles of care for people with dementia	3 x Evidence-Based Recommendations	The role of antidepressants in the treatment of depression in people with dementia is uncertain. Larger trials conducted in people with dementia have not shown benefit (in group data) for antidepressants for treatment of depression per se. Nevertheless, it is considered that those with a pre-existing history of major depression (prior to developing dementia) who develop a co-morbid major depression should be treated in the usual way. (Recommendation 88, Behavioural and psychological symptoms of dementia p. XV)	*Evidence-Based Recommendation* (i.e., a recommendation formulated after a systematic review of the evidence, with supporting references provided) *GRADE: Moderate*
Guidelines for the prevention, detection, and management of heart failure in Australia 2018	11 x Graded recommendations	Adaptive servoventilation is not recommended in patients with HFrEF and predominant central sleep apnoea because of an increased all-cause and cardiovascular mortality. (10.9. p.1178)	*GRADE: Strong AGAINST; Quality: Moderate*

A2.7 Examples of statements on burden of treatment, quality of life, and patient preferences

Guideline or summary	COPD	Heart failure guideline	Deprescribing	Dementia
Burden of comprehensive treatment on patients or caregivers	The burden of disease and care fluctuates and it may be appropriate to encourage discussion about long term goals prognosis and attitudes to future treatment and care plans can be encouraged (O p.34).	Patients with heart failure are required to adhere to a complex regimen when managing their heart failure at home, to maintain stability, decrease hospitalisation and mortality, and improve quality of life. The regimen includes taking their medications at the right time and right dose, monitoring their heart failure specific signs and symptoms (to determine when these signs and symptoms indicate a deterioration in health), and collaboration with a health professional (8.4. p.1165)	The potential burden of medication management on the carer cannot be underestimated. In addition to stress, worry and the restriction of carer activities associated with the administrative tasks of medication management and managing negative side effects, there is an emotional burden involved in the responsibility of making decisions about medications (Consumer values and preferences p.50)	Carer(s) and family should have access to programs designed to provide support and optimise their ability to provide care for the person with dementia. Programs should be tailored to the needs of the individual and delivered in the home or at another accessible location (Recommendation 102 p.XVII).
Quality of life	The benefits of pulmonary rehabilitation include a reduction in symptoms (dyspnoea and fatigue), anxiety and depression, and improvements in HRQoL, peripheral muscle function and exercise capacity, and, following rehabilitation, participants gain an enhanced sense of control over their condition [evidence level I/II] (O6.1 p. 53).	Predominant obstructive sleep apnoea with nocturnal hypoxaemia and apnoea/hypopnoea index over 30 per hour in patients with heart failure may be treated with nocturnal oxygen supplementation, CPAP, BiPAP or adaptive servo-ventilation to improve quality of life and decrease sleepiness (10.9 p.1179).	The quality of life of the person with dementia is regularly discussed as central to treatment decisions (starting, continuing and discontinuing) (Consumer values and preferences p. 49)	Improving quality of life, maintaining function and maximising comfort are appropriate for people living with dementia throughout the disease trajectory, with the emphasis on particular goals changing over time (Recommendations, Principles of care 2 p.V).

Financial burden on patients	The cost of inhaler devices varies between products. As there are no differences in patient outcomes for the different devices, the cheapest device the patient can use adequately should be prescribed as first line treatment (O5.1 p.52).		… [I]ndividual clinicians should be aware of the cost implications for individuals, based on local subsidisation criteria (Resource implications and cost effectiveness p.54).	Souvenaid® is not listed on the Australian Therapeutic Goods Register and is not considered by any Australian regulatory body to be a therapeutic good. There is no government subsidy available for Souvenaid, so the full cost must be borne by the consumer (Nutritional supplements p.45).
Patient preferences	However, with few head to head comparisons of LAMAs available, the choice of LAMA and inhaler device depends on patient and clinician preferences (O1.2.1 p.38). Managing patients with multimorbidity effectively involves taking a patient-centred approach to balancing multiple, and at times competing, priorities (O7. p.66).	Adjusting management strategies in the setting of multimorbidity and heart failure is integral to better outcomes. Together with a patient's values, preferences, and goals, a list of clinical priorities and an approach to match should be established. This may involve other specialists as appropriate (8.2.3 p.1164). Essentially, a more nuanced approach with clinical judgement and recognition of the contribution of personalised, patient-centred decisions is to be adopted (8.2.3 p.1164)	Good communication between clinicians and people with dementia and/or carers/family about the benefits and harms of continuing versus discontinuing, in the context of their values and preferences, is necessary when discussing a potential trial of deprescribing (p.4). Potential outcomes of deprescribing should be placed in the context of what is important for the person with dementia and their family (Consumer values and preferences p. 50).	Health and aged care professionals should provide person-centred care, by identifying and responding to the individual needs and preferences of the person with dementia, their carer(s) and family (Recommendations, Principles of care 1 p.V). Treat each person as an individual by offering a personalised service (Principles of dignity in care p.9). Enable people to maintain the maximum possible level of independence, choice and control (Principles of dignity in care p.9). Listen and support people to express their needs and wants (Principles of dignity in care p.9).

Notes: *Cancer pain management in adults* was not included in this table as it did not contain statements on the burden of treatment.

Abbreviations: BiPAP: Bilevel positive airway pressure; CPAP: Continuous positive airway pressure; HRQoL: Health-related quality of life; LAMA: Long-acting muscarinic antagonists.

A2.8 Directive guideline content mapped to the PEPSI-COLA framework

Physical	**Cancer: pain management**	Assess pain intensity…. (Evidence Based Recommendation.) Complete a comprehensive assessment if …. (Evidence Based Recommendation.) Pharmacological and non-pharmacological advice for managing pain. (Evidence Based Recommendation.)
	COPD (full)	Palliative care … should include symptom control. (Level II, weak.) Provides specific pharmacological and non-pharmacological advice on managing breathlessness. Refer patients with more challenging situations to specialist palliative care for management of persisting refractory symptoms.
	COPD (concise)	Proactive management of symptoms like chronic breathlessness, and treatments for likely severe complications like panic for severe dyspnoea.
	Dementia	Covers palliative management of fever, pain, agitation, shortness of breath. Hydration, feeding, symptom management and the prescription of medications.
	Dementia: deprescribing	Discontinuation recommended if cognition and/or function has significantly worsened over the past six months (or less, as per the individual).
	Heart failure	Refer advanced HF patients to palliative care to alleviate end-stage symptoms. (Strong recommendation FOR, high quality evidence.)
	PalliAGED	Website has a separate section covering important symptoms and their management in the terminal phase. Covers intimacy and sexuality in separate section.
Emotional	**Cancer: pain management**	Provide support for any psychosocial and spiritual concerns identified during comprehensive assessment. (Evidence Based Recommendation.) Consider referral to a clinical psychologist for psychological therapies and support. (Evidence Based Recommendation.)
	COPD (full)	Palliative care … should address psychosocial issues. (Level II, weak.) Refer patients with more challenging situations to specialist palliative care for psychosocial care. Consider discussing what death might be like.

	COPD (concise)	-
	Dementia	Display sensitivity during the transition to residential aged care.
	Dementia: deprescribing	Deprescribing recommendations can be complicated by life-limiting nature of dementia…with significant hope being placed in these medications by people with dementia and their family. Carers have expressed fears associated with medication discontinuation, and individuals may feel that deprescribing is 'giving up' or a signal that they are no longer worth treating.
	Heart failure	-
	PalliAGED	Separate section on mental illness. Separate section on psychosocial care. Separate section on resilience.
Personal	**Cancer: pain management**	Adopt a person-centred approach to pain management. (Evidence Based Recommendation.) Take into account the patient's needs and preferences. (Evidence Based Recommendation.) Provide culturally appropriate care and information. (Evidence Based Recommendation.)
	COPD (full)	Refer patients with more challenging situations to specialist palliative care for spiritual or existential care. Consider discussing patients' and carers' values and beliefs. Clinical support teams working with the primary healthcare team can enhance quality of life and reduce disability for patients with COPD. (Level III-2, weak recommendation.)
	COPD (concise)	-
	Dementia	Consider: health literacy; the specific needs of people with dysphasia or an intellectual disability; Indigenous Australians; Culturally and linguistically diverse people (CALD).
	Dementia: deprescribing	Consider the values, preferences and experiences of the person with dementia and/or their carer/family when determining if trial deprescribing is appropriate.

		Any discussion about values and preferences with regard to ChEI and/or memantine therapy must consider the expectations of people with dementia and their carer/family in regard to therapy benefit.
	Heart failure	Refer advanced HF patients to palliative care to improve quality of life, [and] decrease rehospitalisation. (Strong recommendation FOR, high quality evidence.)
	PalliAGED	Covers spiritual care in its own section. Covers dignity and quality of life in separate section.
Social support	**Cancer: pain management**	-
	COPD (full)	-
	COPD (concise)	Refer patients to the Lung Foundation to be put into contact with patient support groups and educational resources.
	Dementia	Inform the person with dementia, their carer(s) and family about advocacy services, financial and legal advice, and voluntary support. Provides information on how to join a social support group. Written and verbal information about services available in the community.
	Dementia: deprescribing	The primary care physician or family physician should be aware of the resources available in their local area to support people with dementia and their carers.
	Heart failure	-
	PalliAGED	Includes a separate section on social support and another on self-care and staff support. Includes a separate section on family carers. Includes a separate section on respite care.
Information & communication	**Cancer: pain management**	Provide patients with education about cancer-related pain and its management. (Evidence Based Recommendation.) Provide patients with verbal and written information on pain and its management. (Evidence Based Recommendation.) Include the person's family, carers and significant others in education about pain and its management, if appropriate. (Consensus Based Recommendation.)

	COPD (full)	Discussing goals of care and future treatment wishes should occur early, in a non-acute setting and should involve their General Practitioner. Routinely ask if patients wish to discuss or update their goals of care. Terminal care plans to be documented and communicated to all services involved in the care of the patient for continuity of care. Introduce discussions over multiple appointments… gently adding each new topic gradually … reducing the chance of causing distress.
	COPD (concise)	Encourage all patients to involve carers and family members in their management (e.g., by attending consultations). Initiate discussion about possible future care requirements with the patient to understand their wishes.
	Dementia	Use language that is consistent with the Dementia Language Guidelines and the “Talk to me” good communication guide for talking to people with dementia. Be honest and respectful and use a gradual and individualised approach when communicating the diagnosis to the person with dementia and their carer(s) and family. Health professionals should be trained in communicating clearly with the person with dementia, their carer(s) and family and to provide person-centred care. The health professional should convey to the family when palliative care is indicated, why it is recommended and what is involved. Provide information in the preferred language and an accessible format. Provide professional translators or cultural interpreters. CALD carers and families should receive support, education, and information.
	Dementia: deprescribing	Consider the viewpoints of the person with dementia and their carers and include education about the potential benefits versus harms of both continuing and discontinuing the medications. The individual and/or carer/family should be aware of what to look out for and what to do if a change in condition occurs—consider verbal and written communication. Good communication between clinicians and people with dementia and/or carers/family about the benefits and harms of continuing versus discontinuing, in the context of their values and preferences, is necessary. Other healthcare professionals may need to be consulted to determine the appropriateness to trial withdrawal, or to ensure monitoring is conducted throughout the process. Liaison with other healthcare professionals … e.g., the community pharmacist may need to make alterations to dosage administration aids.

	Heart failure	Shift to a palliative care focus should be discussed with patient, family, cardiologist … and GP. (Rationale.) Discussions concerning ICD deactivation should involve …. (Practice advice).
	PalliAGED	Includes sections on communication skills and communication at the end of life. Includes a section on family conflict.
Control	**Cancer: pain management**	Adopt a person-centred approach to pain management which involves enabling the person to make informed decisions about their care and treatment. (Evidence Based Recommendation.)
	COPD (full)	Terminal care plans, advanced directive, location of care to be documented. Consider discussing treatment options including … admission to intensive care unit … [and] end-of-life care wishes, including place of death preferences.
	COPD (concise)	Anticipatory care planning includes advance care planning and ensuring there is a substitute decision maker. Discuss possible future requirements with patient to understand their wishes.
	Dementia	Discuss the use of an enduring guardianship, enduring power of attorney and advance care plans with patients with dementia, their carer(s) and family while they have capacity.
	Dementia: deprescribing	Decisions surrounding deprescribing should be conducted as shared decision making with the person with dementia and/or their family/carer. Discussions about dementia medication prescribing and eventual decisions about deprescribing should occur early in therapy, when the person with dementia is still able to participate in decision making. The person with dementia should be included in the conversation.
	Heart failure	Patients with heart failure should be encouraged to have an advanced care plan, regardless of clinical status and soon after diagnosis.
	PalliAGED	Includes a section on Advance care planning. Includes a section on goals of care which emphasises importance of patient preferences and shared decision making.
Out of hours & emergency	**Cancer: pain management**	-

	COPD (full)	-
	COPD (concise)	Plans for out of hours care.
	Dementia	-
	Dementia: deprescribing	-
	Heart failure	-
	PalliAGED	Has section on care coordination which states: ‘Establish a list of relevant contact information so that the family and the members of the health team know how to contact the correct people’. Covers ‘emergency planning and management’ as a separate topic.
Late	**Cancer: pain management**	-
	COPD (full)	Refer patients with challenging situations to specialist palliative care for active management of the terminal phase (at home or in a hospice). Hospice or specialist consultations should be available if required. Terminal care plans may be appropriate for patients who elect to avoid active management.
	COPD (concise)	-
	Dementia	Any decision about rehydration should be made in conjunction with the carer(s) and family after providing them with up-to-date information on the potential benefits and harm. In the absence of a valid and applicable advance directive to refuse resuscitation, the decision to resuscitate should take account of any expressed wishes or beliefs of the person with dementia, together with the views of the carer(s) and family and the multidisciplinary team Specific decisions may need to be made (by proxy decision-makers) regarding hydration, feeding, symptom management and the prescription of medications.
	Dementia: deprescribing	Discontinuation recommended if the individual has severe/end-stage dementia or non-dementia terminal illness. We recommend trial discontinuation if the individual has severe/end-stage dementia (some characteristics of this stage include dependence in most

		activities of daily living, inability to respond to their environment and/or limited life expectancy).
	Heart failure	-
	PalliAGED	Complete section on symptoms and medicines in the last days of life (i.e., terminal care). Covers anxiety, dyspnoea, nausea and vomiting, pain, respiratory secretions, terminal restlessness, and other topics.
After care	**Cancer: pain management**	-
	COPD (full)	Refer to specialist palliative care for emotional care and bereavement support of relatives and carers.
	COPD (concise)	-
	Dementia	Families need support to help them in their role as proxy decision-makers and to deal with their grief.
	Dementia: deprescribing	-
	Heart failure	-
	PalliAGED	Complete evidence summary on bereavement care with links to practice points.

A2.9 Additional palliative care content not captured by PEPSI-COLA

Definition of palliative care	**COPD (full)**	Provides WHO definition (2002)
	COPD (concise)	The palliative care approach focuses on alleviation of symptoms and the patient's physical, psychosocial and spiritual needs. (Rationale)
	PalliAGED	Adopts the WHO definition with 'minor modification.'
GP role	**COPD (full)**	Coordinate investigation and management: GPs will manage patients with mild to moderate COPD. Coordinate care in advanced disease: GPs play a crucial role coordinating services provided by a range of healthcare professionals and care agencies (the "multidisciplinary team"). General palliative care practices such as symptom management and aligning treatment with patients' goals should be routine aspects of care. For patients with complex symptoms, referral to specialist palliative care may be required.
	COPD (concise)	Consider developing a GP Management Plan (GPMP, Item 721) and a Team Care Arrangement (TCA, Item 723) in addition to organising a home medicines review with a pharmacist.
	Dementia: deprescribing	It is important that the general practitioner (primary care physician or family physician) be aware of the resources available in their local area to support people with dementia and their carers, and to make appropriate referrals for unmet needs to support the deprescribing process.
	Heart failure	As their disease progresses, a decision to shift treatment from prevention of disease progression to improving quality of life, with a palliative care focus, should be discussed with the patient, family, cardiologist or physician with a special interest in heart failure, multidisciplinary heart failure team, and GP. The development of collaborative care using 'shared care' models between the GP, heart failure nurse, and specialist physician should be encouraged. GPs have a vital role in the management of patients with heart failure in the community.
	PalliAGED	Includes a separate section for GPs including video clips with GPs explaining how they care for older people at the end of life
Role of multidisciplinary team	**COPD (full)**	Active treatment of persisting symptoms or challenging issues may require a multidisciplinary team (which includes primary care, respiratory medicine, and palliative care) May require involvement of multidisciplinary team with primary care team. Terminal care does not always require specialist palliative care. Patients and their family and friends should be actively involved in a therapeutic partnership with a range of health professionals. Many different healthcare professionals are involved in the crucial components of COPD management, including case finding, smoking cessation support, pharmacotherapy, exercise training and self-management and education and exercise training. A program with an emphasis on co-operation and collaboration between these providers should be established for more effective patient care.

		Palliative care - ideally from a multidisciplinary team which includes the primary care team - should be considered early, and should include symptom control and addressing psychosocial issues. [Evidence level II, weak recommendation.]
	COPD (concise)	Some evidence suggests that multidisciplinary teams (where available) assisting GPs can safely and successfully treat carefully selected patients with COPD presenting with exacerbations of COPD, at home with support from respiratory nurses.
	Heart failure	A plan of care should be developed with the multidisciplinary team.
Prognostication (e.g., indicators, tools)	**COPD (full)**	Functional deterioration in the presence of optimum treatment requires a reappraisal of the goals of care. Each exacerbation may be reversible until there is a suboptimal or no response to treatment. At this point the patient may enter their terminal phase and the goals of care may change rapidly to palliation with treatment limitations or palliation alone with withdrawal of active therapy. Well-described barriers to patients with COPD accessing palliative care include: Difficulty prognosticating in COPD. Given the difficulty in determining prognosis in an individual with COPD, including palliative care principles and practices into COPD management should not be dependent on making an accurate prognosis.
	COPD (summary)	Accurate assessment of approaching end of life is difficult. Good chronic disease care involves considering if the person is near the end of life and planning accordingly (see D-Accurate assessment of approaching end of life is difficult). Anticipatory care planning is a suggested approach that: • involves early engagement with palliative care services where available; • anticipates which patients are at risk of dying in a relevant timeframe (e.g., 12 months); • develop a plan for a ‘worst case’ scenario (where deterioration to death may occur); • is appropriate when the patient is severely symptomatic or has had multiple exacerbations in the last 12 months. Ask yourself, “Would I be surprised if the patient dies in the next 12 months?”. This may assist in identifying individuals at risk of dying in the foreseeable future.
	Dementia	Further, the prognosis for people with dementia is often unclear and clinicians may be reluctant or unable to provide a clear prognosis.
	Heart failure	As their heart failure progresses towards end-stage, patients begin to experience diverse debilitating symptoms, increasing the distress of both the patient and their carers, particularly during their last 6 months of life Although the evidence is limited, early post-hospital discharge appointments should be considered to identify potential issues or signs and symptoms that may indicate early exacerbation of heart failure.
	PalliAGED	Includes full section on ‘recognising change’ which includes description and link to SPICT tools and surprise question.

Timing (e.g., of conversations around goals of care, early identification of needs, early involvement of palliative care services)	**COPD (full)**	Early access to palliative care is now recommended for patients with COPD and persisting symptoms. The initiation of long term oxygen therapy and functional deterioration have been found to be an important point at which patient's may be receptive to reviewing the goals of care, end of life care and treatment limitations. … [S]ymptom palliation and palliative care approaches should be considered earlier as patients become more symptomatic, occurring concurrently with disease directed, active treatment.
	COPD (concise)	Early engagement with palliative care anticipates possible future requirements for assisted ventilation, high dependency or intensive care unit admission and initiates discussion about these with the patient to understand their wishes. Good chronic disease care involves considering if the person is near the end of life, and planning accordingly.
	Dementia	…[I]t is important that health professionals are honest and truthful when communicating the diagnosis to the person with dementia and those close to them. How and when that occurs must be managed with sensitivity to the person with dementia's wishes, their relationship with the medical practitioner providing the diagnosis and the context of the discussion.
	Dementia: deprescribing	Discussing future deprescribing early in the treatment course will help the individual/family/carer understand that the medication is not lifelong treatment. This may prevent feelings of guilt of 'giving up' that can be experienced by carers making a proxy decision to deprescribe.
	Heart failure	Involvement of palliative care should be considered early in the trajectory towards end-stage heart failure. (Strong recommendation FOR, high quality evidence) Patients with heart failure should be encouraged to have an advanced care plan, regardless of clinical status and soon after diagnosis.
Benefits of palliative care	**COPD (full)**	The provision of early palliative care can improve survival.
	Heart failure	The integration of palliative care into the multidisciplinary heart failure team is effective in reducing the symptom burden and distress experienced by caregivers and patients with end-stage heart failure. Palliative care services in the home were also effective in reducing rehospitalisation.

APPENDIX 3

Chapter 6. Australian general practitioner perspectives of multimorbidity and its management across phases of care: a qualitative study

A3.1 Consolidated Criteria for Reporting Qualitative Studies (COREQ)[1] checklist

Domain 1: Research team and reflexivity	
Personal characteristics of interviewer	
Interviewer	Raechel Damarell (RD)
Credentials	PhD candidate
Occupation	Full-time Higher Degree Research Student.
Gender	Female
Experience and training	RD has ten years' experience as a Research Assistant/Research Associate in palliative care and bibliometrics research and twenty years as a medical librarian teaching the principles and practices of Evidence-Based Practice to clinicians and students in the health professions. Prior to this, she was enrolled for 3 years of a 6 year undergraduate Medicine programme. She therefore has a reasonable understanding of the health system and medical terminology and concepts. She has previous experience conducting interviews for a study; however, this is the first time she has done so under the supervision of an experienced qualitative researcher (DM).
Relationship with participants	
Relationship established	The interviewer had met two of the participants briefly prior to inviting them to be interviewed. One had been introduced at a conference (GP8) while the other had met the interviewer when she was a medical librarian, and he was a postgraduate student (GP5). Other participants were not known to the interviewer, having been invited to participate via newsletters, a posted invitation sent to a random selection of general practitioners, or recruited by snowballing.
Participant knowledge of the interview	Participants were aware of the interviewer's reason for the study (PhD study) as this information was provided to them prior to the interview via an Information Sheet approved by the Flinders University Social and Behavioural Ethics Committee. Interviewees also knew that the interviewer was conducting the study as part of the Research Centre for

	Palliative Care, Death and Dying which sits within the College of Nursing and Health Sciences at Flinders University.
Interviewer characteristics	The interviewer's affiliation with palliative care and the College of Nursing and Health Sciences was noted by several interviewees who queried if she was a nurse or palliative care clinician. When asked, she explained that her initial interest in the topic stemmed from a background in teaching Evidence-Based Practice to medical students and practitioners. She had wanted to explore how general practitioners work within the limitations of available evidence on multimorbidity. Her research work around palliative care had subsequently broadened this lens to the 'multimorbidity care continuum in the context of life-limiting illnesses'. Awareness of these specific points of interest may have influenced the depth and scope of some of the GPs' responses.
Domain 2: Study design	
Theoretical framework	
Methodological orientation and theory	As the qualitative phase of a larger mixed-methods program of research, this study had a pragmatist worldview,[1] and employed an inductive, 'bottom up' methodological orientation to build generalisations from specific participant views.
Participant selection	
Sampling	Australian general practitioners were purposively invited to participate. Five were recruited via other participants (snowball method)
Method of approach	Notices in newsletters of Primary Health Networks and letters to randomly selected general practitioners using an online health services directory (Health Engine). Twitter and website notices were also utilised.
Sample size	12
Non-participation	It is not possible to know how many general practitioners saw the newsletter invitation to participate and did not respond to it. Of the 25 letters of invitation sent out, 21 general practitioners did not respond for reasons unknown. One general practitioner from the mailout agreed to participate but then withdrew citing lack of time due to onset of the COVID-19 pandemic.
Setting	
Setting of data collection	Data was collected via in-depth interviews conducted over the phone or via an online Zoom conference call. General practitioners were in a place of their own choosing. Most were in their home at the time of the interview, as this was during the first Australian COVID-19 lockdown. However, one was speaking on a hands-free device while driving between a home visit and the office, and another was walking in a park.

Presence of non-participants	Not applicable
Description of sample	Most participants were part-time (n=9) and/or with academic roles (n=6), female (n=8), and working at a metropolitan clinic (n=8). Three participants worked as salaried employees of an Aboriginal Medical Service (or ACCHO). The average number of years since gaining a first medical qualification was 26.7 years (SD +/- 13.3 years, range: 8-52 years).
Data collection	
Interview guide	A piloted (n=1) interview guide of broad questions and prompts was used to structure the interview.
Repeat interviews	None
Audio/visual recording	All interviews were audio-recorded and transcribed verbatim.
Field notes	Field notes were not made.
Duration	Range of duration was 27-90 minutes.
Data saturation	Data saturation was aimed for and possibly achieved at interview 10.
Transcripts returned	Transcripts were returned to those participants who, when asked, stated that they wished to review them. Some participants requested removal of data where they felt it might identify them or their clinic. Where audio quality was poor, participants were specifically asked to check the accuracy of transcription. Several changes were made on this basis.
Domain 3. Analysis and findings	
Data analysis	
Number of data coders	One researcher (RD) coded the data. The initial coding tree was then reviewed by JT and DM and iteratively revised based on their feedback.
Description of coding tree	Coding that informed subthemes and themes is represented by a theme map which is provided as Appendix A3.4. Several iterations of the codebook were also produced during coding to help visualise theme development. A sample of one codebook is also provided in Appendix A5.3.
Derivation of themes	Themes were derived inductively from the data by RD, revised by RD, JT and DM, and then critically reviewed by TS. Themes and subthemes are supported by illustrative quotes.
Software	Data was coded using NVivo 12 (QSR International)

Participant checking	Participants were invited to review and correct their own interview transcript but not findings based on the data.
Reporting	
Quotations presented	Yes
Data and findings consistent	Yes
Clarity of major themes	Yes
Clarity of minor themes	Yes

References

1. Creswell JW, Creswell JD. Research design: Qualitative, quantitative, and mixed methods approaches. 5th ed. Thousand Oaks, Calif.: SAGE Publications, Inc.; 2018.

A3.2 Ethics approval and recruitment items for Project number 8546

8546 ETHICS approval notice (22 January 2020)

Human Research Ethics <human.researchethics@flinders.edu.au>
Wed 22/01/2020 11:39 AM
To: Raechel Damarell <raechel.damarell@flinders.edu.au>; Jennifer Tieman <jennifer.tieman@flinders.edu.au>; Deidre Morgan <deidre.morgan@flinders.edu.au>

Dear Raechel,

Your conditional approval response for project 8546 was reviewed by the Deputy Chair of the Social and Behavioural Research Ethics Committee (SBREC) and was **approved.** The ethics approval notice can be found below.

APPROVAL NOTICE

Project No.: **8546**

Project Title: Australian general practitioner perspectives on multimorbidity with life-limiting illness: its challenges and strategies for management

Principal Researcher: Ms Raechel Damarell

Email: raechel.damarell@flinders.edu.au

Approval Date: 22 January 2020

Ethics Approval Expiry Date: **17 February 2022**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

Raechel Damarell
College of Nursing and Health Sciences

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Raechel.damarell@flinders.edu.au

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https://www.flinders.edu.au/people/raechel.damarell

CRICOS Provider No. 00114A

INFORMATION SHEET
For General Practitioner Interviews

Title: Australian general practitioner perspectives on multimorbidity with life-limiting illness: its challenges and strategies for management

Researcher
Ms Raechel A Damarell
College of Nursing and Health Sciences
Flinders University
Tel: 08 7221 8887

Supervisors
Professor Jennifer J Tieman
College of Nursing and Health Sciences
Flinders University
Tel: 08 7221 8237

Dr Deidre Morgan
College of Nursing and Health Sciences
Flinders University
Tel: 08 7221 8220

Description of the study
This study is part of the project titled: Negotiating patient-centred and evidence-based approaches to clinical decision making in the management of multimorbidity with life-limiting illness: the Australian general practitioner experience.

This project will investigate general practitioner (GP) perspectives of managing patients with multiple chronic conditions, the suitability of the available research evidence for doing so, and what GPs believe is needed to better support them in providing this care. This project is supported by Flinders University, College of Nursing and Health Sciences

Purpose of the study
This project aims to find out directly from general practitioners how they experience the management of patients with multiple chronic conditions, especially when one condition is life-limiting (e.g. COPD, cancer, heart failure, dementia). Study findings, which will be published as a journal article, will constitute one form of evidence as to how the Australian health system is working for these complex patients. It is hoped they might also reveal the extent to which existing policies support GPs in providing the wholistic care characteristic of the specialty.

What will I be asked to do?

You are invited to attend a one-on-one interview with a researcher who will ask you a few questions regarding your views about the care of patients with multimorbidity. Participation is entirely voluntary. **The interview will take between 15 to 30 minutes**. It can be conducted face-to-face (if in metropolitan South Australia) or via phone or Zoom. The interview will be audio recorded and transcribed. You can request a copy of the transcript to check for accuracy.

What benefit will I gain from being involved in this study?

In sharing your experiences, you will contribute to a clearer picture of how Australian general practitioners are dealing with what is understood to be a growing concern for health systems worldwide. This will also provide you with an opportunity to reflect on your own practice.

Will I be identifiable by being involved in this study?

We do not need your name and you will be anonymous. Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts if I am involved?

The researcher anticipates few risks from your involvement in this study apart from the inconvenience of giving up your time. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?

Participation is voluntary. You may choose not to answer certain questions, and you are free to withdraw from the interview at any time without effect or consequences.
A consent form accompanies this information sheet. If you agree to participate please read and sign the form. It can be scanned and emailed back to me at Raechel.damarell@flinders.edu.au or posted to me at the GPO box address provided at the top of this information sheet.

Recognition of contribution and time given

If you would like to participate, you will be provided with a $150 gift voucher in recognition of your contribution and participation. This reimbursement will be provided to you on completion of the interview.

How will I receive feedback?

On project completion, a summary of project outcomes will be posted to all participants.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 8546). For queries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

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CRICOS Provider No. 00114A

14 February 2020

LETTER OF INTRODUCTION
(for General Practitioners)

To whom it may concern,

This letter is to introduce Raechel Damarell who is a PhD candidate in the College of Nursing and Health Sciences and the Research Centre for Palliative Care, Death and Dying at Flinders University.

Raechel is undertaking research leading to the production of a thesis and other publications on the subject of Australian general practitioner experiences of managing patients with multimorbidity with life-limiting illness. This program of research will investigate if and how multimorbidity creates challenges in general practice. It will also ask general practitioners for their opinions on what is needed, if anything, to improve care provision, both for them and their patients.

Raechel would like to invite you to assist with this project by agreeing to be involved in an interview which covers certain aspects of this topic. No more than 15-30 minutes on one occasion would be required. Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since Raechel intends to make a tape recording of the interview, she will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed, and to make the recording available to other researchers on the same conditions (or that the recording will not be made available to any other person). It may be necessary to make the recording available to secretarial assistants (or a transcription service) for transcription, in which case you may be assured that such persons will be required to sign a confidentiality agreement which outlines the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 08 7221 8237 or e-mail Jennifer.Tieman@flinders.edu.au

Thank you for your attention and assistance.

Yours sincerely

Professor Jennifer Tieman
College of Nursing and Health Sciences
Flinders University

Flinders
UNIVERSITY

CONSENT FORM FOR PARTICIPATION IN RESEARCH

(Interview)

Australian general practitioner perspectives on multimorbidity with life-limiting illness: its challenges and strategies for management

I ....

being over the age of 18 years hereby consent to participate as requested in an interview for the research project with the title listed above.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio-recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

5. I understand that:
   - I may not directly benefit from taking part in this research.
   - Participation is entirely voluntary, and I am free to withdraw from the project at any time; and can decline to answer particular questions.
   - The information gained in this study will be published as explained, and my participation will be anonymous and confidential.
   - I may ask that the audio-recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

6. I understand that only the researchers on this project will have access to my research data and raw results; unless I explicitly provide consent for it to be shared with other parties. If the need to seek your consent to share your research data with other parties does arise, I will be contacted by the researchers via email.

Participant's name………………………………………………………..........................

Participant's signature……………………………………………Date…………………...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name…………………………….…………………………….................

Researcher's signature……………………………………....Date…………………….

NB: Two signed copies should be obtained (one for researcher; one for participant). The copy retained by the researcher may then be used for participant review and approval of interview transcripts (point 8) where relevant.

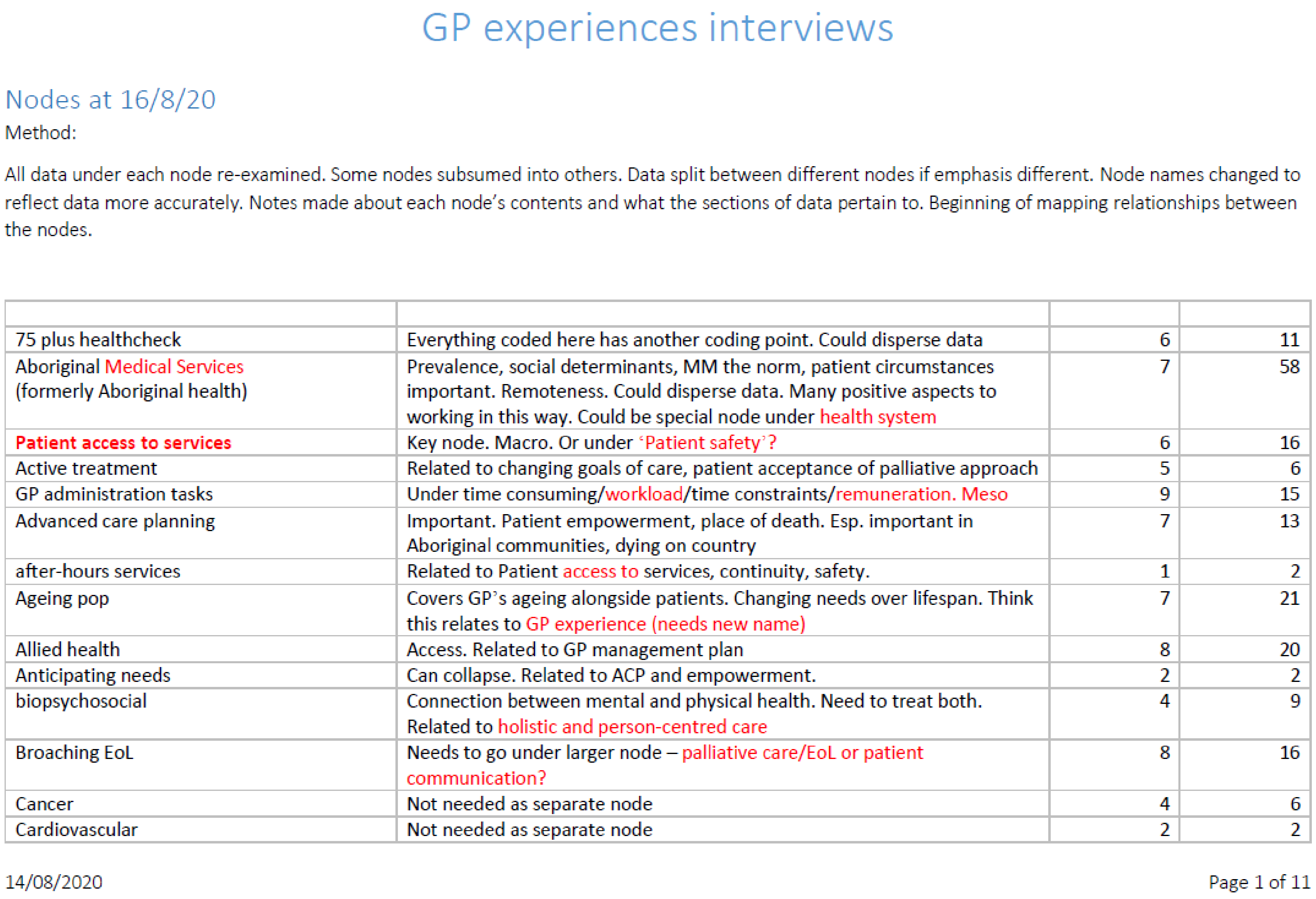
Review / Approval of Interview Transcriptions

7. I, the participant whose signature appears below, have read a transcript of my interview participation and agree to its use by the researcher as explained.

Participant's signature……………………………………………Date…………………...

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 8546). For queries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

A3.3 Excerpt from codebook



GP experiences interviews

Nodes at 16/8/20

Method:

All data under each node re-examined. Some nodes subsumed into others. Data split between different nodes if emphasis different. Node names changed to reflect data more accurately. Notes made about each node's contents and what the sections of data pertain to. Beginning of mapping relationships between the nodes.

75 plus healthcheck	Everything coded here has another coding point. Could disperse data	6	11
Aboriginal Medical Services (formerly Aboriginal health)	Prevalence, social determinants, MM the norm, patient circumstances important. Remoteness. Could disperse data. Many positive aspects to working in this way. Could be special node under health system	7	58
Patient access to services	Key node. Macro. Or under 'Patient safety'?	6	16
Active treatment	Related to changing goals of care, patient acceptance of palliative approach	5	6
GP administration tasks	Under time consuming/workload/time constraints/remuneration. Meso	9	15
Advanced care planning	Important. Patient empowerment, place of death. Esp. important in Aboriginal communities, dying on country	7	13
after-hours services	Related to Patient access to services, continuity, safety.	1	2
Ageing pop	Covers GP's ageing alongside patients. Changing needs over lifespan. Think this relates to GP experience (needs new name)	7	21
Allied health	Access. Related to GP management plan	8	20
Anticipating needs	Can collapse. Related to ACP and empowerment.	2	2
biopsychosocial	Connection between mental and physical health. Need to treat both. Related to holistic and person-centred care	4	9
Broaching EoL	Needs to go under larger node – palliative care/EoL or patient communication?	8	16
Cancer	Not needed as separate node	4	6
Cardiovascular	Not needed as separate node	2	2

14/08/2020

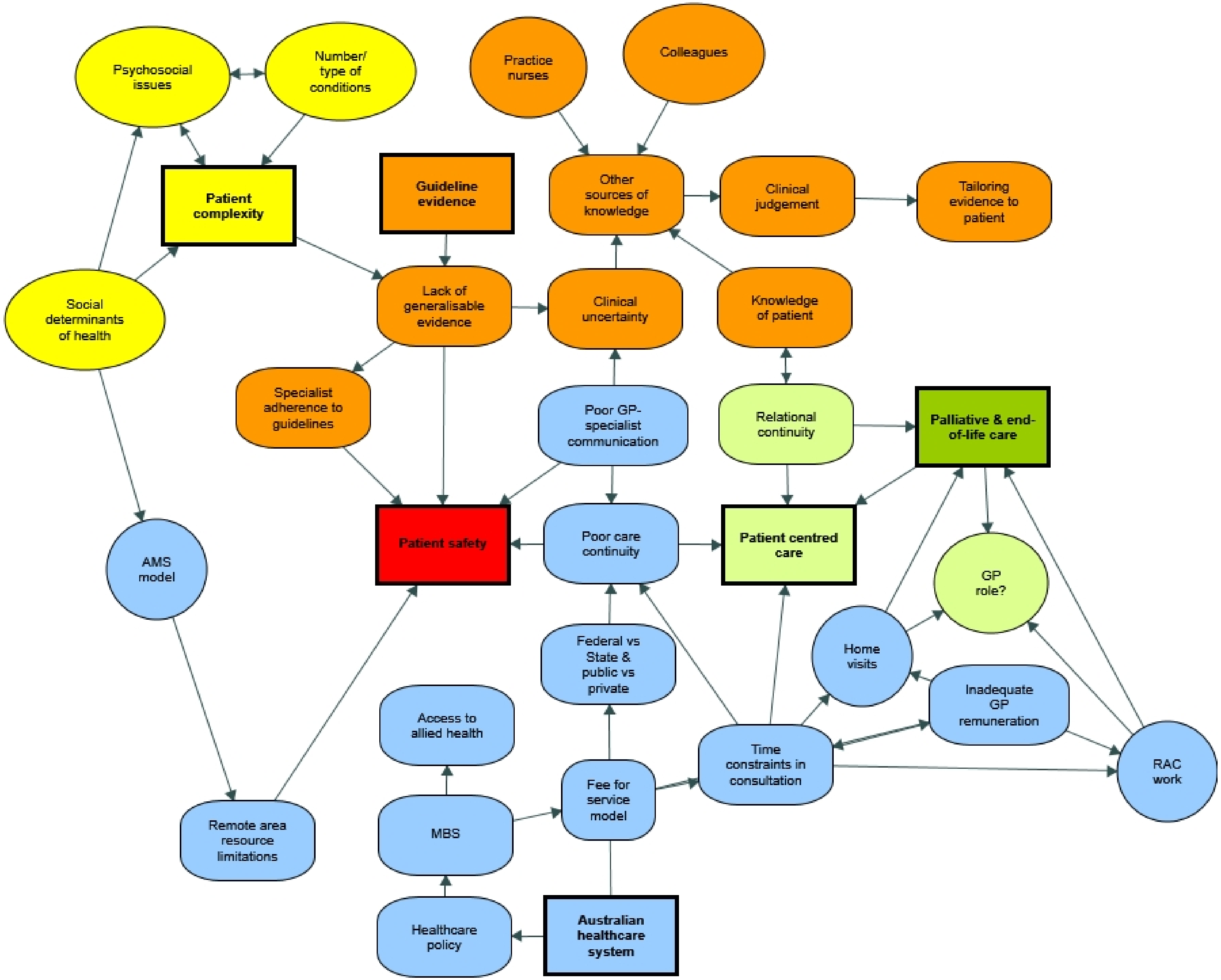
Page 1 of 11

Care coordination	Seen as GP role, challenge with fragmentation, specialist communication Relates to workload (extra). Scope of practice	5	11
carers	Not too much here. One good quote moved to intuition	2	4
cerebrovascular disease	Collapse	1	1
Changing goals of care	Patient receptivity and preferences. Related to palliative care. May be key node??	10	27
child abuse	Relates to social determinants == complexity	1	2
chronic kidney disease	Collapse	3	5
Clinical judgement	Important. Relates to evidence and intuition	11	28
Collaborations with other health professionals (positive)	Subnode under Other Health professionals? What is helpful and works. See also Practice nurses and Specialist palliative care.	9	15
Community	Person's place in the community. GP's engagement with the community	5	12
Comorbidities	Can collapse	5	22
Complex patients	Important node. Relates to Aboriginal health care, ageing pop, Biopsychosocial, child abuse, comorbidities, decline, depression, disability, Mental health, patient heterogeneity, patient function, social determinants, social circumstances	10	35
Compliance	Relates to patient burden of care, patient safety	7	12
compromise	Relates to competing priorities/goals. Put with Conflicting or competing priorities	4	5
Computer literacy	Relates to patient safety	4	4
Conflicting or competing priorities	May be key node or about knowing the patient? Often relates to preventative care. Also time management of the GP as it relates to the consultation. So really two different contexts – overall priorities and priorities within the consultation. Need to differentiate.	8	23
Continuity	This relates to the way the health system is structured. Also GP-specialist relations and fragmentation. Fragmentation should come under health systems.	4	9
COPD	Collapse	1	1
coronary artery disease	Collapse	1	1

COVID	Special section under Patient safety. But also something about GP care/compassion for their patients. Expressed worry. Professional responsibility.	5	21
Decision support software	Needs improvement. Alert fatigue. Relates to Evidence. Also Practice software	2	2
Decline (gradual)	Relates to End of life and patient understanding and acceptance of decline. Gradual, rather than expected, approach of death. Really terrific content. Is it the nature of the end of life? Not always dramatic and clear cut. Prognostication? Challenges in talking to people about the things they must let go of…. Ask Deidre!! Participation in activities of life. Compromising their relationship.	2	4
Defensive medicine	Relates to Evidence	2	4
Defining MM	Inadequacy of the label. Doesn't capture complexity. Does asthma + hypertension = depression + disability + CV disease? Need to consider weighting of issues (different systems involved). Veering towards complex patients only. Not all disease related problems either. Relates to complex patients	3	8
Deprescribing	Often triggered by realisation of pending EoL. Subnode under Changing goals of care. Simplifying treatment	9	14
depression	Collapse	2	2
diabetes	Could be dispersed to AMS, PNs, lifestyle,	7	12
diabetes educator	Could be collapsed	3	5
Dietary_Nutrition	Related to lifestyle and preventative	3	4
Disability	Relates to Complex patients	2	4
disease centric view	Relates to Biopsychosocial – GPs seems to have a strong feeling about seeing the whole person	3	9
draining	Relates to patient complexity and time constraints	2	3
Drugs	Can be dispersed to different nodes. Patient safety, Interactions, GP knowledge	9	45
Electronic health record	Comes under Interprofessional communication	3	4
emotionally	Comes under GP involvement in EoL	2	2

Evidence (GPs attitudes to)	Major node. Subgroup = guidelines. Positive and negative. Checklist mentality, burden of treatment	12	61
Evidence certainty	Subsume into Evidence	9	21
Evidence insufficiency	Subset of Evidence	11	31
Family	Important as a source of information. Also clearly a concern for the GP, especially in the context of EoL. GPs make efforts to communicate with family and support them. Source of conflict also.	7	20
Fragmented care	Major node. Some attributed this to health system structure. Some at the level of specific specialists (GP-specialist relations). Why are GPs concerned? Patient safety, impact on workload – theirs and the patient’s, duplication of effort, trying to pull things together for the patient to make things easier for them. Especially some of the more complex patients with mental health and disability. At odds with GP holistic view of patient. Feel as though they are sending them off into danger. GPs critical of the specialist approach and superspecialisation. Relates to interprofessional communication, GP-specialist relations. This is the antithesis of the holistic/biopsychosocial. Put under Healthcare System?	6	23
frustrating	Can be collapsed	2	2
Generalists	Collapse into Scope of practice (Role of GP)	4	17
GP chronic management plan	Covered by Accessibility. Remuneration. Inadequacy. Need heading on financial drivers promoting comprehensive assessment and management	9	27
GP experience	Important. Improved EoLC with experience. MM as challenging, even for the experienced. Extrapolating from guidelines comes with experience. Listening to the patient and understanding their circumstances something to be learnt over time. Growing into MM care over time as patients age. Ageing with the patient can give insight and understanding.	6	20
GP involvement in EoL	‘Rewarding’, ‘charity’, ‘community service’, ‘doing it out of love’, ‘fantastic thing to do’, ‘intimate’, bonding. Would do even at a cost to themselves. Acknowledged colleagues might not. Difference between AMS and other systems in terms of time and remuneration. Conflicting views	12	53

A3.4 Visual thematic map of early theme development



A3.5 Additional data supporting study themes

Theme 1. Multimorbidity as an encounter with complexity and contingency	
Patient complexity	*The rates of dialysis are extraordinary and even amongst young people. And sometimes that's a result of glomerulonephritis, which can be from strep infections, and overcrowding. But sometimes it's more of that early onset metabolic picture. And people being more at risk of that, you know, because perhaps it was diabetes in pregnancy when they were … before they were born. But I guess, all that aside, addressing those risk factors at a community level, rather than individual level, would be, you know, would be great. (GP2)* *And, you know, it can be challenging if you've got multimorbidity and your doctor wants to prescribe you 15 tablets a day, and you need to remember to take them three times a day, but you're also taking care of … a number of children, supporting elderly relatives, sort of running around and then managing it all when you may have limited access to transport or lots of appointments. So … it's normal for us, for our patients, to have a lot of the social stresses that accompany that, you know, are familiar to people who are experiencing economic disadvantage. (GP2)* *For me, that said, being very experienced, it's not so difficult, but it's still difficult. But for junior… young doctors, especially our registrars, it's really challenging because they've got three or four different conditions and each of the conditions interacts with the other conditions in some way. (GP6)* *[T]he hard core intellectual aspects of dealing with their medical conditions is really complicated. Especially if you are new to the game and haven't built up that level of experience and knowledge. (GP6)* *It's challenging for an experienced GP but definitely challenging when you're at the beginning as well [laugh]. There's a whole load of complexities aren't there? (GP11)* *The challenges of looking after people with multiple chronic conditions is it's hard to harmonise the care for each of the conditions tailored to the patient. So sometimes treating one might not be helpful to the treatment of the second condition or the third condition. (GP12)*
Converging system and practice challenges	*Luckily where I work, I am on a salary so I don't have such time pressure as I would in a private practice. I don't think I would cope in a private practice with the same sort of patient demographic. (GP3)* *I think it's really difficult. It would be better, you know, if there was some sort of other… some better Medicare system for patients with complex co-morbidity. (GP3)* *Because patients who have chronic conditions or complex comorbidity … they really seek out doctors who actually care. And they probably find it difficult to find doctors who can spend the time or want to spend the time and tackle their issues. So once they find one, they'll tend to stick to them religiously. And so if you're one of those doctors in a bulk billing practice then you'd definitely be at high risk of burnout and finishing late and running late and all those pressures. (GP3)* *In the long term, I think the only model that is going to work in some of the aged care facilities is that they employ doctors who are salaried to do it. A bit like the Aboriginal Medical Service*

	model. (GP5) *So it's a question of getting the drivers to balance out to make a good quality health system. (GP8)* *I think that increased remuneration would be of benefit because you do spend a lot of time outside of the consultation doing certain things for those patients, whether it be talking to other health professionals who are involved in their care etc. (GP11)*
Contingency problem solving	*So that's my specific approach with all the multimorbid patients. Predict problems before they happen. So it's a very preventative approach but it takes time and it's got to be actively done. (GP6)* *... [I]f you're dealing with like your complex drug people, you drag them in very frequently because they don't get naughty then [Laughs] (GP7)* *But then, when you want to refer to anybody else who's not a medical person, then either you're looking at the public system, which may or may not be easily accessible, or you're looking at private practices, which are probably not financially accessible for the patients. (GP9)* *That's definitely challenging because you've got something that might be a first line treatment but for that particular patient that's not going to be an option. (GP11)* *You know scripts cost money. Even if we do not bill privately, we – it certainly does put a dent in some people who are more vulnerable to the financial stress. (GP12)*
Theme 2. Evidentiary constraints in multimorbidity care	
	If the guidelines say to keep adding but the patient either can't afford them or, you know, doesn't … they've got too many risk factors for it, then I won't follow it to a tee but try and have a balance between what the guidelines say and what would suit the individual patient. (GP3) *I think because the patients are so complex, and one thing can affect the other so easily, I tend to always look to guidelines. Yeah, I rely on them a lot. (GP3)* *You're not just reading the medical textbooks and saying, 'right, you need to do this, this and this' because it won't work unless you are interacting with people and getting them on board. (GP4)* *Guidelines are good but they're good for populations. They don't apply to individuals. (GP6)* *So the guidelines aren't necessarily based on our age group. And usually they nearly always pick patients who don't have other co-morbidities to develop their guideline. (GP8)* *And I think people who want a computer solution that has a zillion guidelines all somehow merging in an algorithm are just being ridiculous. (GP9)* *Yeah, but if you happen to have really old patients, and they have other problems, then you don't always want…. you would rather put up with a slightly higher HbA1c than risk them becoming hypoglycaemic. (GP9)* *I mean, when you get guidelines running to 180 pages or something, which some do, you know. I've sometimes looked up the bowel cancer ones as well, but they're also written with surgeons in mind. (GP9)*

	Yes, and so guidelines are good but of course everything's got its limitations when you have the individual in front of you. (GP11) *Some of them play a role but guidelines tend to be system-specific, and it is difficult for guidelines to be more than that. (GP12)* *And I see it very much as the role of practitioners to look at the guidelines, look up what the evidence is, look at the patients and what else is going on in their lives and negotiate a plan that is tailored for them. (GP12)*
Integrating other forms of knowledge	*I think that's one of the things that is good here [AMS], that it's not just guidelines. You do have to try and use your head a little bit and say, really engage with patients because you notice when you work here that for the first six months, I would say, patients look you up and down and say 'yes doctor, three bags full doctor.' But it's only when you've been there a while and people see that you come back and that you try and do the best thing (GP4).* *I'm probably not an ideal person to interview because I'm probably somebody that should use the guidelines more and look things up. And of course, I can, and I will, but I'm more interested in understanding the situation and what's really going on. (GP5)* *Third year medical students can learn an amazing amount of social and traditional medicine because all the medical stuff that they probably need to know for their exams is walking and talking in the reality of a person in front of them. The diabetes, the heart failure, the cancer, la, la, la. All this stuff in the textbooks, walking and talking in front of them. In a story. (GP5)* *But that only comes with experience and actually building that relationship with a person and seeing what happens over time with different scenarios and situations and just getting that... a bit more of a feel about how you manage people rather than conditions because that's what we're treating. Individuals, not conditions. (GP6)* *I frequently go and ask my registrars questions because I know that they're sharper on protocols and stuff like that. And so I think that general practice is much better in a team environment when you're dealing with multiple morbidity. (GP7)*
Theme 3. Concerns for patient safety	
Dangerous lack of communication with specialists	*'What communication are you talking about?'* (GP6) *Tests get done and nothing comes through. The results don't get sent through, so you have to go chasing which is more time. (GP6)* *The worst, the absolute worst is if someone goes to a private hospital. … The patients admitted there will receive a nursing discharge summary which will say the patient's name, what they went in for, and that's about it. And then it will say 'management, as per doctor's letter'. And there'll be no doctor's letter, nothing will come out. Very, very poor. (GP6)* *… [T]he financial models of medical practice don't reward people taking time and doing things properly. The rewards are for high turnover, which usually, in terms of these patients, means things are done wrong, medication errors, unplanned hospital admissions, unplanned events, high risk of complications played a major complication because someone hasn't taken the time to sort them out properly. (GP6)* *[A]nd we don't regularly enough review their medications and aggressively or actively deprescribe. And I include myself in the group that don't do enough of it, yet I'm really enlightened so I do actively do it. But I do recognise that I could do a lot more than I do. Which*

	makes it worrying for the other people who don't actually recognise it. (GP6) *People are on a lot of medications and that's not actually very good for you when you're old. ...And even though I've sent [specialists] the medication list … they're definitely not totally across what might occur, what interactions might occur. (GP8)* *…[I]t's hard to actually get to talk to them [specialists]. So it's not a simple thing to chase them up, to do something quickly. And then doing it by fax or letter is slower. So there's a sort of a gap of a week or two where you kind of best guess what to do for the patient as the GP. (GP8)* *That's the only goal. It's to keep them out of the hospital system but then they won't invest in the community stuff to keep them out of the hospital system. (GP9)* *There were certain specialists at the hospital to which I would not refer because we needed to be working as a team and we needed to be respecting each other and there hasn't at times been a great deal of respect between specialists and GPs. (GP10)*
Concern for patient access	*I mean, some of them would go use all their five visits in a year on podiatry. Some might only go for a check-up in which case you are then left with something to use for something else, like physio or whatever. If someone truly has complex morbidity, it's completely inadequate. (GP9)* *The one that's most technically proficient sounded very anxious when I suggested we do a Zoom teleconference. She said, 'I have to download the thing'. I said, 'No, you don't have to download anything. I just send you a link.' 'Oh. It sounds hard.' (GP8)* *The problem with it is it doesn't give them access to much; you know. Five visits to a podiatrist per year. It's not terribly exciting to do a whole heap of paperwork for five visits to a podiatrist. You think 'why bother?' (GP6)* *… [I]f things can be managed in community, that's their preference, you know, when it's safe. But then also there's limits on health system resources. An ambulance trip into town takes, you know, staff. (GP2)*
Theme 4. Multimorbidity management at the end of life	
Determining and communicating prognosis	*Because some patients have COPD and you think 'you might not be around in 12 months.'…. You can broach it and often they have to be in a state where they know that they've deteriorated quite a lot to accept that. (GP1)* *I had a lady today. She's got pancreatic cancer, but no one told her that no, she may not see Christmas. So that was my job. So I told her but she's not necessarily wanting to go down a palliative care or a palliative approach yet. She's still managing. She's still trying chemo, as she would, you know. She's quite young. (GP1)* *So, if ever we had clarity around the fact that someone was in that, you know, entering into the palliative phase, we tried to have that conversation. People respond differently to that conversation. But it was certainly very useful because, you know, I had that conversation with a patient and she said, 'I know I'm dying. I've got cancer. One hundred percent my number one priority is I want to die on country'. The family were happy to support her. We affirmed that at a family meeting. They'd cared for other family members on country and we were able to facilitate that. (GP2)* *I had a conversation with another bloke who had advanced heart failure and you know; I think [he] was definitely in that about 12 months-ish category. And, he was very much of the opinion*

	that if it was looking like it wasn't sure which way he was going to go, he absolutely wanted everything done, and transfer, and as much medical intervention as was appropriate. And, you know, that was really good to know as well, because he equally could have given an answer like the first lady, but absolutely didn't. So, I think clarifying those things is critical. (GP2) *I think the goals do trigger a re-evaluation and sometimes that would involve, you know, deprescribing. Sometimes it would involve palliative care services. A lot of the times it would just involve talking to the patient about what's important to them. (GP2)* *And if you know the duration of their life is limited, and they really hate certain therapies, you know, you have to ask, 'what's the point of continuing them?' (GP2)* *Yes, it's so important, particularly because most of my patients have the preference to die at home, rather than in hospital. There's a huge belief in Aboriginal culture that a hospital is a place that you go to die so that's why people avoid it. (GP3)* *Yeah, we don't do nearly as many advanced care directives as I'd like to do. I know that it's so important and it might be on the to do list, but it's usually not the only thing going on. So it often gets delayed and delayed and forgotten about. (GP3)* *And I think that's a difficult area where people may not have a long-life expectancy but they're not truly palliative in the sense that they're relatively well. They're still a position that they would want to be resuscitated and, you know, some fairly intensive interventions might well be appropriate for those people. (GP4)* *So when you sit down and do advanced care directives with most people, most people say, 'do what you think. I want to do what's reasonable. I don't want to overdo it. You know, I don't want heroics…. So doing the advanced care directive process, I think it's a very good process. (GP5)* *Because of the way we structure health care into little blocks of time for which we get paid, then we don't have that conversation. It would be a GP conversation because certainly the specialists assume that they want the optimal guideline directed treatment. (GP8)* *…[O]n a whole number of different levels [palliative care] can be challenging. I mean sometimes it can be. Sometimes it's quite straightforward and it's … a conversation that just happens so naturally. You know them, they know you, … you know there's a trust relationship. They're ready to talk about it. (GP11)* *Look you do have patients where there's a denial of moving to end of life and they want everything done regardless. But I think also … for the majority of people it is about negotiating what you know, what they are wanting and what their priorities are. (GP11)* *People will have different priorities. You've got to explore that so that you engage with the patient so it's a journey you're taking together, you're not the authoritarian saying, "Oh this is what you've got to do." People may not have any interest in doing those things. Regardless of how much you think it's helpful. (GP11)*
The GP role at the end of life	*Yes, I see it's a very important role for GPs. I thought it was a very important part of our practice. It was often rather exhausting and difficult but being able to help people to have a good death, and for the relatives to feel supported and see that they had a good death is just a most fantastic thing to do. (GP10)*

	GPs are doing much less nursing home visits, many less home visits. … [W]e used to do so much more in the past. And unless they go out and get themselves trained, they really … are not getting much training in palliative care. (GP10) *We really need to enable the people who want to do it by doing it as a team. We could not have provided palliative we did in our practice without being a part of the palliative care team. And having a very, respectful working relationship with them. (GP10)*

APPENDIX 4

Chapter 7. Multimorbidity in Australian general practice: a cross-sectional survey of general practitioner perceptions, attitudes, and practices

4.1 Ethics approval for project number 2744 and recruitment materials

19 October 2020

HUMAN ETHICS LOW RISK PANEL

APPROVAL NOTICE

Dear Ms Raechel Damarell,

The below proposed project has been **approved** on the basis of the information contained in the application and its attachments.

Project No:	2744
Project Title:	Survey of Australian general practitioners on their experiences managing patients with multimorbidity
Primary Researcher:	Ms Raechel Damarell
Approval Date:	19/10/2020
Expiry Date:	17/05/2021

Please note: *Due to the current COVID-19 situation, researchers are strongly advised to develop a research design that aligns with the University's COVID-19 research protocol involving human studies. Where possible, avoid face-to-face testing and consider rescheduling face-to-face testing or undertaking alternative distance/online data or interview collection means. For further information, please go to https://staff.flinders.edu.au/coronavirus-information/research-updates.*

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)* an annual progress report must be submitted each year on the approval anniversary date for the duration of the ethics approval using the HREC Annual/Final Report Form available online via the ResearchNow Ethics & Biosafety system.

Please note that no data collection can be undertaken after the ethics approval expiry date listed at the top of this notice. If data is collected after expiry, it will not be covered in terms of ethics. It is the responsibility of the researcher to ensure that annual progress reports are submitted on time; and that no data is collected after ethics has expired.

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please either submit (1) a final report; or (2) an extension of time request (using the HREC Modification Form).

For student projects, the Low Risk Panel recommends that current ethics approval is maintained until a student's thesis has been submitted, assessed and finalised. This is to protect the student in the event that reviewers recommend that additional data be collected from participants.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, researchers and supervisors)
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes to information / documents to be given to potential participants;
- changes to research tools (e.g., survey, interview questions, focus group questions etc);
- extensions of time (i.e. to extend the period of ethics approval past current expiry date).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available online via the ResearchNow Ethics & Biosafety system. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Yours Sincerely,

Ms Andrea Mather

on behalf of

Human Ethics Low Risk Panel
Research Development and Support
human.researchethics@flinders.edu.au
P: (+61-8) 8201 2543

Flinders University
Sturt Road, Bedford Park, South Australia, 5042
GPO Box 2100, Adelaide, South Australia, 5001

http://www.flinders.edu.au/research/researcher-support/ebi/human-ethics/human-ethics_home.cfm

ResearchNow
Ethics & Biosafety

Flinders University
Research Development and Support
Proactively supporting our Research

Newsletter recruitment announcement

Australian GPs and multimorbidity

Australian general practitioners are invited to complete a short online survey (**5-10 minutes**) on their experiences in managing patients with multimorbidity. The survey is part of a Flinders University PhD program of research investigating general practitioner perspectives on multimorbidity in the context of life-limiting illness. For more information about this study and the survey itself, go to: https://qualtrics.flinders.edu.au/jfe/form/SV_1FVUBaOJJaIM0xT

Accompanying image

Introductory email to GPs (sent via AMPCo)

Subject line: Multimorbidity and General Practitioners: Invitation to brief online survey

----

Dear Dr [AMPco to fill in name]

I am writing to invite you to contribute to a PhD research study on Australian general practitioner experiences in managing patients with multiple chronic illnesses. This study is supported by Flinders University, College of Nursing and Health Sciences.

Your participation would involve completing a survey estimated to take between **5-10 minutes.**

Full details and access to the survey itself are at https://tinyurl.com/y5l35vsb

Thank you very much for considering this request. I hope this study may be of interest.

Yours faithfully,

Raechel Anne Damarell

PhD Candidate
Flinders University

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Title: Survey of Australian general practitioners on their experiences of managing patients with multimorbidity

Chief Investigator
Ms Raechel Damarell
Research Centre for Palliative Care, Death and Dying
College of Nursing and Health Sciences
Flinders University
Ph: 08 7221 8887

Co-Investigator
Dr Tim Senior
Tharawal Aboriginal Corporation (Aboriginal Medical Service)
Airds, New South Wales
Ph: 02 4628 4837

Supervisors
Professor Jennifer Tieman and Dr Deidre Morgan
Research Centre for Palliative Care, Death and Dying
College of Nursing and Health Sciences
Flinders University
Ph: 08 7221 8237 or 08 72218220

Description of the study

This survey is part of a larger PhD project investigating general practitioner (GP) perspectives on managing patients with multiple chronic conditions, the suitability of the available research evidence for doing so, and what GPs believe is needed to better support them in providing this care. This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study

This project aims to find out directly from general practitioners how they experience the management of patients with multimorbidity, especially when one condition is life-limiting (e.g. COPD, cancer, heart failure, dementia). The study findings--to be published as a journal article--will constitute one form of evidence as to how the Australian health system is working for these complex patients. It is hoped findings might also reveal the extent to which existing policies support GPs in providing the holistic care characteristic of their specialty.

Benefits of the study

In sharing your experiences, you will contribute to a clearer picture of how Australian general practitioners are dealing with what is understood to be a growing concern for health systems worldwide. This will also provide you with an opportunity to reflect on your own practice.

Participant involvement and potential risks

If you agree to participate in the research study, you will be asked to participate in a print survey which should take **no more than 5 to 10 minutes** to complete. Your participation is entirely voluntary.

Withdrawal Rights

You may, without any penalty, decline to take part in this research study or start the survey and decide not to complete it.

Confidentiality and Privacy

Only researchers listed on this form have access to the individual information provided by you. Privacy and confidentiality will always be assured. The research outcomes may be presented at conferences, written up for publication or used for other research purposes as described in this information form. However, the privacy and confidentiality of individuals will always be protected. You will not be named, and your individual information will not be identifiable in any research products without your explicit consent.

No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without your explicit consent.

Data Storage

The information collected may be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes unless indicated otherwise. All data will be securely transferred to and stored at Flinders University for at least five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

How will I receive feedback?

It will not be possible to provide individual feedback to participants. However, we anticipate that the survey results will be published in a journal article at some point in the future.

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (Project no. 2744).

Queries and Concerns

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 3116 or email human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet which is yours to keep. If you accept our invitation to be involved, please print, sign, and return the enclosed Consent Form.

CONSENT FORM

Consent Statement

☐ I have read and understood the information about the research, and I understand I am being asked to provide informed consent to participate in this research study. I understand that I can contact the research team if I have further questions about this research study.

☐ I am not aware of any condition that would prevent my participation, and I agree to participate in this project.

☐ I understand that I am free to withdraw at any time during the study.

☐ I understand that I can contact Flinders University’s Research Ethics & Compliance Office if I have any complaints or reservations about the ethical conduct of this study.

☐ I understand that my involvement is confidential, and that the information collected may be published. I understand that I will not be identified in any research products.

I further consent to:

☐ completing a questionnaire

Signed:

Name:

Date:

Raechel Damarell
Research Centre for Palliative Care, Death and Dying
College of Nursing and Health Sciences

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Adelaide SA 5001
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Raechel.damarell@flinders.edu.au

https://www.flinders.edu.au/people/raechel.damarell

CRICOS Provider No. 00114A

Dr [Insert name]
[Address]

[Date]

Re: Invitation to participate in a survey on general practitioner experiences of multimorbidity management

Dear Dr [Surname],

I am writing to invite you to contribute to a PhD research study on Australian general practitioner experiences in managing patients with multiple chronic illnesses. This study is supported by Flinders University, College of Nursing and Health Sciences. Full details are provided in the accompanying information sheet; however, these are the brief details:

- Your participation would involve completing a survey estimated to take between **5-10 minutes.**
- A print survey is enclosed here for you to fill in. Alternatively, you can complete an online version, available at https://tinyurl.com/y5l35vsb
- Return the completed print survey along with the signed consent form (also enclosed) using the reply-paid envelope provided.

Thank you very much for taking the time to read this letter. I hope this study may be of interest.

Yours faithfully,

Raechel Anne Damarell

PhD Candidate
Flinders University

4.2 Survey instrument

Flinders University

A survey of Australian GPs on their experiences managing patients with multimorbidity

Some questions about you and your work context

Q1 What is your gender?

☐ Female
☐ Male
☐ Prefer not to say
☐ Other ______________________________

……………………………………………………………………………………

Q2 Year of gaining your ***first*** medical qualification (e.g. MBBS) ______________

……………………………………………………………………………………

Q3 Current employment status

☐ Full-time ☐ Part-time ☐ Other, please specify ________

……………………………………………………………………………………

Q4 What is the postcode of your ***main*** place of work? ______________

Q5 What is the setting of your main place of clinical work?

☐ GP owned practice
☐ Corporate owned practice
☐ Aboriginal Medical Service
☐ Community health centre
☐ Other, please specify ______________________________

……………………………………………………………………………………

Q6 How many GPs work at your service? (Head count only, including registrars)

☐ 1-4 ☐ 5-9 ☐ 10 or more

……………………………………………………………………………………

Q7 What proportion of your patients are bulk billed?

☐ 0-10% ☐ 11-50% ☐ 51-90% ☐ 91-100%

……

Q8 Do any of the following apply?

☐ I provide care to a residential aged care facility

☐ My place of work is part of the Health Care Homes trial

……

Managing patients with multimorbidity

This study defines multimorbidity as ***the co-existence of two or more chronic, symptomatic conditions in the one person.*** This excludes acute issues and asymptomatic precursor risk factors such as hypertension.

Q9 Based on this definition, approximately what proportion of your patients would you define as having multimorbidity?

☐ None (please go to Q10)
☐ 1-25% (skip to Q11)
☐ 26-50% (skip to Q11)
☐ 51-75% (skip to Q11)
☐ 76-100% (skip to Q11)

……

Q10 If you answered 'None' to question 9, please provide a brief reason for your answer (e.g. 'I mostly see young families') ____

____

____

As the following questions all relate to management of multimorbidity, you have now completed the survey. Thank you.

Q11 Compared to managing patients with single chronic conditions, I ***generally*** find managing patients with multimorbidity to be:

☐ More challenging to manage
☐ Just as challenging to manage
☐ Less challenging to manage

……

Q12 Please indicate your level of agreement with the following statements on **Multimorbidity research evidence and guidelines**

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
There is little available evidence on how to manage patients with multimorbidity	○	○	○	○	○
I tend to adhere to guideline recommendations in managing patients with multimorbidity	○	○	○	○	○
Single condition guidelines are difficult to generalise to people with multimorbidity	○	○	○	○	○
I tend to rely more on what patients want and their personal circumstances than what the guidelines recommend	○	○	○	○	○
Peers can be a trusted source of guidance on how to manage complex patients	○	○	○	○	○

……

Q13 Please indicate your level of agreement with the following statements on the **GP-patient consultation**

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
A standard consultation is long enough to manage the problems and concerns of patients with multimorbidity	○	○	○	○	○
I spent a lot of time outside of consultation time managing the care of patients with multimorbidity	○	○	○	○	○
I usually find time to address lifestyle risk factors and preventative health concerns with these patients	○	○	○	○	○
Having more consultation time, adequately remunerated, would improve general practice care of patients with multimorbidity	○	○	○	○	○
I always run late when I see patients with multimorbidity	○	○	○	○	○

Q14 Please indicate your level of agreement with the following statements on **multimorbidity patient care**

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
The potential for adverse interactions between drugs and conditions in multimorbidity concerns me	○	○	○	○	○
Patients with multimorbidity risk being burdened by too much treatment	○	○	○	○	○
I usually receive clear and timely information from the other specialists involved in the management of my patients	○	○	○	○	○
I am occasionally uncertain as to the best course of action with these patients	○	○	○	○	○

Q15 Which of the following currently makes a **positive difference** to your management of patients with multimorbidity? (Select as many as apply)

☐ Working with skilled practice nurses

☐ Knowledge of my patients, gathered over time

☐ Sharing knowledge and experiences with GP colleagues

☐ Collaboration with secondary care specialists

☐ Government initiatives such as GP management plans, 75+ health checks etc.

☐ The availability of clinical practice guidelines and other evidence tools

☐ Other ____

....

Q16 Is there anything else you'd like to add about managing patients with multimorbidity (positive or negative)?

____

____

____

....

Multimorbidity and life-limiting illness

You are now nearing the end of the survey. The last few questions ask you about caring for patients with life-limiting chronic illnesses and palliative care. We define a life-limiting illness as one expected to contribute ***directly*** to a patient's death. This includes heart failure, cancer, COPD, dementia, CKD, MND, and frailty in the elderly.

Q17 If palliative care involves identifying and treating symptoms and issues associated with life-limiting illness (physical, emotional, spiritual, or social) and focusing on maintaining quality of life; which of the following best describes your ***usual*** palliative care practice?

☐ I lead provision of palliative care, supported by Specialist Palliative Care, if needed

☐ I share care with a Specialist Palliative Care team

☐ I refer patients to Specialist Palliative Care in the first instance

☐ I don't provide palliative care, but I refer patients to GPs who do in the first instance

☐ Other ____

....

Q18 If the 'end of life' phase is defined as the **last 6 months** of a patient's life, do you generally find approaching this phase makes managing multimorbidity: (select as many as apply)

☐ Simpler: the focus becomes symptom management and quality of life

☐ Simpler: some medications and therapies can be ceased

☐ More complicated: more medications are added to manage symptoms and side effects

☐ It depends on the life-limiting condition

☐ Other, please specify ____

....

Q19 In your experience, the presence of comorbidities makes determining the transition point between the active management and end of life phases of care:

☐ More challenging, regardless of the type of index condition

☐ More challenging but only for non-cancer conditions

☐ More challenging but only for malignant cancer conditions

☐ Comorbidities usually have little bearing on prognostication

You have reached the end of the survey. We sincerely thank you for contributing your time and relating your experiences and look forward to receiving your survey.

A4.3 Additional verbatim quotes from the GP survey

Theme	Verbatim quotes
Subjective experience	• I find it can be some of the most rewarding work. • Impacting my family/non work time.
Multimorbidity care challenges	
Remuneration for time spent	• It is near impossible to make a reasonable GP income managing multimorbidity patients. I am lucky my family are grown up and can afford to be paid the insulting amounts the Medicare rebate offers.
Lack of time with patients	• I'm finding my caseload getting increasingly heavy and unmanageable some days with dealing with complex multimorbidity cases. Rarely enough booked appointment slot time to manage them so always running late and impacting my other patients' appointment times. • I need 30–60 mins per appointment.
Other specialists	• The most complicated patients are too unwell to attend non-GP specialists. • The demise of the general physician has meant single organ/system specialists excel with their speciality but often struggle to provide guidance regarding the 'dance' of navigating multimorbidities.
Patient complexity	• Presentation can be ambiguous or confused or there can be weird stuff which there isn't literature on at all. • Measuring quality by KPIs is challenging in these patients. The attempts to define quality by single disease markers fail to take into account the complexity.
Evidence	• GP led research will help develop better guidelines for these patients. • Difficult to apply guidelines when someone has multiple conditions on multiple medications, and I don't fully understand why they are what they are on.
Patient access to services	• Affordable access to allied health practitioners and a network of good local resources. • Access to valid and timely input from specifically aware medical and allied health practitioners is essential to maintaining function and equilibrium for the increasing cohorts of patients with multiple comorbidities, and for their GPs.
Government initiatives for chronic disease management	• These government initiatives are pointless bureaucratic nonsense that are only done because it's the only way to fund GP standard care. Scrap stupid incentives on plans and just fund GP at a base level. • Health checks are not helpful- just a money spinner.
Multimorbidity care facilitators	
Taking the extra time	• I mostly manage chronic disease and preventative care. I only do long consults.
GP personal factors	• Time management, interviewing skills (+++). • It is important to "not take things home" and remember it is the patient's journey, not your own.

APPENDIX 5

A5.1 Copyright permissions for included images

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Frailty and Multimorbidity: A Systematic Review and Meta-analysis

Author: Vetrano, Davide L; Palmer, Katie

Publication:
Journals of Gerontology - Series A: Biological Sciences and Medical Sciences

Publisher: Oxford University Press

Date: 2018-05-03

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About Your Work

Title	Negotiating evidence-based and patient-centred approaches to the management of multimorbidity across the adult lifespan: the Australian general practitioner experience
Institution name	Flinders University
Expected presentation date	Jul 2021

Additional Data

Portions	Figure 2. Overlap of frailty and multimorbidity (pooled data from nine studies including community-dwelling people). p. 662

Requestor Location

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Raechel Damarell

From: Copyrights <copyrights@aafp.org>
Sent: Friday, 4 June 2021 8:10 AM
To: Raechel Damarell
Subject: RE: Request to reproduce image from Annals of Family Medicine in thesis

Good afternoon,

We have no objection to you using this material in your thesis. Should you publish the work at a later date, you will need to obtain permission again, and there would be a fee incurred.

Kind regards,

From: Raechel Damarell <raechel.damarell@flinders.edu.au>
Sent: Wednesday, June 2, 2021 11:50 PM
To: Copyrights <copyrights@aafp.org>
Subject: Request to reproduce image from Annals of Family Medicine in thesis

Dear Sir/Madam,

I am writing to request permission to reproduce a figure (without modification) from your journal in my unpublished PhD thesis. The article containing the figure is:

Valderas JM, Starfield B, Sibbald B, Salisbury C, Roland M. Defining Comorbidity: Implications for Understanding Health and Health Services. Ann Fam Med. 2009;7(4):357-63.

The figure of interest is Figure 2. Comorbidity constructs on page 359.

My thesis is titled: Negotiating evidence-based and patient-centred approaches to the management of multimorbidity across the adult lifespan: the Australian general practitioner experience.
The figure will be used to illustrate the differences between concepts comorbidity, multimorbidity, and complexity in the Introduction.

Please let me know if you need any further details.

Yours sincerely,
Raechel Damarell

Raechel Damarell

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A Scoping Review and Thematic Classification of Patient Complexity: Offering a Unifying Framework

Author: Alexis K. Schaink, Kerry Kuluski, Renée F. Lyons, et al

Publication: Journal of Comorbidity

Publisher: SAGE Publications

Date: 01/01/2012

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Publication Title	ABC of Multimorbidity	**Country**	United Kingdom of Great Britain and Northern Ireland
Author/Editor	Mercer, Stewart, Salisbury, Chris, Fortin, Martin	**Rightsholder**	John Wiley & Sons - Books
Date	05/12/2014	**Publication Type**	e-Book
Language	English		

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Title	Negotiating evidence-based and patient-centred approaches to the management of multimorbidity across the adult lifespan: the Australian general practitioner experience	**Institution name**	Flinders University
		Expected presentation date	2021-07-01
Instructor name	Professor Jennifer Tieman		

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Volume of serial or monograph	N/A	Publication date of portion	2014-05-12
Page or page range of portion	31		

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Rethinking End-of-Life Care and Palliative Care: Learning From the Illness Trajectories and Lived Experiences of Terminally Ill Patients and Their Family Carers

Author: Maria Sercu, Ilse Beyens, Marc Cosyns, et al
Publication: Qualitative Health Research
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Publication Title	International perspectives on public health and palliative care	**Country**	United Kingdom of Great Britain and Northern Ireland
Author/Editor	Sallnow, Libby., Kumar, Suresh, Kellehear, Allan	**Rightsholder**	Taylor & Francis Informa UK Ltd - Books
Date	01/01/2012	**Publication Type**	Book
Language	English		

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Volume of serial or monograph	N/A
Page or page range of portion	31
Title of the article/chapter the portion is from	Illness trajectories and palliative care: implications for holistic service provision for all in the last year of life
Author of portion(s)	Murray SA & McLoughlin P.
Issue, if republishing an article from a serial	N/A
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Publication Title	ACP journal club	**Rightsholder**	American College of Physicians - Journals
Article Title	Clinical expertise in the era of evidence-based medicine and patient choice.	**Publication Type**	Journal
Author/Editor	AMERICAN COLLEGE OF PHYSICIANS.	**Start Page**	A11
Date	01/01/1991	**End Page**	A14
Language	English	**Issue**	2
Country	United States of America	**Volume**	136

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Instructor name	Prof Jennifer Tieman	**Expected presentation date**	2021-07-01

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Title, description or numeric reference of the portion(s)	Figure 2 An updated model for evidence-based clinical decisions
Editor of portion(s)	Haynes, R Brian; Devereaux, P J; Guyatt, Gordon H
Volume of serial or monograph	7
Page or page range of portion	37

Title of the article/chapter the portion is from	Clinical expertise in the era of evidence-based medicine and patient choice.
Author of portion(s)	Haynes, R Brian; Devereaux, P J; Guyatt, Gordon H
Issue, if republishing an article from a serial	2 (March/April)
Publication date of portion	2002-03-01

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