Pharmaceutical Care of the Dying

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ABSTRACT

Australians may well live the last year of their life at home, challenging governments and organisations to administer safe and affordable palliative care beyond the acute sector. While multiple factors contribute to safe and cost-effective palliative services in the home, good medication management is critical in managing symptoms.

However, people with palliative needs are vulnerable to medication-related problems, resulting in hospital admission, noncompliance, and out-of-pocket costs - impacting how those living in the community manage symptoms. As medication experts, pharmacists are uniquely placed within the multidisciplinary team to review and evaluate these risks and facilitate better strategies. However, the complex environment in which people and their caregivers receive palliative care jeopardises the pharmacist's routine involvement.

This thesis aimed to make an original and significant contribution to knowledge about pharmacists, caregivers, and medications regarding the care of the dying in the home environment. Rather than use a standard approach, this thesis considered six previously published works to form a PhD by Prior Publication (PhD PP). A PhD PP is a unique approach that takes previously published studies and examines these collectively, within the context of hindsight. Significantly, I wrote these six publications while conducting this research primarily as a clinician-researcher, which was declared and addressed throughout the thesis. In addition, the thesis used a conceptual model describing the complexity of managing people with multiple comorbidities to facilitate this collective examination.

Understanding the challenges pharmacists and caregivers face in managing the use of medications in people with palliative needs in the home environment is fundamental to developing and appropriately using resources. The first two publications investigated the various medications stocked in South Australian community pharmacies and a strategy for improving the reliability of medications stocked. A further two publications considered the impact of this strategy from the perspective of the community pharmacist and how this impacts their collaboration with a broader multidisciplinary team. A fifth publication identifies the evidence underpinning the community-based pharmacist's role in collaborating with the multidisciplinary team to support older people with palliative needs. The final publication studied the factors associated with caregivers indicating which factors were associated with more significant support in understanding the medications when caring for someone with palliative needs. In re-examining these publications, this thesis establishes new insights that provide a window into the critical issues in how people with palliative needs manage medications in the home environment, with learnings for other aspects of care delivery.

Three insights inform the findings, including challenges with funding models, clinical communication, and standardised approaches to care. In detailing these, it became evident that clinicians used some helpful strategies poorly when managing the care of people with palliative needs in the community. Furthermore, this thesis identifies gaps in how governments and organisations fund and allocate resources. Finally, this thesis identifies significant omissions in the evidence base regarding good pharmaceutical care for the dying.

As organisations and governments grapple with the challenge of delivering safe and affordable care for a rapidly growing number of people with palliative needs, this analysis will be critical in future planning.

DECLARATION

I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university
2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and
3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text

Signed......Paul Tait..

Date......19th July 2022..

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I acknowledge the traditional custodians of the lands across which we work, research, and reside. Furthermore, I recognise the Aboriginal and Torres Strait Islander peoples' spirit, imagination, and rich storytelling history that inspires all Australians. This thesis was developed and composed on Kaurna Land, Adelaide.

I wish to acknowledge the clinicians and caregivers that contributed their time to the research by sharing their insights. Without such willingness, these studies would have struggled to identify such significant findings.

The research that underpins this thesis has been more substantial through collaboration. With its challenges, I could not have done the initial work alone. My gratefulness goes to my colleagues and co-authors John Gray, Paul Hakendorf, Professor Deb Rowett, Bel Morris, Dr Tim To, Weng Hou Cheung, Dr Michael Wiese, Dr Kirsten Staff, Kylee Sheehy, Nina Muscillo, Dr Poppy Sindhusake, Dr Amal Chakraborty, Professor Jen Tieman, Dr Liz Cuthbertson, and Professor David Currow. They were exceedingly kind in sharing their clinical and research experience and expertise while supporting my, at times, naïve approach to conducting and reporting research. I also extend a heartfelt thank you to Emma Dubrich, Kate Swetenham, Win Greenshields, Bec Larcombe and Dr Tim To for their clinical leadership. While I speak of pragmatism within the thesis, I am indebted to their support in managing the challenges of conducting research in the clinical space.

I am a proud recipient of an “Australian Government Research Training Program Scholarship”. In addition, I am grateful to Professor Di Chamberlain and Professor Jo Arciuli for awarding me a stipend to complete this thesis. Undertaking this PhD was only possible through taking leave from my usual role, and these opportunities were greatly appreciated.

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Thanks to my supervisors, Professor Jen Tieman and Emeritus Professor Eimear Muir-Cochrane, at Flinders University. Chapter Three describes the PhD by prior publication as a unique and unusual approach to higher degree research. However, I could not have achieved it without their patient input and support. They provided supervision through different and complementary approaches focusing on structure, consistency, methodology, and academic rigour. In addition, they have helped me to create a valuable re-examination of a decade of work, allowing me to see more in the original publications than I would have realised myself.

With an equal measure of curiosity and experience in 2011, I commenced a research journey examining ways to improve subcutaneous medication access through community pharmacies for the dying. This research has been a big part of my life for over a decade. Again, I thank Terry for his love, support, and patience over these years.

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GLOSSARY

ANZSPM	Australian and New Zealand Society of Palliative Medicine
DAA	Dose Administration Aid
ELDAC	End of Life Directions for Aged Care
GP	General Practitioner
HC	Home Care
HMR	Home Medicines Review
HOS	Health Omnibus Survey
MBS	Medicare Benefits Schedule
MCQ	Multiple Choice Question
MHR	My Health Record
MRP	Medication Related Problem
NP	Nurse Practitioner
NPCS	National Palliative Care Strategy
NSW	New South Wales
OTC	Over-the-Counter
PBAC	Pharmaceutical Benefits Advisory Committee
PBP	Performance-Based Payment
PBS	Pharmaceutical Benefits Scheme
PCA	Palliative Care Australia
PCP	Primary Care Pharmacist
PhD PP	PhD by Prior Publication
PHN	Primary Health Network

PSA	Pharmaceutical Society of Australia
QUM	Quality Use of Medicines
RAC	Residential Aged Care
RACH	Residential Aged Care Home
RMMR	Residential Medication Management Review
SA	South Australia
SAPS	Southern Adelaide Palliative Services
SPCS	Specialist Palliative Care Service
TGA	Therapeutic Goods Administration

DEFINITIONS

Caregiver: A person who provides unpaid support to another individual who needs it because of an underlying terminal illness.[1]

Clinician: A trained health care professional, including registered and non-registered practitioners.[1]

Cost-shifting: Transferring activity so that a different tier of government funds it than the actual one involved.[2]

End-of-life care: The final week or months of life and into bereavement.[3]

Evidence-Based Practice: Making decisions about someone's care by balancing the current best evidence against their situation and values and the clinician's experience.[4]

General Practitioner (GP): A medical officer delivering care to individuals and their families in the home, RACH, or general practice.[5]

Home Medicines Review (HMR): A thorough review of someone's medications performed in their home by a clinically endorsed (or accredited) pharmacist and a reported to the referring medical officer with recommendations.[6]

Medicare Benefits Schedule (MBS): The listing of services provided in general practice and funded by the Australian Government.[5]

Medication Management: A broad approach that incorporates all tasks required to safely use medications, from manufacture to monitoring.[1]

Medication Review: A thorough review of someone's medications to optimise them and align with therapy outcomes.[1]

Medication: A legal substance used to prevent, diagnose, cure, control, or relieve a condition and includes prescription, over-the-counter, investigational, clinical trial and complementary medications, irrespective of their route of administration.[1]

Medication-Related Problem: Any circumstance involving treatment with a medication harming a person's health or preventing a favourable outcome, including under, inappropriate or overuse, adverse reactions, interactions and noncompliance.[1]

Multidisciplinary Team: A group of clinicians from various disciplines collaborating to deliver care that manages as many health and other needs as possible for an individual.[1]

Multimorbidity: The circumstances where someone has two or more coexisting health problems.[7]

My Health Record: An online secure electronic record for recording someone's health information.[5]

Nurse Practitioner: A nurse with extra credentials to permit advanced clinical tasks (such as prescribing) and delivering care to individuals and their families in the home, or RACH.[8]

Out-of-Pocket Costs: The costs incurred by someone, and their caregiver, for services beyond any subsidy from government funding arrangements such as the PBS.[5]

Palliative Care: Wrap-around care centred around the person living with a life-limiting, such as dementia or cancer, and their caregiver.[3]

Pharmaceutical Benefits Scheme (PBS): The listing of medications funded by the Australian Government for people living in the community.[5]

Pharmaceutical Care: Various duties conducted by pharmacists beyond the supply of medications, including clinical activities, clinical governance, education and training.[9]

Primary Care Pharmacist: Pharmacists working in dispensing and non-dispensing roles in various community-based organisations across health, aged and disability care services, including community pharmacy, general practice, and RACHs.[10]

Residential Aged Care Home (RACH): An institution that provides accommodation and care as a package, with the predominant service being care.[11]

Residential Medication Management Review (RMMR): A thorough assessment of someone's medications performed in a RACH by a clinically endorsed (or accredited) pharmacist and a reported to the referring medical officer with recommendations.[6]

Specialist Palliative Care Service (SPCS): An integrated clinical service publicly funded at the state or territory level usually operates out of a publicly funded hospital and provides specialised and expert palliative care across community and acute care settings.[3]

Terminal Phase: The last days or hours of a person's life.[3]

Transitions of Care: Transfer someone's care between locations, providers, or care levels, as their condition and needs change.[1]

Unwarranted Clinical Variation: Clinical care that fails to align with the medical evidence or the person's health care needs.[12]

CHAPTER ONE: INTRODUCTION

"You matter because you are you, and you matter to the end of your life. We will do all we can, not only to help you die peacefully, but also to live until you die." Dame Cicely Saunders, nurse, social worker, physician, and writer (1918 – 2005)

Introduction

Australia ranks well in life expectancy amongst other Organisation for Economic Co-operation and Development countries, with Australians benefiting from significant investment into healthcare advances.[13, 14] Long life expectancy reflects the low death rates reported nationally.[15] While half of Australians die suddenly from acute and unexpected causes, the remaining deaths are likely life-limiting illnesses, including cancer, dementia, and lung disease.[15-17] Notably, death is an expected outcome when diagnosed with a life-limiting illness. While the approach to death at the individual level is unique, medications play a critical part; symptom burden dominates the last phase of life.[18, 19]

This thesis aims to examine the roles of pharmacists, caregivers, and medications in caring for people living in the community with an advanced life-limiting illness. It does so by examining the contribution and significance of six previously published articles and examining the complexity of managing people approaching death using a conceptual model. Importantly, this thesis is a PhD by prior publication (PhD PP), a genre of PhD used by clinician-researchers like myself.[20] Unlike traditional approaches, the PhD PP involves selecting *"a series of peer-reviewed academic papers, books, citations, or other materials that have been published, accepted for publications, exhibited or performed, usually accompanied by a substantial commentary linking the published work and outlining its coherence and significance"*.[20](p2)

This chapter introduces the clinical, policy, and organisational context of delivering services for the dying in the community, focusing on the use of medications and the pharmacist's role.

Background

Globally, medications provide the most frequent health care intervention.[21] In general, clinicians employ medications for various reasons, including improving the quality of life, diagnosing, preventing or controlling chronic conditions, and managing acute symptoms.[1] As someone approaches the end of their life, this latter point becomes a key focus of medications.[22]

While poorly managed symptoms are likely to increase the burden on hospital systems, evidence shows that most people living with a life-limiting illness spend most of the last phase of their life in their home environment.[23-25] Someone's home environment may include a private dwelling, a clustered domestic model of care, or a residential aged care home (RACH).[26] However, people often require appropriate support to continue in their preferred place of care. Mitchell explains that support predominantly involves integration and coordination of services, adding that this is the skillset of primary care clinicians.[27] Just as medications have a significant part in managing symptom burden, their use is a complex process involving prescribing, dispensing, administering, and monitoring.[28] Indeed, managing medications in the home environment is a multidisciplinary concern, with primary care clinicians having a critical role.

While medications are a vital part of managing symptoms throughout the last phase of life, they can also contribute to medication-related problems (MRPs).[29-31] The Australian Commission on Safety and Quality in Health Care (the Commission) explains these as *"any event involving treatment with a medicine that (harms) a patient's health or prevents a positive outcome"*.[1](p79) Indeed, the literature provides good evidence of why MRPs are more prevalent in people in the last phase of life.[32]

People with a progressive life-limiting illness often take medications to manage various symptoms or prevent long-term conditions, resulting in polypharmacy and an increased risk of medication interactions. Likewise, comorbidities may impact the range of medications or doses that people can safely use to manage symptoms. Medications used to control one symptom can cause another. Adding medications to manage a symptom is referred to as a prescribing cascade.[33] With some increasing the risk of falls, the person may be at greater risk of harm from hip fractures.[34] Medication reconciliation has been acknowledged as an essential process in care transitions to prevent MRPs; older adults are more likely to experience multiple changes to their medications which can be confusing as they transition between acute and long-term care settings.[35-37] As the individual's function deteriorates, this challenges their cognitive and physical ability to manage their medications.[38] With the responsibility of managing medications in the home environment shifting to the caregiver, they are also likely to find this challenging as it may be something new or involve unusual routes of administration.[39-41] Finally, issues with swallowing and digestion can impact the ability to take solid oral medications, increasing prevalence in people with a stroke, head and neck cancers or neurological conditions.[42] Swallowing is also a significant issue in the last days of life.[43]

While successfully reducing MRPs is a multidisciplinary challenge, the literature is clear: given the growing proportion of older Australians living in the community, the pharmacist's role across primary care is crucial.[44, 45]

Building upon its origins in medication supply, the pharmacist's role has evolved considerably over recent decades.[46] Contemporary pharmacy practices are diverse, with pharmacists involved in various duties beyond the supply of medications, including clinical activities, clinical governance, education and training. In shifting beyond simply supplying medications, Hepler and Strand coined *pharmaceutical care*.[9] Described as *"the process through which a pharmacist cooperates with a* *patient and other professionals in designing, implementing, and monitoring a therapeutic plan that will produce specific therapeutic outcomes for the patient"*.[9](p534)they envisioned pharmaceutical care as critical in connecting the pharmacist with the broader multidisciplinary team. Some decades later, the literature continues to debate this term, with some authors adapting the term to match the local needs, considering various barriers and facilitators.[47] In reviewing the range of definitions, the Pharmaceutical Care Network Europe reviewed the range of definitions in 2013, concluding that pharmaceutical care is the "pharmacist's contribution to the care of individuals in order to optimize medicines use and improve health outcomes"(p552).[48]

Consider this against the term *medication management*. Medication management expresses the broader involvement of all levels of government, clinicians, the person, and their caregivers whose actions impact safe and appropriate medication use.[49-51] While this thesis will contain both terms, *medication management* will depict the broader multidisciplinary role of prescribing, purchasing, administering, regulating and monitoring medications. *Pharmaceutical care* will pertain to pharmacist specific tasks such as dispensing, clinical, governance, education, and training roles.

Traditionally, the term *community pharmacist* has been used to portray the pharmacist working in the community setting with a dispensing function. Indeed, it is a term used regularly throughout the six publications. However, given the expansion of the pharmacist's role beyond the dispensary setting, this term risks confusing the reader. Therefore, this thesis will use the term community pharmacist only if the location is a community pharmacy. When describing the broader role of a pharmacist delivering community-based services, such as medication management reviews, staff education and drug utilisation reviews, this thesis will employ the overarching term of *primary care pharmacist (PCP)*.[46, 52]

What is Palliative Care?

Since Dame Cicely Saunders's early work in developing the hospice model, various researchers have explored the value of services to provide palliative and end-of-life care.[23, 53-56] In doing so, authors have used "*palliative care*" and "*end-of-life care*" interchangeably in describing these services involved in the care provided throughout the last phase of life.[57] While multiple definitions exist, this introduces confusion in how these terms are used and understood.[3, 42, 57, 58] This thesis uses the definitions provided by Palliative Care Australia (PCA), the national voice of clinicians providing palliative care services. PCA differentiates these two terms as follows:[3]

> *"Palliative care is person 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 goal is to optimise the quality of life."*

> *"End-of-life care is the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death. The needs of patients and their carers is higher at this time. This phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the health care team is being delivered. This takes into account the terminal phase or when the patient is recognised as imminently dying, death and extends to bereavement care."*

While palliative care is an all-encompassing term, end-of-life care describes the last weeks or months of life. Furthermore, these definitions embed a third term known as the *terminal phase*. Associated with sudden and rapidly evolving symptoms and the loss of the ability to swallow solid oral formulations, medication management in the home becomes complex in the terminal phase.[59] Notably, these definitions provide a practical and temporal perspective of care incorporating the needs of caregivers and family members into bereavement.

However, Clark suggests that these high-level descriptors are flawed. They fail to acknowledge the many interrelated factors determining the operationalisation of palliative care.[57] Before examining the thesis publications, it is essential to address some potential ambiguities arising from definitional terminology. The term *family* can lack clarity, with the risk of confusing the critical connections for the person with the life-limiting illness. This thesis uses the broad encompassing term of *caregiver*, describing a *"person who provides unpaid support to another individual who needs it because of an underlying terminal illness"*.[1](p74) Funding ambiguity can also be associated with how governments and organisations deliver palliative care services. In comparison, the Australian Government funds all private organisations providing primary care services, while the state and territory governments fund specialist palliative care services (SPCSs). While the terminology designates the "*health care team*" role, disability and aged care teams also administer palliative care. The latter is particularly relevant to the publications associated with this thesis. Descriptions of "*increased services and support*" can fail to stress the multidisciplinary nature of these services and the need for collaboration. Multidisciplinary care discussed throughout this thesis may involve any arrangement of clinicians involved with medication management. These broad definitions can imply that the distribution of services is equal. The evidence shows that while SPCS extend throughout rural parts of the country, they do not share the resources of those based in metropolitan centres.[60, 61] Finally, it fails to illustrate the comprehensive approach to care. While this thesis examines the role of medications in managing symptoms, it will refer to *palliative needs* to designate the holistic needs of someone living with a life-limiting illness. Palliative needs include emotional distress, social isolation, poor quality of life, inability to communicate, and symptom burden.[62]

On a policy level, the Australian Government has developed several frameworks, accreditation, and policy documents to guide how services are delivered.[1, 51, 63-66] Developed in consultation with relevant stakeholder groups, the Australian Government intends that all tiers of government and private organisations and individuals use these to improve the delivery of services for all Australians. The National Palliative Care Strategy (NPCS) explains how governments, organisations and clinicians can operationalise palliative care through six guiding principles.[65] First, *palliative care is person-centred care*. People with palliative needs have specific concerns that change throughout their journey, impacting how organisations need an adaptive approach to delivering services.[67] Second, *death is recognised as part of life*. As such, services for people with a life-limiting illness need a tailored approach respecting the cultural and geographic diversity of the population; one size does not fit all.[41, 68] Third, *caregivers are valued and receive the support and information they need*. Caregivers are integral in managing support for someone with palliative needs, yet they can find this role challenging without appropriate assistance.[69] Fourth, *care is accessible*. All Australians living with a life-limiting illness need access to quality services, including access to support from organisations outside the traditional healthcare model.[54] Fifth, *everyone has a role to play in palliative care*. As not one discipline can provide all the support required, delivering services across this population relies upon the interconnectedness of a dynamic and collaborative multidisciplinary team that considers the person's holistic needs.[70] Sixth, *care is high-quality and evidence-based*. The evidence base is critical in providing strong feedback loops between the research and clinical aspects of care, ensuring that clinicians, organisations, and funders adapt and grow as the latest information emerges.[71]

Considering the limitations to the broader definitions provided by PCA, the NPCS' six guiding principles illustrate the delivery of contemporary palliative and end-of-life care services for all Australians.

While integrating and coordinating multiple services – including those provided by the government and private organisations – is critical to operationalising safe and efficient care for people with palliative needs living in their home environment, many other factors are at play.[72] Indeed, the term *"healthcare system"* is too limiting to encapsulate the entire delivery of effective palliative care for people in the community. Instead, we require a broader term to encompass all the elements. Lusch designates these large structures as *ecosystems*, defining them as *"communities of organisms interacting, over time and space, with other organisms and other elements in the system"*.[73](p2958) Braithwaite adds that the interacting living and structural components, where their relationships evolve with time, make ecosystems complex.[74]

This thesis uses the term *palliative care ecosystem* to illuminate the various elements involved in caring for people with palliative needs. Including the broader care team, the caregiver, and medications, the thesis will use this term to designate all the resources used to support care in the home environment. Furthermore, Chapter Two will introduce a conceptual model that aims to connect the components of the palliative care ecosystem while assisting in the understanding of how these components interrelate. This conceptual model will emphasise tensions, challenges, and opportunities to recognise which factors contribute to good medication management for people with palliative needs living within their home environment.

Underpinning the palliative care ecosystem is evidence-based practice (EBP).[75] Greenhalgh explains EBP as the *"conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients"*.[4](p2) From a clinician's perspective, sound scientific research justifiably guides decisions relating to how they treat an individual. However, issues such as availability of resources, limitations of time, the clinician's experience and the patient's values shade its application, defending the individualisation of EBP to suit the situation.[4, 76] While research guides EBP, the experience and needs of clinicians and their patients provide nuance in its application.

To date, Australian research evidence into delivering services across the palliative care ecosystem has scant references to medication management.[77] Given that people with palliative needs are vulnerable to MRPs, the lack of research evidence about medication management in this population is somewhat surprising.[32] Without ongoing research, the critical issues associated with managing medications in the home environment are not explicit, and the evidence on best practices remains inadequate. One of the fundamental challenges confronting governments from across the globe is how to ensure clinicians can manage people with life-limiting illnesses in their home environment.[54] Understanding the nuances of managing medications within the palliative care ecosystem is critical to this approach.

A Personal Note

In 2011, I joined the Southern Adelaide Palliative Services (SAPS), an SPCS in metropolitan Adelaide, in a new position. While there were several aspects to the role, the initial focus was to address a significant concern about accessing subcutaneous medications through community pharmacies for people in or entering the terminal phase. Failure to access these subcutaneous medications quickly through a community pharmacy resulted in uncontrolled symptoms, unplanned hospital admissions, and significant caregiver distress. With three decades of experience as a pharmacist with a strong interest in practice improvement, this role presented opportunities and challenges.

With time, I took on an additional role with the CareSearch project, based out of Flinders University. Federally funded, CareSearch consolidates online information about palliative care for clinicians, people living with a life-limiting illness, and caregivers. Providing a national perspective to palliative care, the role with CareSearch complemented the position within the SPCS.

As a clinician-researcher, I have identified *"real-world"* challenges involving medication management for people with life-limiting illnesses. While these challenges have considered the pharmacist's role in delivering pharmaceutical care across various settings, there has been a focus on caring for those with palliative needs in their home environment. Furthermore, over the last decade, I have taken the opportunity to publish these findings widely (see Appendix Seven).

At the beginning of this chapter, I stated the thesis aimed to examine the roles of pharmacists, caregivers, and medications in caring for people living in the community with an advanced life-limiting illness. In reviewing all these publications against this aim, six publications stand out (see Table 1).[78-83] They stand out because they describe the critical challenges, strategies and outcomes associated with delivering pharmaceutical care for the dying in their home environment.

Table 1. List of the Publications Making Up the Body of Work in this Thesis

Publication [78-83]	**Citation**
One	Tait, P., Gray, J., Hakendorf, P., Morris, B., Currow, D. C., & Rowett, D. S. (2013). Community pharmacists: a forgotten resource for palliative care. BMJ Supportive & Palliative Care, 3(4), 436–443.
Two	Tait, P., Morris, B., & To, T. (2014). Core palliative medicines: Meeting the needs of non-complex community patients. Australian Family Physician, 43(1/2), 29–32.
Three	Tait, P., Cheung, W. H., Wiese, M., & Staff, K. (2017). Improving community access to terminal phase medicines in Australia: Identification of the key considerations for the implementation of a 'core medicines list' Australian Journal of Primary Health, 23(4), 373–378.
Four	Tait, P., Sheehy, K., Sindhusake, D., & Muscillo, N. (2020). Factors affecting access to subcutaneous medicines for people dying in the community. Progress in Palliative Care, 28(5), 326–333.
Five	Tait, P., Chakraborty, A., & Tieman, J. (2020). The Roles and Responsibilities of Community Pharmacists Supporting Older People with Palliative Care Needs: A Rapid Review of the Literature. Pharmacy, 8(3), 143.
Six	Tait, P., Cuthbertson, E., & Currow, D. C. (2020). What Are the Factors Identifying Caregivers Who Need Help in Managing Medications for Palliative Care Patients at Home? A Population Survey. Journal of Palliative Medicine, 23(8), 184–1089.

Thesis Overview

This thesis examines the roles of pharmacists, caregivers, and medications in caring for the dying within their home environment. Furthermore, this thesis individually and collectively reconsiders the contribution and significance of the six prior publications and the complexity of managing people approaching death using a conceptual model. It, therefore, provides a window into critical issues faced by those receiving, providing, funding, and directing care across the palliative care ecosystem. Governments are identifying new models of care to improve the efficiency and affordability of care for the dying as the system is experiencing unprecedented change. Therefore, these new insights will be critical in informing how the system could adapt to the stressors of an ageing population and unprecedented numbers of people with palliative needs. In addition, it will pose new questions for academic and clinical researchers alike.

Table 1 lists these six publications in the order this thesis considers them.

This thesis divides into nine chapters.

Chapter One begins by providing the clinical, policy and governance structures underpinning this thesis. Next, the chapter lists and outlines various key terms used throughout the thesis, including *pharmaceutical care*, the *palliative care ecosystem* and *evidence-based practice*. A brief personal reflection follows, describing the beginning of working in an SPCS and at CareSearch. Finally, the chapter concludes with an outline of the thesis structure.

Chapter Two tells the role of complexity in the functioning of the palliative care ecosystem. Given this complexity, it is essential to show how it plays out to show the tensions inherent in delivering care. In addition, this chapter presents a conceptual model. In applying the conceptual model to the publications throughout the thesis, I discuss the various issues arising from each publication and frame the interplay between the parts of the system.

Chapter Three, the methodology chapter, explains the merits and challenges of the clinician-researcher role. It then, retrospectively, considers the *"real-world"* approach taken in developing this body of work with the philosophical underpinnings of the thesis. Finally, it closely appraises the methods employed across all six publications listing the merits and challenges of each within the clinical context.

Chapter Four begins with the issue of accessing medications through community pharmacies for managing terminal phase symptoms. It introduces the first two publications. Publication One presents results from a South Australian Community Pharmacists' questionnaire about their involvement with people with palliative needs. One of the recommendations was the need for a *Core Medicines List* – a specified list of medicines to guide prescribing and which medicines to stock. Publication Two considers the development of such a list.

Chapter Five explores Publications Three and Four, considering how organisations could operationalise the Core Medicines List in a multidisciplinary setting. Publication Three specifically considers the Core Medicines List from the multidisciplinary perspective, providing five factors for consideration in implementation. Publication Four returns to the viewpoint of the community pharmacist, demonstrating the role of a Core Medicines List at a broader policy level.

Chapter Six reviews Publication Five, which investigates the PCP's role in caring for people with palliative needs who receive services from an aged care organisation within their home environment. This chapter offers insights into how pharmaceutical care may support people with a life-limiting illness in the future- building a case for the earlier engagement of the PCP beyond their dispensing role.

Chapter Seven assesses Publication Six, which investigates the features of caregivers who may require assistance when managing someone's medications. Caregivers are essential partners as PCPs deliver pharmaceutical care for the dying in their home-dwelling.

Chapter Eight considers the six publications collectively, eliciting new understandings from examining these throughout the thesis. It provides three insights into the roles of pharmacists, caregivers, and medications in caring for the dying in their home environment. Additionally, Chapter Eight discusses their practical implications, provides future direction for researchers, and reflects on two critical concepts considered throughout this thesis: research within a complex ecosystem and the role of the conceptual model as a research framework.

Chapter Nine concludes the thesis, recognising the original contribution these published articles have made in the context of time.

CHAPTER TWO: COMPLEX SYSTEMS

"The world as we have created it is a process of our thinking. It cannot be changed without changing our thinking." Albert Einstein, theoretical physicist (1879 – 1955)

Introduction

The previous chapter introduced the palliative care ecosystem. While this term helps present a structure to fit the components associated with receipt, provision, funding and directing of services for people living with a life-limiting illness, it fails to provide the characteristics that demonstrate how various components interact. At the heart of all ecosystems is complexity.[74]

In this chapter, I will study how the components of the palliative care ecosystem interact through the lens of complexity. I will do so by reviewing the characteristics of complexity, including the involvement of high numbers of components, interrelatedness, and changes over time. In addition, I will explain how these characteristics are inherent within the palliative care ecosystem and investigate the issues associated with studying complex systems. Finally, I will present, discuss, and compare three conceptual models. Following this review, I will demonstrate how one of these satisfactorily describes the palliative care ecosystem. This model will form the basis of examining the publications that make up the body of work in this thesis.

Background

Over recent decades, there has been a considerable shift in how leaders think about healthcare services.[74] On the one hand, is the simple mechanistic approach describing how components fit together, and on the other is seeing these as forming part of a complex system. Understanding the differences between the characteristics of each approach is essential; their characteristics have important implications for researching how components interact and understanding change.

A simple mechanistic view of healthcare implies a single path between components to achieve the desired outcome.[84] It applies the approach taken to the automobile industry, which considers that the components exhibit rigid and predictable behaviours, and the outcomes will improve by focusing on the quality of the components.[74] Leaders take a top-down approach in mechanistic, linear processes to instil change, making modifications time-consuming. Like a conveyor belt, disruptions can shut down the entire process and cannot resolve at the local level.

While obtaining good outcomes in a simple mechanistic process depends upon the component's quality, complex systems rely upon the quality of the interactions *between* the components. Highly integrated components self-organise and form synergies in response to feedback loops.[85, 86] Through feedback, the components constantly learn about the system they reside in, which guides their adaption.[87] These feedback loops allow for evolution when most components collectively respond similarly. Like a school of fish, a disturbance (or innovation) in an individual component rapidly and unpredictably influences the behaviour of the collective. Peer interaction at the local level across the highly interconnected and interdependent components is a crucial feature of complex systems, making local adaptions to disruptions possible and timelier than a top-down approach. Furthermore, it also allows for evolution, which aims to enhance the ecosystem's efficiency by learning from and adapting to environmental changes.[84]

Decisions about influencing ecosystems are often complex and loaded with uncertainty. So while focusing solely on the components may seem logical, greater control of complex systems comes about through a better understanding of their interactions.

In publishing her account of the evolution of palliative care, Dame Saunders stressed the characteristics of complex systems. She recognised that understanding perspectives, addressing knowledge gaps, and seeking holistic solutions through effective feedback loops could improve care for people at the end of life.[53] For instance, while drug dependence and tolerance concerns initially hindered the management of cancer pain, research into the issues informed the evidence base, demonstrating what worked well and what did not. In publishing the evidence, Dame Saunders created a feedback loop that, in this case, challenged the link between cancer pain management and drug dependence, influencing practice change. Through international channels, the sharing and debating of this evidence resulted in most clinicians and researchers embracing the research. As the majority embraced the research, it became embedded in usual practice. In describing how techniques for pain management developed, she demonstrated the importance of feedback loops through highly integrated groups of researchers and clinicians in developing a majority perspective that drives change.

Over the last seven decades, the delivery of services for people with a life-limiting illness has substantially evolved.[88] While the care of the dying was once an extension provided through cancer specialists, palliative care is now an independent specialty area.[89] Over time, there has been a shift from only supporting people with cancer to including all with life-limiting illnesses, including dementia and end-stage organ failure.[42] As a result, the number of people under palliative services has increased. Delivery of services has expanded beyond just acute hospitals or hospices. Today they support people to remain in their home environment, necessitating greater collaboration between specialist and generalist healthcare providers.[27, 35] Care is often delivered earlier in the palliative journey, along with disease-modifying therapies.[42] As such, providers of palliative services have a more extended role beyond merely managing the terminal phase and can support the person and their caregiver for longer.

The evolving nature of palliative care demonstrates characteristics of a complex system and suggests that they will continue to influence its development. Examining the characteristics of interdependency, interrelatedness, and evolution can assist leaders, researchers, policy writers and funders to understand drivers within the system and respond to emerging challenges.

As a complex system, palliative care relies on multiple components to deliver thorough and safe services. Even though governments and organisations aim to organise services to align with clinical guidelines, organisational policies, government regulations and funding mechanisms, outcomes differ across the system.[90] We know this because researchers examining the broader system report significant unwanted outcomes.[85, 90, 91] Just as complexity helps us understand what went wrong, it also helps explain how systems can change.[92] Indeed, understanding change is paramount as leaders identify and address the problems inherent within the system.

Studying Complex Systems

With the palliative care ecosystem evolving, having a tool to map the connections can add value. Braithwaite has described repellents and attractors of change in healthcare and argues that change requires us to address the system's inherent complexity.[93] Just as mapping the connections is critical in developing research, it is also vital to understand it by emphasising the interplay between aspects of care delivery, such as policies that do not align with practice.[24, 75] Conceptual models can illustrate the ecosystem and provide a framework that co-locates complexity and solutions while supporting a thorough understanding of tensions that coexist.[94, 95] However, the literature wavers between support and criticism of conceptual models in research of complex ecosystems.[75, 96]

The main argument against using conceptual models in examining complex ecosystems is that they overly simplify the issue. Turner and Baker suggest that *"simple linear epistemology"* is too reductionistic.[84](p18) They conclude that the unpredictability of complex systems makes the use of conceptual models less reliable. Others suggest that a helpful conceptual model provides an overview of the components involved and their broad association.[97, 98] While seeing how components interact can highlight the connections and interplay, understanding the system through an in-depth analysis may be unnecessary.[84] An appropriate conceptual model highlighting the interactions and tensions between multiple components is critical in understanding complex systems, such as palliative care.

On balance, using a conceptual model that considers the complexity of the palliative care ecosystem would be a helpful tool. Such approaches have also been considered more broadly within the health policy context to explore the roles and services provided and the needs and contexts of those requiring health services.[99] Using a model within this thesis could provide structure to guide the examination of the six publications that make up this body of work while characterising the interplay between system parts. This latter point could, in turn, help identify new insights into these six publications.

Conceptual Models

As this thesis focuses on the roles of pharmacists, caregivers, and medications in support of the dying in the home environment, the choice of a conceptual model also needs to reflect matters intrinsic to delivering good palliative care. Chapter One introduced the NPCS, listing and describing the strategy's six guiding principles.[65] These underlying principles form a crucial consideration in selecting a model seeking to investigate the complexity of palliative care delivery. As part of the initial work in developing the publications' contextual statement, I explored three models addressing systems, context, and outcomes to consider the framing factors for palliative care provision as determined in the NPCS. Exploring these models in the initial preparatory work highlighted the possibility of using a model as a structure to review and analyse the individual studies. Additionally, it provides an opportunity to critically appraise the collective body of research to understand its value and insights into the palliative care ecosystem. The following section outlines each of these models.

Abel's *Circles of Care* model views healthcare through six levels of support (or domains) that sit at increasingly removed steps from the person living with the life-limiting illness (see Figure 1).[100] In designing this as concentric circles, Abel suggested that the dividers between the circles were permeable and may highlight an area of focus for clinicians as they coordinate services.

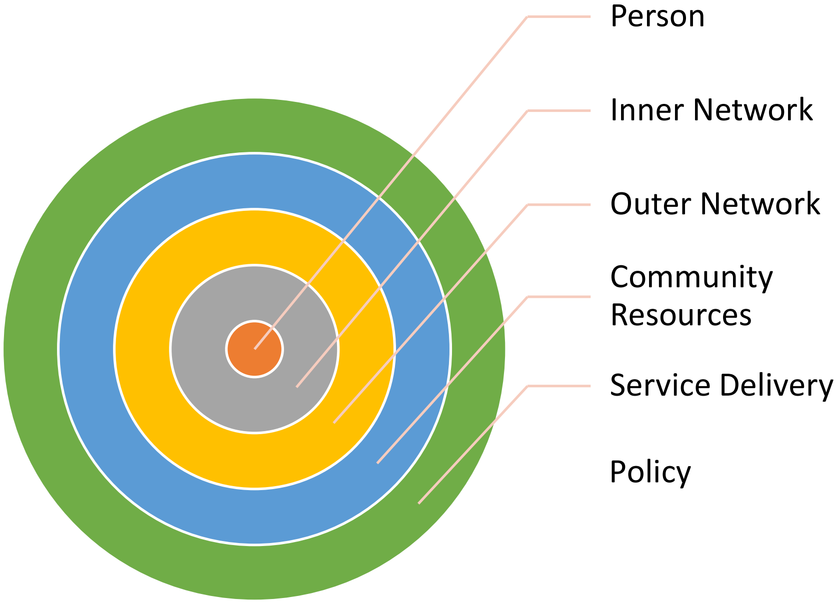

Figure 1. Circles of Care[100]

Designed around the caregiver's needs, this model suggests responses to gaps that need to be addressed by service providers, either by identifying supports within their existing network or by adjusting the policy frameworks that guide service delivery. In addition, it allows for discussion of the interplay between various domains. However, it fails to accommodate organisations indirectly involved in care delivery, such as the pharmaceutical industry. While Abel's "*Community Resources*" considers community organisations such as church groups and sporting organisations, it does not fit the intention of "*everyone has a role to play in palliative care*" highlighted in the NPCS.

In his *Conceptual Model of the Role Of Complexity in the Care of Patients with Multiple Chronic Conditions*, Grembowski rationalises that five broad domains contribute to patient needs and the ability to deliver services (see Figure 2).[101] Alignment between these influences the need-services gap. Using the five domains, this conceptual model depicts facilitators and barriers to increasing and reducing this gap. For example, "*Community Resources*" speak of partnerships between clinicians and organisations that sit outside healthcare's traditional view, including the media, the pharmaceutical industry, and organisations providing aged care. In addition to providing domains, this model also provides factors that mitigate this gap, including service mix, quality of care provided and health outcomes such as the person's function and well-being. Given that death is a reasonable and appropriate outcome for people with palliative needs, *"Outcome"* may represent a better term than *"Health"* for this population.

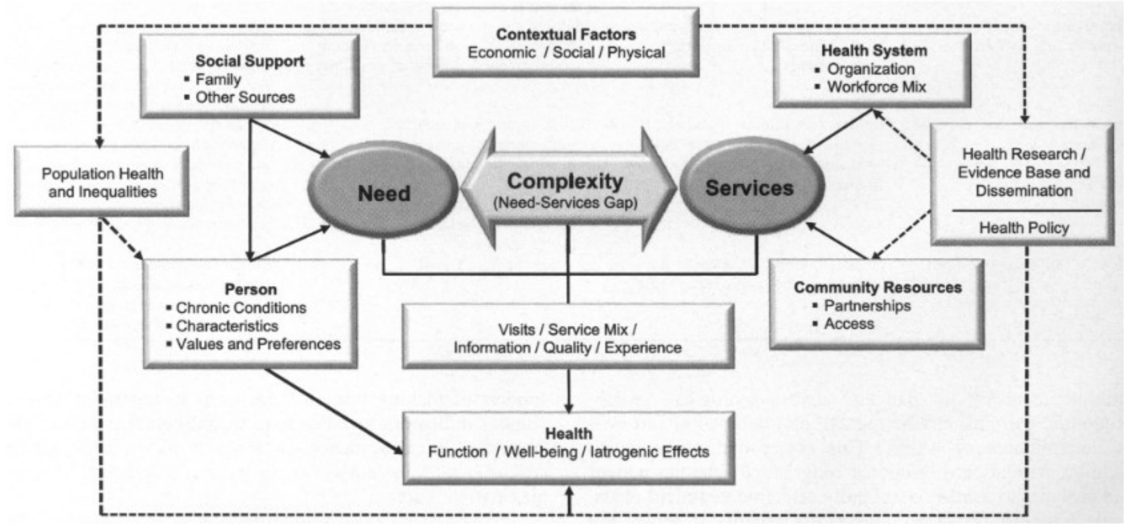

Figure 2. Conceptual Model of the Role of Complexity in the Care of Patients with Multiple Chronic Conditions[101]

Murali adapted Grembowski's model, arguing that it fails to address the services required to manage terminally ill adults with multiple chronic illnesses (see Figure 3).[102] Interestingly, in her adaptation, the *Conceptual Model of a Person with Critical Illness and Multiple Chronic Conditions*, she adds palliative care as a mitigating factor to improve service delivery which implies that it is an add-on service to mitigate the complexity. However, in Australia, generalist providers, such as the general practitioner (GP), nurse practitioner (NP) and PCP, are well placed to deliver care to people with palliative needs alongside SPCSs.[27] Furthermore, in Australia, "*Health System*" and "*Community Resources*", such as aged care, collectively deliver services for people living with life-limiting illnesses and their caregivers. Adding it as a mitigating factor could complicate the analysis.

Furthermore, Murali switched the term *"Health"* to *"Outcomes",* which she suggests better illustrates the relationships between the delivery of services and outcome measures for people living with a life-limiting illness, including *"costs"* and *"site of death".* Incorporating palliative care–specific outcomes is a constructive adaptation, acknowledging issues pertinent to a deteriorating population by focussing on supportive needs, such as psychosocial distress and care planning.[42]

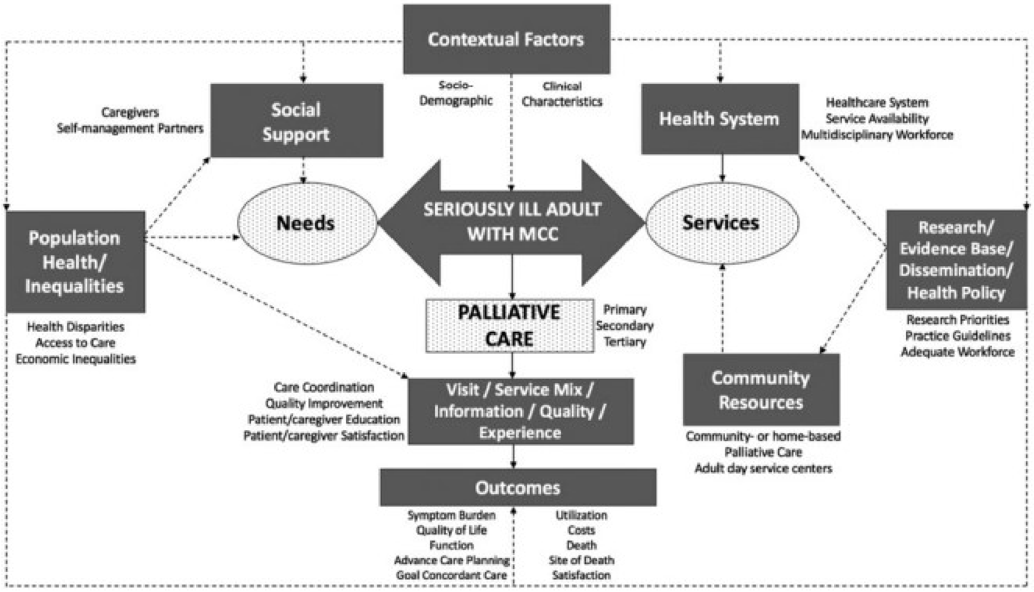

Figure 3. Conceptual Model of a Person with Critical Illness and Multiple Chronic Conditions. [102]

While these three conceptual models were considered, only one addressed all the principles outlined in the NPCS. Table 2 compares the three models against the six guiding principles identified in the NPCS.

Table 2. Mapping the Conceptual Model Descriptors Against the Guiding Principles of the NPCS

Conceptual Model **NPCS Guiding Principles**	**Abel's Circles of Care[100]**	**Grembowski's Conceptual Model of the Role of Complexity in the Care of Patients with Multiple Chronic Conditions[101]**	**Murali's Conceptual Model of a Person with Critical Illness and Multiple Chronic Conditions[102]**
Palliative care is person-centred care	Person	Person - Chronic conditions - Characteristics - Values and preferences	Needs
Death is a part of life	Policy	Contextual Factors (part I) - Population health and inequalities	Contextual Factors (part I) - Population health and inequalities
Caregivers are valued and receive the support and information they need	Inner Network and Outer Network	Social Support - Family - Caregivers	Social Support - Family - Caregivers
Care is accessible	Service Delivery	Health System - Organisation - Workforce	Health System - Organisation - Workforce

Conceptual Model **NPCS Guiding Principles**	**Abel's Circles of Care[100]**	**Grembowski's Conceptual Model of the Role of Complexity in the Care of Patients with Multiple Chronic Conditions[101]**	**Murali's Conceptual Model of a Person with Critical Illness and Multiple Chronic Conditions[102]**
Everyone has a role to play in palliative care	-	Community Resources - Partnerships - Access	Community Resources - Partnerships - Access
Care is high-quality and evidence-based	-	Contextual Factors (part II) - Health research - Evidence base & dissemination - Health policy	Contextual Factors (part II) - Health research - Evidence base & dissemination - Health policy

With strong similarities between the six guiding principles from the NPCS and the dimensions proposed by Grembowski's conceptual model, this appears to have the most robust capacity of the three models to characterise the resources that sit within and influence the palliative care ecosystem.[101] Furthermore, the subdomains could also help examine the depth of the published findings. Importantly, Grembowski has published two examples of how the model applies to the mapping of research outcomes.[101] Using the domains helps consider many of the practical applications of the research findings.

Therefore, the thesis will adapt the Grembowski model to underpin the reinterpretation of the published papers included in this thesis. This model offers a practical way to view pharmaceutical care for the dying and the interplay between aspects of the ecosystem.

Table 3 provides definitions for each of the domains and subdomains, ensuring that the model is applied consistently to each of the published papers which make up the body of work included in this thesis.

Table 3. Descriptors for Grembowski's Conceptual Model as Used in this Thesis

Domain	Subdomain	Descriptor
Contextual Factors	Population health and inequalities	Lacking equality or fair process in the sharing of assets or prospects.[2]
	Health research evidence base & dissemination	Evidence supported by peer-reviewed scientific research.[4]
	Health policy	An outline of the approach taken at the government or organisational level reflects the overall direction.[1]
Social Support	Family	Those nearest to the patient in understanding and consideration. While the family may include biological relatives, it may include a spouse or people from their friendship circle.[63]
	Other supports	Associations between people and the organisations they belong to assist in "making things happen".[103]
Person	Chronic conditions	Health condition or disease that has ongoing effects.[104]

Domain	Subdomain	Descriptor
	Characteristics	A distinguishing trait, quality, or property.[105]
	Values and preferences	The weight that a person puts on the health outcomes.[106]
Health System	Organisation	A publicly or privately funded institution providing healthcare services.[1]
	Workforce	All people employed by a healthcare service.[1]
Community Resources	Partnerships	A formally recognised relationship between organisations or individuals.[107]
	Access	Freedom or ability to obtain or make use of something.[108]

Chapter Three: Methodology

"Every thinker puts some portion of an apparently stable world in peril, and no one can wholly predict what will emerge in its place." John Dewey, philosopher, psychologist, and educational reformer (1859 – 1952)

Introduction

In research, the methodology is an essential consideration. It connects our understanding of the nature of the knowledge and how we develop knowledge by selecting methods that underpin the research.[109] In conventional PhDs, researchers consider the methodology initially.[20] In doing so, the elements underpinning the research align, ensuring academic rigour.

As a clinician-researcher, I have spent the past decade studying the roles of pharmacists, caregivers, and medications in caring for the dying in the home environment. The resultant studies have formed the foundations of published articles, blogs, and conference papers. While these connect through common threads, there was initially little foresight into how this journey would develop; each step was driven more by following opportunities and instinct than a planned strategy. However, despite this lack of foresight, the resultant work provided robust evidence addressing *"real-world"* dilemmas in delivering palliative care in the home environment.

In undertaking this PhD PP, I have selected six previously published papers from this extensive body of work for examination over the following four chapters.[78-83] Appendices One to Six contain their full text. Through selecting each, I considered their significant and original contribution to knowledge toward the *"real-world"* dilemmas faced by people with palliative needs. The collection of publications highlights various aspects of care for people with palliative needs. It is worth mentioning that the PhD PP is a unique approach to higher degree research in that it allows for the methodology for the body of work to be considered retrospectively. In considering the methodology retrospectively, there are opportunities to develop learnings around the philosophical underpinnings of conducting research.

This chapter explores the assumptions about the sources and the nature of knowledge, how they shape the research process, and how they have influenced the research reported in these six publications. First, by describing the role of the clinician-researcher, I establish the unique opportunities, challenges, and biases that influence the research journey. Then, using the *"real-world"* clinical circumstances and EBP as foundations, I discuss my new understandings regarding ontology and epistemology and how they underpin the research process. From this, I explain the retrospective consideration of pragmatism as the research methodology and its natural alignment with mixed-methods approaches. This retrospective assessment of the appropriateness of pragmatism allows for a discussion of its strengths and limitations. I then assess the specific qualitative and quantitative methods used throughout these six publications. Finally, I consider how examining these six publications against Grembowski's *Conceptual Model of Complexity in The Care of Patients with Multiple Chronic Conditions* will offer new insights.

Clinician-Researchers

With experience in delivering palliative care within the home environment, clinicians understand what needs doing, what works, and what can be improved. However, clinical experience alone is insufficient in solving these problems; integrating research into patient care is crucial.[110] Greenhalgh explains research as a *"focused, systematic enquiry aimed at generating new knowledge"*.[4](p3) While clinical research often develops from challenges in practice, clinical and research environments are inherently different.[111] As such, Groot argues the importance of collaboration between clinicians and researchers.[112] Inextricably tying clinical experience to good quality research is vital in managing problems that arise in the clinical setting.

As care models evolve, so too does the growth of clinician-researcher roles.[113] With direct exposure to *"real-world"* clinical circumstances, they support the linking of clinical and research communities while encouraging the development of clinically relevant research and embedding EBP into routine clinical care.[114] Furthermore, with established relationships with the clinical workforce and knowledge of the organisation's governance structures, they can *"make things happen"* by knowing whom to approach when challenges threaten the research integrity.[115] The clinician-researcher role is valuable in coordinating research within a clinical setting.

The published literature outlines the challenges for the clinician-researcher in integrating the two roles. With time constraints placing different values on clinical and research activities at professional and organisational levels, it can be challenging to achieve similar results to colleagues who work full-time in either setting.[116] Harvey suggests that clinical service pressures can lead to some clinician-researchers considering research as a personal priority rather than a workplace priority.[114] Furthermore, tensions can develop between the study's aim and the interests of all involved, including ethical dilemmas arising between the research outcomes, the participant's clinical needs and the organisational demands.[112] Indeed, clinical settings are notorious for the scarcity of resources, resulting in compromised funding of research activities.[116]

While challenges can hinder the research process, poor funding, time constraints, and perceived ethical challenges in the involvement of the people they see clinically and in research ensure the research strongly aligns with *"real-world"* circumstances.[116]

While resources, ethical dilemmas and time constraints provide limitations to which clinician-researchers need to adjust the research around, positionality provides insight into their biases which may skew the way they conduct research or limit their interpretation of the research findings.

Jacobson describes positionality as *"knowing what we are bringing to the research … helps us … see our data in productive, insightful ways and immeasurably furthers our capacity to do creative analysis and theorisation"*.[117](p2) This position extends to how researchers develop, conduct, analyse, and interpret their research. Where and how clinician-researchers position themselves provides a lens through which they examine the world.[117] Being conscious of positionality can reveal underlying biases, allowing recognition and mitigation.

In Chapter One, I considered my role as a clinician-researcher within the SPCS and CareSearch in more detail. In doing so, I provided evidence of the workplace circumstances and positionality while describing the opportunities, challenges, and biases they introduced into the research.

Retrospective Consideration of Methodology to the Published Research

The methodology provides a set of rules and procedures to drive the research while providing a framework for evaluating claims.[118] Oliver asserts that the clinical research methodology is *"based on this higher-order thinking and conceptualising of reality, and knowledge and the particular epistemologies will direct the nature of data collection method"*.[109] Within the research context, two distinctive aspects of reality influence the research's methodology. First, ontology considers *"what is the nature of reality?"*.[119, 120] Second, epistemology considers how individuals understand reality, including their thinking approach and how they believe others understand information.[121]

Bærøe argues that researchers need to establish a rational connection between ontology, epistemology and methodology, strengthening the scientific standing of their research.[122] Berman adds, *"it would be illogical for students to achieve the required standards unless they were able to frame their study appropriately, investigate a phenomenon thoroughly and assure the examiners that their work was new and* trustworthy".[123](p130) Understanding the methodology is essential because the ontological and epistemological assumptions shape the methodological decisions made throughout the research process. While the six publications discussed in this thesis link through common threads, the retrospective consideration of the methodology supports analytic rigour in examining the original research.

Ontology deals with what we believe can be known.[122] Over time, scholars have shifted their perspective of reality. While earlier scholars have understood the whole by studying its components, they now understand that the whole can be as significant as its parts.[124] The latter perspective aligns with the *"real-world"* clinical circumstances within which the clinician-researcher finds themselves working.[84] Generally, reality falls along a continuum between the objective and the subjective.[124] When researchers believe that reality is objective, they identify with only a single reality and place the research as external and separate: they are an invisible part of the research, observing the outcomes and reporting these objectively. Research questions around palliative care, especially medication effectiveness, are amenable to this approach as they provide specific results. For example, the research that studied opioids in managing dyspnoea is objective and has influenced medication practice and symptom management.[125]

On the other hand, where the researcher sees that reality is subjective, they identify multiple possible realities and immerse themselves within the research. The researcher is an active part of the research process, interpreting what they observe. Bærøe provides further support for this approach, explaining that in viewing the ontology through a healthcare lens, "*we cannot conclude directly from descriptive evidence how the world is compared to how it should be; additional, normative arguments are needed to take that step*".[122](p959) Bærøe resolves that while evidence is critical, the *"real-world"* dilemma of delivering healthcare necessitates its interpretation rather than strict adherence. This perspective aligns with the rational approach of a clinician-researcher needing to make research adapt to *"real-world"* circumstances.

In reflection, the ontological stance of this research on the management of medications for people living in the home environment with palliative needs was that of multiple possible realities.

Epistemology is the philosophical position describing ways of knowing. According to McNeill, it helps us understand what forms knowledge and its acquisition in developing a scientific understanding of any given experience.[122, 126] Furthermore, Nowell adds, *"knowledge is understood as being constructed based on the reality of the world we experience and live in and encompasses not only the reality of the past but also what is possible to create for the future"*.[127](p143) Knowledge helps us to manage interactions throughout our surroundings. While most scientific knowledge stems from clinical research conducted on a broad population, clinical decisions involve knowledge of the results of treatments on individuals.[76] Chapter One considered EBP in detail, describing it as incorporating scientific knowledge, the clinician's experience, and the individual's values.[4] Kochovska depicts the researcher's role in EBP as the *"ability to target a defined and reproducible population representative of broader populations or clinical care settings to optimise generalisability"*.[128](p458) Also, by bringing a *"lived"* understanding of these issues, the clinician-researcher connects research with the *"real-world"* and bodes well in furthering EBP.[116]

In retrospectively considering my approach to this research, the epistemological stance involves EBP.

Pragmatism

At the heart of all the research were issues associated with complexity. While Grembowski's conceptual model demonstrates the interplay between the system's policy measures, commercial drivers, and the individual's needs, these are everyday concerns experienced within a *"real-*

world".[78, 83] Furthermore, challenges faced in the clinical environment lend themselves to being addressed using problem-solving techniques through the principles of pragmatism.

According to Dewey, pragmatism is underpinned by experience while providing practical approaches to problem-solving.[129] Significantly, pragmatism goes beyond problem-solving, with Dewey stressing the emotional part, which provides a vital connection involving thoughts and actions, solving practical problems within a *"real-world"* environment. From this stance, a pragmatist approach is where the researcher uses whatever method suits the question and the available data. As Dewey puts it, this research aims to do *"what works"* while gathering *"human experience"*.[129] As such, pragmatism best describes the approach to the design and planning of the original studies.

Remarkably, given its complexity, there is a paucity of published literature on how PCPs apply pharmaceutical care to people with palliative needs and caregivers.[77] Furthermore, working clinically, I saw the practical challenges in how PCPs deliver care across the palliative care ecosystem. While I watched my peers working in the SPCS apply workarounds to these challenges, the lack of measurement and objectivity concerned me. These concerns led to me wanting to measure the problems I saw and inform EBP. Indeed, my clinical experience brought a *"real-world"* understanding of how PCPs provide pharmaceutical care for Australians living with a life-limiting illness.

Complex problems lend themselves to a mixed-methods approach, whereby quantitative and qualitative data are desirable to answer the research questions: using the most suited research method to address *"real-world"* problems.[130] As Greenhalgh explains, *"it is important to understand that not everything can be known or discovered through one way of looking at the social world; therefore, by combining methods, knowledge that is not accessible through using one method alone can be gained by the employment of a mix of methods"*.[4](p89) Augmenting the merits of quantitative and qualitative research methods, mixed-methods provide an opportunity to build a body of work that contributes to a broader picture while enhancing and validating the initial research findings. The mixed-methods approach strengthens this work, enabling a more thorough description of the palliative care ecosystem while increasing the result's rigour and validity. Importantly, it speaks of the pragmatic need to consider clinically relevant issues from various perspectives.

Examining the Published Research

While I wrote each of the six publications individually, they result from three separate threads. Before outlining these threads, Table 4 outlines the methods used for each of the six publications. I will group the publications into quantitative and qualitative methods to support a discussion.

Table 4. Aim, Research Methods, Population, and Analysis Approach for the Six Publications

Publication[78-83]	Aim	Research Methods	Population	Analysis
1. Tait, P., Gray, J., Hakendorf, P., Morris, B., Currow, D. C., & Rowett, D. S. (2013). Community pharmacists: a forgotten resource for palliative care. BMJ Supportive & Palliative Care, 3(4), 436–443.	Provide objective baseline data to identify gaps that may exist in the timely access to palliative medicines for patients being cared for within the community and consequently recommend strategies for improvement.	Observational. Quantitative using an anonymous structured questionnaire posted to all (455) registered community pharmacies in SA, using MCQs and free text.	105 pharmacists working in community pharmacies from throughout SA.	Wilcoxon rank-sum (Mann-Whitney) test, c2 test, logistic regression, multiple logistic regression.
2. Tait, P., Morris, B., & To, T. (2014). Core palliative medicines: Meeting the needs of non-complex community patients. Australian Family Physician, 43(1/2), 29–32.	Describe the development of a core medicines list, which is aimed at guiding prescribers, community nurses and pharmacists in supporting the care of patients in their homes, during the terminal phase of life.	Qualitative using a focus group of multidisciplinary clinicians working across three SPCSs in Adelaide. I used a broader review group to validate the results.	Seven participants from SPCSs, including a palliative care director (with a social work background), palliative care consultant, two NP Candidates and three palliative care pharmacists.	Consensus from an expert group, using published criteria.[131]

Publication[78-83]	**Aim**	**Research Methods**	**Population**	**Analysis**
3. Tait, P., Cheung, W. H., Wiese, M., & Staff, K. (2017). Improving community access to terminal phase medicines in Australia: Identification of the key considerations for the implementation of a 'core medicines list' Australian Journal of Primary Health, 23(4), 373–378.	Identify and describe the considerations for the implementation of the list to improve access to medicines for people who wish to remain in the community (including RACHs) during the terminal phase.	Qualitative using three focus groups of MDT clinicians working across SPCSs, primary care and ambulatory services in Adelaide.	26 clinicians – six doctors, six pharmacists and four nurses - from SPCS and primary care	Thematic analysis by two independent researchers.
4. Tait, P., Sheehy, K., Sindhusake, D., & Muscillo, N. (2020). Factors affecting access to subcutaneous medicines for people dying in the community. Progress in Palliative Care, 28(5), 326–333.	Identify the (1) proportion of community pharmacies stocking formulations useful in managing all six terminal phase symptoms and (2) factors associated with stocking a broad range of medicines, across two Australian states.	Observational. Quantitative using an anonymous structured survey distributed to all (2,440) registered community pharmacies across SA and NSW. MCQs and free text.	729 pharmacists from community pharmacies throughout SA and NSW.	c2 test, Descriptive statistics, Fisher exact test, logistic regression, multiple logistic regression

Publication[78-83]	Aim	Research Methods	Population	Analysis
5. Tait, P., Chakraborty, A., & Tieman, J. (2020). The Roles and Responsibilities of Community Pharmacists Supporting Older People with Palliative Care Needs: A Rapid Review of the Literature. Pharmacy, 8(3), 143.	Identify international published literature that describes the roles and responsibilities of community pharmacists supporting older people receiving HC or RAC with their palliative care needs, to synthesise key themes emerging from the data, as well as identify any gaps in knowledge.	Qualitative using a rapid review of the literature.	Fourteen publications researching the pharmacist's role in managing palliative needs for the aged in the home environment.	Thematic analysis by two independent researchers.
6. Tait, P., Cuthbertson, E., & Currow, D. C. (2020). What Are the Factors Identifying Caregivers Who Need Help in Managing Medications for Palliative Care Patients at Home? A Population Survey. Journal of Palliative Medicine, 23(8), 184–1089.	Determine whether any clinico-demographic factors identify caregivers who perceive they need additional support in managing medicines.	Observational. Quantitative using an anonymous face-to-face, cross-sectional, whole-of-population, multistage, systematic clustered area sampling survey. Survey participants came from throughout SA.	1085 respondents acknowledged that more assistance would have been practical when managing medicines for someone with a life-limiting illness.	Logistic regression, multiple logistic regression.
Abbreviations: home care (HC); multiple-choice questions (MCQs); New South Wales (NSW); nurse practitioner (NP); residential aged care (RAC); residential aged care home (RACH); South Australia (SA); Specialist Palliative Care Service (SPCS)				

Threads

In working across a SPCS and the CareSearch project, I had an opportunity to consider various local and national perspectives on how clinicians work across systems to deliver palliative services. First, *"Access to Medications"* broadly considered the reliability of accessing subcutaneous medicines through community pharmacies and was linked with the first four publications.[78-81] Collectively, they identified the size of the problem, offered a strategy to tackle the issue, provided insights into key considerations in rolling out the strategy and demonstrated patterns and outcomes. Second, *"Older people with palliative needs receiving aged care services in the home environment"* formed the basis of Publication Five.[82] While this publication focused on PCPs' roles in supporting older people receiving home care (HC) and residential aged care (RAC), it shifted the focus to care provided at various points of the palliative journey beyond the terminal phase. Third, *"Caregivers"* was the basis of Publication Six, which analysed the South Australian Health Omnibus Survey (HOS) findings.[83] In analysing the data set from SA, this project aimed to understand better the types of caregivers that need more significant support in medication management when caring for someone with a life-limiting illness.

Quantitative Research

Quantitative research methods rely upon a designed approach to sampling and data collection.[4] In addition, researchers use statistics to understand the findings to answer a specific problem or evaluate an approach. While the reasoning of quantitative research is deductive, its strength is in the reliability of the findings. Reliability is the ability to obtain similar measurements when repeatedly applied.[7] Publications One, Four and Six employed quantitative observational studies.[78, 81, 83]

With observational studies, the researcher examines events as they happen without attempting to make changes.[4] Observational study designs include descriptive, diagnostic accuracy, epidemiological, systematic reviews and meta-analysis. Publications One, Four and Six used a descriptive study design: describing a sample and comparing groups by their characteristics. Usually, the data collection method of descriptive studies is through questionnaires. Through their ability to predict any significant association between groups within the sample, descriptive studies are valuable in assisting health service development. For instance, researchers can use demographic or geographical information to compare subgroups within the sample to identify if these factors influence the outcome of interest. As a clinician-researcher, this approach was attractive, providing a practical and economical way of approaching the problem strategically while demanding little time to conduct and analyse.

Publications One and Four employed a bespoke questionnaire to understand the range of formulations stocked in community pharmacies helpful in managing terminal phase symptoms.[78, 81] A bespoke questionnaire was necessary as national coding systems fail to combine Pharmaceutical Benefits Scheme (PBS) and non-PBS dispensing data in Australia. Without a national dataset capable of capturing dispensing data of medications used to manage terminal phase symptoms, it is challenging to see the breadth of the issue at the population level. Furthermore, while pharmacists dispense using electronic software, unconnected dispensing programmes are used, with no single data repository. In developing a bespoke questionnaire, I had the opportunity to connect information that had otherwise been a challenge to link. For example, the questionnaire asked about patient-level pharmacy services (e.g., home delivery), pharmacy demographics (e.g., postcode), and stock holdings of various subcutaneously administered medications. Through the connection of information, I could perform a separate analysis of subpopulations, such as pharmacies with a formal link with RACHs. While a bespoke questionnaire was necessary, it allowed linking the data to identify influences on the range of subcutaneous medications stocked. Both studies were of an appropriate sample size to represent the population of interest.

Publication Six detailed the South Australian Health Omnibus Survey (HOS) findings relating to caring for someone with a terminal illness in the home environment.[83] Designed to assess health-related behaviours throughout the population of SA, the HOS provides researchers with the opportunity to purchase questions and compare the answers across the demographic details collected. Importantly, the survey was standardised and validated while employing the exact wording over the data collection period. Furthermore, the results apply to the broader population as the HOS was a significant representative state-wide survey. While using an alternative measure such as a focus group or a series of interviews would gain rich data resulting in themes, we could not have answered the research question with such rigour. Furthermore, as a clinician-researcher, I could interpret the findings against experience in supporting people with palliative needs and their caregivers.

Qualitative Research

Qualitative research methods reflect the participants' and researchers' subjective understanding and expertise.[4] Nevertheless, they examine the issue in detail. Valuable to discover and explore ideas, qualitative research relies on the ability of the researcher to observe and interpret the various issues that arise. While the reasoning is inductive, its strength is in the truth value of the findings.[132] Truth value is improved when the researcher combines methods (known as triangulation), understands how their own biases influence the data interpretation (reflexivity) and work in combination with other researchers to interpret the data (inter-rater reliability).[4] Publications Two, Three, and Five used qualitative research methods through a focus group or rapid review.

Focus groups have been increasingly used in clinical research to gather greater detail of an issue with the benefit of the swiftness of data collection and reduced face-to-face researcher-participant contact.[133] Greenhalgh distinguishes a focus group as a *"method of group interview that explicitly includes and uses the group interaction to generate data"*.[4](p36) While face-to-face interviews are similar research methods, the notion of group interaction critically separates focus groups.[134] Parker argues that the group interaction afforded to focus groups provides transparency in the decision-making process, determines a range of opinions, and provides insights into how different people (or professions) perceive a situation.[133] With stronger personalities driving the debate, group interaction can be harmful, too. Parker adds, *"this becomes even more important if there are significant differences in social characteristics between individuals in the focus group"*.[133](p32) The ability to conduct and analyse the discussions from the focus groups promptly made this method valuable for the research underpinning Publications Two and Three.

Developing a Core Medicines List (the List) to guide clinicians from SA on which medications to prescribe and stock in community pharmacies was a key recommendation from Publication One.[78] Its development employed a three-pronged approach, strengthening its rigour.[79] First, an expert group debated the selection of formulations for the draft List. They comprised a multidisciplinary group of pharmacists and prescribers representing three SPCSs across metropolitan Adelaide. Second, a more extensive review group comprising pharmacists, nurses, and prescribers in SPCSs and private settings critically reviewed the drafted List. The key to this review was that the expert group asked them to offer published evidence supporting any claims made in their feedback. Third, the expert group reviewed all feedback anonymously, ensuring the discussion was not biased by who provided the feedback.

Employing this approach allowed for robust debate within the expert group while ensuring all stakeholders had an opportunity to highlight concerns. To guide the discussion, the expert group used Rowett's work on the history of palliative care and the PBS to build patient-centred guiding principles against which to cross-reference all the decisions.[131] The use of guiding principles was in response to criticism of previous attempts to create a consensus list: failure to consider person-centred issues such as the cost for the consumer.[136] This guided consensus, ensuring that recommendations considered the consumer cost. Furthermore, the involvement of private providers, such as GPs, in the review group informed the final decision.

While the List development intended to guide communication between prescribers caring for people in the terminal phase in the home environment and community pharmacists, Publication Three considered alternative applications.[80] The robust multidisciplinary debate that evolved from the focus groups, highlighting the interconnectedness between disciplines, strengthened this publication. While using an alternative measure such as a series of interviews would gain rich data resulting in themes we would not have gained from such rich and constructive debate. Concerned that the clinicians would dampen caregiver voices in the room, I deliberately omitted caregivers from the focus group. Still, I noted apparent professional differences, with pharmacists holding back and preferencing the voice of the medical officers.

Publication Five detailed the findings of a rapid review I conducted while working on the End of Life Directions for Aged Care (ELDAC) project.[82] Designed to assess the community-based pharmacist's role in supporting people with palliative needs receiving aged care services, it provides an overview of the published literature. Featherstone proposes that rapid reviews are *"intended to synthesise available evidence and meet the time constraints of healthcare decision-makers"*.[137](p1) They are well suited for new or emergent problems and use systematic review methods in assessing the published evidence.[138] The strengths of this study approach include using a librarian to conduct the initial scan of the literature and having two researchers independently assess the publications. Access to software such as the web-based Covidence systematic review management system allowed the researchers to maintain independence as we assessed the publications. Notably, the PCP's role in supporting people with palliative needs receiving aged care services is a new and emerging area of research. A more resource-intensive systematic review would have been more appropriate if the initial search had identified more publications. On reflection, the rapid review methodology was appropriate given the resource constraints and the number of publications on the issue.

Opportunities to study the roles of pharmacists, caregivers, and medications in caring for the dying in the home environment and interpret the findings were possible because of my role as a clinician-researcher. Data access through the local hospice meant I could identify the commonly prescribed formulations helpful in managing terminal phase symptoms. This data was vital to informing the final list of formulations used in the questionnaire in Publications One and Four.[78, 81] Sharing a professional rapport contributed to the ease of recruiting peers to the focus groups used for Publications Two and Three.[79, 80] It also provided credibility in distributing the questionnaire that formed the basis of Publications One and Four.[78, 81] Publishing my experiences built a reputation as an expert in medication use in people with palliative needs. As a result, I was invited to various clinical forums to share my experience, and Publication Four evolved from the discussions with the New South Wales (NSW) Clinical Excellence Commission (CEC).[81]

Pragmatism was a driver for conducting the research underpinning these publications. With cost restraints at the forefront, I approached these challenges creatively and inventively, ensuring the studies succeeded. The discussion for all publications profited through understanding the Australian health experience and its challenges.[78-83] The clinician-researcher role significantly influenced the six publications and will continue to provide strength as I investigate these in greater detail throughout the subsequent chapters.

Using Grembowski’s Conceptual Model

A PhD PP enables a critical reflection of completed work and an opportunity to collectively re-examine and reconsider their findings to discover new insights into the palliative care ecosystem.[78-83] Using a structured framework to critically analyse the characteristics and contributions of the collected studies offers a mechanism for assessing the study in terms of its design, findings, and impact. Grembowski's *Conceptual Model of the Role of Complexity in the Care of Patients with Multiple Chronic Conditions* identified five domains, including *"Contextual Factors”, “Health System”, “Community Resources”, “Person”,* and *“Social Support"*.[101] In addition, there are twelve subdomains. This model provides a framework against which I can review each publication - identifying how the research has contributed to a system of care addressing the role of the PCPs in providing pharmaceutical care for the dying and their caregivers.

I will use this conceptual model throughout the thesis in three ways. First, in critically reflecting on the findings within the six publications, I will use Microsoft® Excel to match these against Grembowski’s five domains and twelve subdomains. Using the functionality of Microsoft ® Excel, I will graphicly represent the weights applied to each domain and subdomain by counting the number of times the finding applies to each. As such, I will produce a series of concentric circle diagrams for each chapter that illustrates the weight of the findings. Second, using the concentric circle diagrams, I will identify and reflect upon the relative weights provided within the publications to the various parts of the conceptual model while discussing the tensions identified and the future research opportunities it may uncover. Lastly, in collectively reviewing these tensions, the discussion chapter will identify emergent patterns throughout the thesis as three clear overarching themes emerge.

In selecting these six publications and examining their meaning against Grembowski's conceptual model, I demonstrate an insight into the complexity underpinning pharmaceutical care for the dying.

Significance of the Findings

Writing this chapter has demonstrated how my clinician-researcher role has influenced the evidence to better understand the palliative care ecosystem. Using Grembowski's conceptual model, which examines the need-services gap, provides a framework to explore these six publications and offers a special and unique lens for researchers to consider clinical and pragmatic research.

The lack of a mechanism to link dispensing data required the development of a bespoke questionnaire to measure access to formulations through community pharmacies. As a result, Publication One is the first to objectively specify the issues faced by community pharmacists when presented with a prescription to manage terminal phase symptoms. Using the same questionnaire, Publication Four demonstrates the changes observed with the rollout of the List in SA. Similarly, the lack of ability of community pharmacy staff to anticipate which medications they could stock, which would help manage terminal phase symptoms, necessitated the development of the List. Using pragmatic criteria against which to develop the List ensured the formulations stocked by community pharmacies were also affordable. Given that there are multiple ways that medications are employed to manage the terminal phase, Publication Three provides an account of a multidisciplinary focus group illustrating the issues and opportunities in operationalising the List into various practice settings. While this group shored up support for diverse ways to use the List in practice, it was crucial to understanding clinicians' issues in the processes underpinning the management of terminal phase symptoms in an Australian environment.

With the growing use of aged care services in Australia, understanding the role of PCPs in supporting people with palliative needs is critical. Publication Five used rapid review techniques to organise and theme the growing literature on the issue.

Finally, while authors have told of the caregiver's burden in managing medications previously, the use of the HOS was unique in describing the characteristics of South Australian caregivers who have noted challenges in managing medications in the terminally ill.

CHAPTER FOUR: NEEDLES AND HAYSTACKS

"If you think of standardisation as the best that you know today, but which is to be improved tomorrow; you get somewhere." Henry Ford, industrialist (1863 – 1947)

Introduction

When asked about the place of death, most Australians wish for their own home.[139] While this is feasible for many, they require access to timely symptom control, ensuring comfort throughout the terminal phase.[43, 140] It is reasonable for those caring for people living with a life-limiting illness to expect the terminal phase and plan accordingly.[56, 141] As medications have a crucial role in managing the expected symptoms, it is appropriate to access these close to home. Prescribers from general practice and SPCS have access to the same range of medications to manage terminal phase symptoms - the difference is where their prescriptions are received.

General practice plays a crucial role in supporting those in or approaching the terminal phase, particularly GPs, in prescribing medications useful for managing anticipated symptoms.[27] Importantly all GP prescriptions are valid at community pharmacies, with the PBS subsidising most formulations. With limits on what it can subsidise, the PBS is a finite list of formulations. For instance, the PBS lists injectable morphine formulations helpful in managing pain in the terminal phase. As a result, the consumer pays a modest co-contribution with the PBS subsiding the cost. On the other hand, for non-PBS analgesics, such as fentanyl injection, the consumer pays the total cost if the prescriber chooses to prescribe this. So, while GPs can contribute to symptom management into the terminal phase, the out-of-pocket costs incurred depend upon which medications they prescribe.

Like GPs, prescribers working in an SPCS have access to all elements of the PBS, with similar cost implications for consumers. Prescribing from the PBS is helpful in the outpatient clinic, at discharge from the hospital and when visiting the person in the home environment. However, as state and territory governments fund SPCSs, their prescriptions are also accepted at publicly funded hospital pharmacies. Having prescriptions accepted at either community or public hospital pharmacies has significant consequences for the costs of non-PBS medications. For example, when public hospital pharmacies dispense both PBS and non-PBS medications, a subsidy is applied, with the state and territory governments subsidising the latter. While access to medications through either community or hospital pharmacies improves affordability for people supported by SPCS, this presents inequalities for people assisted by general practice, such as those living in regional communities.

It is reasonable to want to die with dignity and with loved ones at home. For Australians, dying at home is achievable through the assistance of either their general practice, the local SPCS or both.

This chapter will argue that regardless of who coordinates services, community pharmacists are integral in the supply of medications helpful in managing symptoms into the terminal phase.

Background

In addition to accepting prescriptions from both SPCS prescribers and GPs, community pharmacies have a range of qualities that make them fundamental in supplying medications to all Australians.[142] With over 5700 registered community pharmacies across the country, there are two per postcode on average, benefiting more people living in urban spaces. Compared to the 693 public hospitals, with many of these being without an onsite pharmacy, community pharmacies are more convenient to access. Previous studies demonstrate that Australian community pharmacists are also eager to support people with palliative needs and caregivers.[143] Despite their eagerness, they identified that developing more effective communication skills was needed to fulfil this role. Several services offered by the community pharmacy can complement their dispensary.[144] For instance, home delivery of medications can be helpful as reduced function limits people’s ability to leave home.

With proximity, eager staff, and assorted services on offer, complementing the dispensing role, community pharmacies are a valuable resource for people with palliative needs and caregivers.

The literature documents the symptoms commonly encountered in the terminal phase, including dysphagia, fatigue, and pain and appropriate ways to manage them.[136] Critically, dysphagia results in the need for people in the terminal phase to have medications administered subcutaneously. Pragmatically, the Therapeutic Guidelines Group have published Australian consensus palliative care evidence-based practice guidelines, complete with subcutaneous dosing guidance.[42] It lists an extensive range of medications, equating to over 40 unique formulations that GPs or SPCS prescribers could use in managing terminal phase symptoms. Given the various groups using injectable medications in a hospital environment, public hospital dispensaries can easily justify stocking this broad range of formulations helpful in managing terminal phase symptoms. On the other hand, pharmacists would struggle to justify stocking such a broad range in their dispensaries with fewer reasons to employ injectable medications across community care.

In Australia, the PBS provides a key role in ensuring medications are available to all Australians in an affordable way, underpinned by data demonstrating safety, quality, and effectiveness. Listing a formulation on the PBS is traditionally guided by the pharmaceutical company (or sponsor) and requires two stages. First, the sponsor submits evidence of the formulation's safety, quality, and effectiveness to the Therapeutic Goods Administration (TGA) for evaluation. The TGA only approves the use of formulations for the indication, route and population for which the sponsor provides evidence.[2] Second, once the TGA approves the formulation for use in Australia, the sponsor can apply for listing on the PBS through the Pharmaceutical Benefits Advisory Committee

(PBAC). The role of the PBAC is to compare the sponsor's application with any other medications listed on the PBS, with listing dependent upon cost-effectiveness data. Notably, prescribers can use medications beyond the circumstances of the registration by the TGA or PBAC, such as in an unlisted indication. Prescribing medications in this way is termed *off-label prescribing*.[145]

According to the published literature, off-label prescribing is common when prescribing for people with palliative needs; sponsors often exclude this population from the research that underpins the medication's quality, safety, and effectiveness.[145, 146] While it is often clinically appropriate, the lack of PBS subsidy results in out-of-pocket expenses when accessed through a community pharmacy.[147] While dispensing prescriptions from an SPCS prescriber at the local public hospital can overcome the costs associated with off-label prescribing, further travel would likely be required. Australian community pharmacies can supply a range of medications to manage terminal phase symptoms, including those prescribed off-label, albeit with associated out-of-pocket costs.

In response to the issue of off-label prescribing, the Australian Government has led reforms to how the PBS lists medications. An independent assessment by the PBAC has granted a range of formulations, already approved by the TGA, eligibility for PBS subsidy when prescribed for people with palliative needs.[131] This process is particularly suited where research on medication use develops post-marketing.[148] As a result, the PBAC has created a subsection of the PBS, known as the PBS Palliative Care Schedule. It provides a mechanism to improve further the PBS availability of medications helpful in managing terminal phase symptoms in the home environment. As the variety of medications on the PBS Palliative Care Schedule increase, the advantage of access to hospital dispensing of medications prescribed off-label decreases.

It is a decent public health approach that enables people in the terminal phase to obtain professional assistance in their home environment.[5] For Australians living with a life-limiting illness, dying in their home environment is achievable; appropriate planning ensures the availability of practical support.[140] People can take all prescriptions to the community pharmacy for dispensing, regardless of who writes the prescription. Significantly as the government reduces the barriers to the funding of medications in people with terminal phase symptoms, the community pharmacy will be an economical option. The publications associated with this chapter (Publications One and Two) identify the need for and describe the development of a standardised list of medications to guide conversations between community pharmacists and prescribers in managing terminal phase symptoms within the home environment.[78, 79]

Publications Associated with this Chapter

In 2011, shortly after commencing with the SAPS, peers approached me with criticisms about the community pharmacies across the region. Not all community pharmacies could immediately supply urgently required medications to manage terminal phase symptoms despite receiving appropriately written prescriptions. Instead, the pharmacist would offer to order stock the following day or send the caregiver to another pharmacy. In accessing medications through community pharmacies, caregivers found it hard to find one with stock, travelling between multiple pharmacies before finding what the prescriber ordered. This delay in getting the medication to the home would hold up the caregiver's education in administering the medications and contribute to poor symptom control.

There are two publications associated with this chapter. Publication One reports on a questionnaire provided to all community pharmacies across SA to gather their perspective in managing terminal phase symptoms.[78] It aimed to provide objective baseline data to identify gaps in the timely access to useful formulations in managing the terminal phase, while recommending strategies for improvement. Publication Two describes the development of a concise list of core medicines that can provide symptom control in non-complex patients in the terminal phase.[79] For context, Box 1 and Box 2 provide each abstract, while Table 5 and Table 6 provide the publication findings, and recommendations. Appendices One and Two provide the entire publications.

Publication One

Timely access to medicines within the community is important for palliative patients where their preferred place of care is the home environment. The objective of this observational study is to establish baseline data to quantify the issue of poor access to medicines for symptom control in the last few days of life. The list of 13 medicines was generated from medicine use within a metropolitan palliative care unit. A survey was designed to determine which of these 13 medicines community pharmacies stock, the expiry date of this stock, awareness of palliative care patients by community pharmacists and basic demographic characteristics of the community pharmacies. Surveys were distributed, by post, to all community pharmacies in South Australia. The response rate was 23.7% and was representative of all socioeconomic areas. Each pharmacy stocked a median of 3 medicines (range 0-12) with 1 in 8 pharmacies having none of the 13 medicines listed in the survey. When the data was combined to identify the range of medicines from all pharmacies within a geographical postcode region, the median number of medicines increased to 5 medicines per postcode. Just over 1 in 5 pharmacies reported learning about the palliative status through another health practitioner. Community pharmacies remain an underused resource to support timely access to medicines for community-based palliative patients. Palliative care services and government agencies can develop new strategies for better access to medications to benefit community patients and their carers.

Box 1. Abstract of Publication One

Before identifying solutions, it is crucial to understand the factors contributing to access to formulations through community pharmacies. Often, terminal phase prescribing involves a mix of

PBS and non-PBS medications. However, national coding systems fail to combine PBS and non-PBS dispensing data. As such, data are often difficult to capture. Without a national dataset capable of capturing dispensing data of medications helpful in managing terminal phase symptoms, it is challenging to see the breadth of the issue at the population level. Furthermore, national data relating to dispensing of PBS medications and provision of patient-level pharmacy services are unable to be linked. As such, a bespoke questionnaire was deemed necessary.

This publication ascertains that community pharmacists cannot anticipate which medications to stock.[78] Finding a community pharmacy with the appropriate medications helpful in managing terminal phase symptoms becomes challenging. So, while they are both accessible and affordable, the inability to anticipate which medications to stock undermine their ability to deliver timely services. It differed from previous studies in that it considered the perspective of the community pharmacist, collecting data on the range of formulations that their community pharmacies stock and the services they offer.[149-151]

Table 5. Findings and Recommendations from Publication One

Finding	**Recommendation**
Community pharmacies that stocked formulations helpful in managing the terminal phase learnt about people with palliative needs through interdisciplinary communication.	Health care professionals should identify the patient's usual community pharmacy and involve the pharmacist in discussing care planning related to medications for community-based palliative patients in advance.
Pharmacists working in dispensaries could not anticipate which medications to stock by observing prescribing practices alone. A factor contributing to this is the large variety of formulations available in Australia, leading to variable prescribing practices.	Palliative care organisations should collaborate with medical, nursing and pharmacy organisations to develop an agreed core medications list to support symptom management in non-complex community palliative patients.
Not all community pharmacies stocked formulations helpful in managing terminal phase symptoms.[3] Choosing not to stock formulations could be a commercial decision to avoid bearing the cost of the expired stock.	Policymakers need to incentivise community pharmacies to hold a small range of medications that may be required urgently, but so infrequently, that loss of stock due to expiry is otherwise a financial burden.

Publication Two

There are a number of challenges facing people in the last days of life who wish to receive care in their home environment. This includes timely access to medicines for symptom control. This article outlines the development of a concise list of core medicines that can provide symptom control in non-complex patients in the last days of life. The list is based on practical criteria including evidence of efficacy, affordability, the option for parenteral administration, availability on the Pharmaceutical Benefits Scheme and the doctors' emergency drug supply list. A list of core medicines can facilitate timely prescribing and supply of essential medicines for end-of-life symptom management. However, the development of this list should not replace planning and routine involvement of community resources. Multidisciplinary education strategies are needed to ensure that the core medicine list is utilised effectively by doctors, pharmacists and community nurses.

Box 2. Abstract of Publication Two

Human factors theory explains the importance of standardisation in improving basic healthcare processes.[91] Human factors "*encompasses a range of methods and principles to help understand, model, improve, optimise, and integrate complex sociotechnical systems (and systems of systems), often with multiple goals and stakeholders, to yield the best overall system performance, including safety*".[85] Importantly, human factors provide a system thinking lens to the problem, where interventions may positively or negatively impact other resources. So, while standardisation may promote safe practices, it may also have unintentional consequences.

Other Australian clinicians have developed standardised medication lists to guide the delivery of palliative care. In 2006, Good published a list of 20 medications to manage Australians with palliative needs.[152] Surprisingly, Good's list - based on consensus by a few palliative care medical officers - only provided generic medication names without specifying formulations. Also, the published list included non-PBS medications. These overlooked details make it challenging to apply this sizeable list to guide community pharmacy practice.

Publication Two identifies a list of five formulations helpful in managing terminal phase symptoms for people wishing to die in the community.[79] This standardised list provided a tool to engage with all disciplines involved in managing medications in the terminal phase.

Table 6. Findings and Recommendations from Publication Two

Finding	**Recommendation**
Prescribers, through personal preferences, will prescribe formulations they know. Collectively this results in diverse prescribing practices across a region and makes it challenging for community pharmacies to anticipate stock needs.	General practitioners should engage with the patient's usual community pharmacy when prescribing for symptom control at the end of life to ensure the suitability and availability of medications.
There is a diversity in guidelines to guide clinical practice, particularly for managing terminal phase symptoms, resulting in prescribers having a broad range of prescribing options.	Palliative care organisations should collaborate with community-based medical, nursing and pharmacy organisations to implement a core medications list.
Not all community pharmacies stocked appropriate medications. For infrequently dispensed formulations, pharmacists chose to order stock upon receipt of a prescription, thus reducing the risk of stock expiring.	Policymakers need to incentivise community pharmacies to hold these five core medications to support end-of-life care in the community, in a similar model to the PBS Prescriber Bag list.

Critical Reflection on the Publications Associated with this Chapter

Publication One identified factors that contribute to a community pharmacy holding a range of medications helpful in managing terminal phase symptoms. In contrast, Publication Two identified five formulations that would form the List to guide community pharmacists in which ones to stock and prescribers to prescribe. Figure 4 shows how the findings from both these publications map against Grembowski's *Conceptual Model of the Role of Complexity in the Care of Patients with Multiple Chronic Conditions*. Of the five Grembowski domains, these publications focused on *"Health System", "Person",* and *"Contextual Factors"*. Conversely, the findings of Publications One and Two poorly reflect the domains of *"Community Resources"* and *"Social Support".*

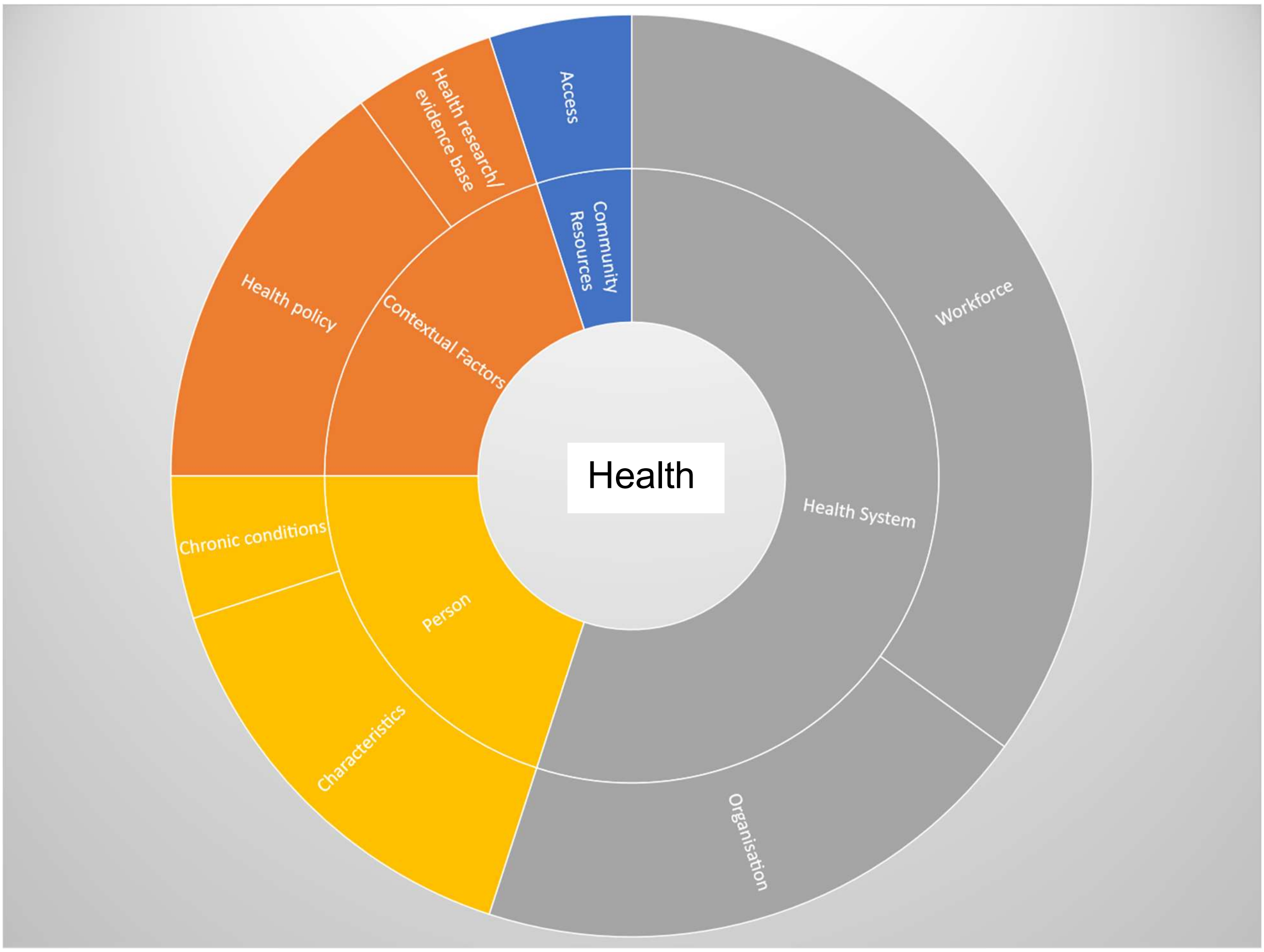

Figure 4. Plot of Publication One and Two Findings Against the Conceptual Model.

As described in Chapter Three, I mapped the findings from each publication against the Grembowski conceptual model. Figure 4 demonstrates how I identified four of the five domains discussed across these two publications in doing this.

Despite the PBAC developing the PBS to consider the needs of people in the terminal phase, there is poor alignment between PBS listing and inclusion of indications relevant in the terminal phase, leaving caregivers to pay out-of-pocket costs. Caregivers should expect a coordinated approach that considers the cost of accessing medications, particularly as the person deteriorates. Just as the PBS subsidises the cost of medications for the consumer, it is also the community pharmacy's payment mechanism, creating tensions between managing clinical workload and financial viability.[153] Expired medications become a business expense; while the PBS subsidises dispensed medications, it stops short of covering the cost of medications that reach their shelf-life. Furthermore, poor availability of medications impacts the experience of how and where the person dies and is a problem requiring cross-discipline collaboration. Involving various parts of the workforce and understanding how they interact were vital to understanding the problem and developing the strategy that considered the consumers' needs to overcome it.

As such, the impact on the person and their caregiver should be an essential driver of practice change and the focus of future research initiatives.

As the first publication of its kind, Publication One demonstrated the depth of the issue relating to access to medications through community pharmacies.[78] It resulted in the development of the List and guided consistent education programmes for all prescribers and pharmacists throughout South Australia (SA).[79] In addition, the List provided the framework for clinical guidance for managing terminal phase symptoms, developed through SA Health. Furthermore, this dataset was used in future studies as a baseline to compare the impact of interventions.[80, 81]

Improved access to formulations in managing terminal phase symptoms through community pharmacies was associated with interdisciplinary communication. Publication One echoed suggestions from others to improve the interdisciplinary engagement of pharmacists through greater use of clinical information systems and telehealth services.[19, 78, 154] eHealth was in its infancy in Australia, and while it showed promise in improving interdisciplinary communication, poor uptake limited its usefulness.[155, 156] Significantly contributing to the poor uptake was the requirement for Australians to sign up for the eHealth record voluntarily. Things changed in 2019, with the Australian Government adopting an opt-out participation model. This increased participation in the My Health Record (MHR) – as it is now known - reaching a critical mass, allowing for consistent use by clinicians, and providing a medium to support improved interdisciplinary communication.[157]

In 2012, there was no standard approach to guide community-based prescribers and pharmacists in useful formulations to manage symptoms into the terminal phase. However, in 2015, the Australian and New Zealand Society of Palliative Medicine (ANZSPM) produced and endorsed a national medications list to guide community-based prescribers and pharmacists in useful formulations to manage symptoms into the terminal phase. This list provided a national approach for building local strategies to improve access to critical medications at this critical time.

Instituting mechanisms to manage off-label prescribing, the PBAC has delivered remarkable results. In 2012, while the PBS listed formulations helpful in managing terminal phase symptoms, the indication linked with subsidy did not always align with the clinical need. For example, the PBAC included hyoscine butylbromide injections on the PBS for managing gastric colic yet excluded the subsidy when prescribers used it to manage respiratory secretions contributing to the "*death-rattle*". Over the past decade, the PBAC has aligned a broader range of formulations subsidised by the PBS with the indications expected in managing terminal phase symptoms through the PBS Palliative Care Schedule. In turn, this has reduced the need for caregivers to contribute out-of-pocket costs to pay for medications in the terminal phase.

As time progresses, so too does the evidence-base from which clinicians practice. The Therapeutic Guidelines (Palliative Care) is an essential consensus-based document that guides terminal phase prescribing for community-based prescribers.[42] Over time, the editors have considered practical issues, such as PBS availability, listing costly non-PBS formulations secondary to cheaper and clinically equivalent alternatives. As the primary Australian palliative care clinical resource, this now sends a clear message to prescribers about bearing in mind the affordability of medications when prescribing. Importantly, these changes align with the List and thus strengthen it.

In 2017, SA Health commissioned a palliative care Shared Care Project. The project aimed to provide stronger collaborative links between GPs and SPCSs in managing people with a life-limiting illness and their caregivers living in their home environment. GPs involved in the project received consistent training regarding the delivery of palliative care for people living in the community, including the use of the List. This collaborative project between SPCSs and general practice was vital; it can be challenging for the state and territory governments to collaborate with organisations working in the primary care space about shared concerns without a shared governance mechanism.

Significance of the Findings

In reflecting upon the issue of access to formulations through community pharmacies, I have recognised critical points about the current and future palliative care ecosystem. When driving projects to improve palliative care delivery for people living in home environments, it is essential to consider commercial needs. Private providers of clinical services need appropriate remuneration for clinical activities, including anticipating needs. Furthermore, interdisciplinary communication is an essential driver towards aligning the medications prescribed with those stocked across all community pharmacies. Finally, community pharmacists cannot anticipate which medications to stock in the absence of structured programs. Contributing factors include a lack of preparedness for the rapid loss of swallowing associated with the terminal phase, a broad range of management options available on the Australian market, and variable prescribing practices.

CHAPTER FIVE: SAFETY IN NUMBERS

"Alone we can do so little; together we can do so much." Helen Keller, author, disability rights advocate, political activist, and lecturer (1880 – 1968)

Introduction

Managing medications within the terminal phase necessitates an integrative approach across different disciplines and settings. In addition to the roles of the community pharmacist and the GP, circumstances may warrant the involvement of other disciplines, including aged care nurses, paramedics, and nurse practitioners.[158-160] When terminal phase symptoms are managed well in the home environment, it reduces unnecessary distress and suffering for the person, their family, and the clinicians supporting care.[161] Chapter Four introduced the issue of rapidly shifting symptoms and the person's inability to swallow, necessitating a switch from the oral to the subcutaneous routes.[42] Notably, clinicians can anticipate terminal phase symptoms in many circumstances, allowing them to plan their role in managing medications ahead of time.

Palliative care organisations from across the globe advocate for clinicians to consider anticipatory prescribing of subcutaneous medications prior to the terminal phase.[162] Anticipatory prescribing is the *"prescription and dispensing of injectable medications to a named patient, in advance of clinical need, for administration by suitably trained individuals if symptoms arise in the final days of life"*.[59](p161) Having these medications available when and where needed enables a streamlined transition to the subcutaneous route when the person can no longer manage solid oral dosage forms. The literature proposes that anticipatory prescribing circumvents several practical challenges that the terminal phase presents, such as rushed prescribing, the caregiver leaving the person to access medications, and searching for a community pharmacy with appropriate stock.[18, 60, 163]. Anticipatory prescribing is fundamental in ensuring people in the terminal phase receive effective and timely symptom control in the home environment.

Nevertheless, anticipatory prescribing is not always possible. While clinicians can expect the decline into the terminal phase, the circumstances may disallow time to engage in anticipatory prescribing.[67] For instance, poor timing of clinical response ahead of the terminal phase could result from various issues, including a late referral or the precipitous deterioration in functional decline associated with some life-limiting conditions, like cancer. Additionally, research shows that talking about dying can be contentious for many families, particularly those in denial of the person's imminent death: caregivers are known to demonstrate death-avoidant behaviours, attempting to sidestep the inevitable.[164] Hence, while anticipatory prescribing makes good sense, it may be unfeasible for some due to specific circumstances.

Chapter Four introduced the need for the List, supporting engagement with GPs and community pharmacists while ensuring that the formulations prescribed align with the ones in stock. However, with other clinicians such as aged care nurses, paramedics and NPs also supporting people in and approaching the terminal phase, there are opportunities to develop systems using the List to support the preparedness of a range of disciplines. For instance, having medications in the ambulance aligning with those prescribed by GPs allows more flexibility in reacting to the needs of the deteriorating person; consistency is key. This chapter will argue that, while standardised medication lists have a role in guiding GPs and community pharmacists around medication management in the terminal phase, there are other practical applications for this List across the palliative care ecosystem to support various clinicians.

Background

Traditionally, paramedics are called to the home to stabilise the person and transport them to the nearest hospital. In SA, the SA ambulance service (SAAS) has developed the role of an extended care paramedic (ECP) to address better the emergency needs of people in their home environment.[165] The role has proved to be particularly beneficial in partnering in care; they supplement the role of SPCS and general practice by attending to people living with palliative care needs after-hours, including those in the terminal phase.[158] Notably, paramedics and ECPs carry a finite list of medications to support the management of symptoms. It is advantageous to have the medications carried to the home aligned with the medications prescribed by GPs and SPCS prescribers. On the one hand, if the paramedic responds to circumstances where the dying person has run out of medications, they can continue the medications initiated by the usual prescriber. On the other hand, if the person enters the terminal phase after-hours, the paramedic's choice of medications to stabilise the person can then be continued by the usual prescriber. As emergency response providers, paramedics provide a crucial role, complementing the prescribing of other clinicians.

Contracted to dispense the resident's medicines within dose administration aids (DAAs), the off-site pharmacy plays a critical role in assisting RACH staff to administer medications safely and according to legislation. In addition, many RACHs have a medication imprest system.[166] The medication imprest system contains medications such as antibiotics and analgesics, which the contracted community pharmacy supplies as emergency stock. While prescribers still need to issue a legal medication order for RACH staff to use these medications, having the formulations available on-site provides a valuable means to access them quickly. It circumvents the urgent need to send prescriptions to the community pharmacy, be dispensed, and transported back to the RACH, especially after hours. For RACH residents entering the terminal phase, nurses can promptly act on anticipatory prescribing orders through accessing the medication imprest, where their contents align with prescribing practices.

In addition to prescribing from the PBS, Australian community-based prescribers, including NPs, GPs, and those from SPCSs, are entitled to carry various formulations when conducting a home visit. The Australian Government funds these formulations through the PBS Prescriber Bag, and they form an essential part of the prescriber's response to the terminal phase.[167] Importantly, the prescriber is responsible for ordering, maintaining these within their expiry dates and storing them securely once dispensed. As these formulations are mostly also available through the PBS, it assists in care coordination in two ways. First, the ongoing ordering of the same formulations issued from the PBS Prescriber Bag establishes a consistent prescribing practice. Second, as PBS Prescriber Bag items are only available through community pharmacies, the turnover of medications helpful in managing terminal phase symptoms is improved, limiting stock expiry. Accessing formulations from the PBS Prescriber Bag can complement anticipatory prescribing practices and send a consistent message to community pharmacies about which formulations to stock.

While the terminal phase is a typical and expected outcome for people living with a life-limiting illness, a planned approach to care may be challenging for all. Even though a rapid response to the terminal phase may be necessary, planning for systems that ensure experience, ability, and support are on hand still benefits from forethought and planning.[59, 168] Safety nets are in place so that paramedics, RACH-based nurses and community-based prescribers can facilitate this crisis response when circumstances prevent or disrupt a planned approach to deterioration into the terminal phase.[158-160] The publications associated with this chapter (Publications Three and Four) describe how the List can be employed in community pharmacies and beyond to support timely access to medications in the home environment.[80, 81]

Publications Associated with this Chapter

In 2014, shortly after developing the List, peers suggested that this forms the basis of a just-in-case box. Just-in case boxes contain a range of medications, suitable equipment and documentation, ensuring prompt medication administration for people in the terminal phase while in their home environment.[169] To issue the box, clinicians must fulfil all Australian legal requirements in issuing medications, including a prescriber reviewing the person before providing it. The request for developing a process to manage medications in crises prompted discussions that uncovered the broad suite of providers that could support people in the home environment. Examining the problem in this way, it was clear that while the dying and their caregivers benefit from anticipatory prescribing, considering the broader multidisciplinary team’s role in supporting care into the terminal phase provides a broader safety net.

In 2018, the NSW CEC launched their Community Pharmacy Palliative Care Initiative.[81] This initiative aimed to improve community access to medicines for people with palliative needs across NSW. As in SA, the CEC identified community pharmacists as critical in accessing medications to manage symptoms of the dying in the home environment. The leadership group was keen to collaborate in measuring the problem, and together we agreed to redistribute the South Australian Community Pharmacists' questionnaire that formed the basis of Publication One to community pharmacies throughout our two jurisdictions. Given that the List had been promoted over five years in SA, the opportunity to compare outcomes across SA and NSW had the potential to show the impact of standardised lists in practice.

There are two publications associated with this chapter: Publications Three and Four. Publication Three reports on a series of multidisciplinary focus groups to identify key considerations in applying the List in practice.[80] Publication Four highlights the impact of the List in community pharmacy practice.[81]. While Appendices Three and Four contain the full text of each publication, Box 3 and Box 4 contain their abstracts, while Table 7 and Table 8 provide the findings and recommendations of each publication.

Publication Three

During the terminal phase, access to medicines is critical for people wishing to spend their last days of life at home. Yet, access to medicines can be problematic. The aim of this study was to report the perspectives of specialist and generalist health professionals (HPs) on the issues of community access to medicines for this vulnerable group. A qualitative descriptive study design investigated the views of HPs working in palliative care roles in South Australia. Nurses, doctors, and pharmacists described their experiences of accessing medicines for management of terminal phase symptoms during semi-structured focus group discussions. Content analysis identified six themes including: 'Medication Supply', 'Education and Training', 'Caregiver Burden', 'Safety', 'Funding' and 'Clinical Governance'. Future projects should aim to address these themes when developing strategies for the management of people wishing to die at home.

Box 3. Abstract of Publication Three

While community pharmacies offer extended hours, it is unusual for them to be available 24 hours a day. By building redundancy into the palliative care ecosystem, the reliability of accessing medications helpful in managing terminal phase symptoms improves. Redundancy introduces duplicate components, which may seem superfluous, but allow for failure in the usual processes.[170] Given the availability of the workforce to collectively provide 24-hour palliative care, there is an opportunity for the List to guide care beyond the traditional GP-community pharmacist interaction. Examples of other applications include just-in-case boxes, anticipatory prescribing, medication impresses within RACHs and paramedic services.[165, 171, 172]

This study involved clinicians from multiple disciplines who collectively identified the factors necessary for implementing the List in alternative ways than initially intended.[80] The broad make-up of the factors identified illustrates the complexity of delivering medication management services. This research differed from previously published studies; it considered a multidisciplinary perspective on how a standardised list of medicines could be applied across various organisations to reduce variability in practice, instead of simply listing the barriers to good quality care for the dying.[149]

Table 7. Findings and Recommendations from Publication Three

Finding	**Recommendation**
Pharmacists working in dispensaries only learn about someone's palliative needs once they receive the prescription, resulting in unpreparedness and inability to fill the prescription immediately.	Clinicians must recognise the value of partnerships with other primary health providers when caring for palliative patients in the home environment.
Embedding the List into practice requires clinicians to consider more than just the community pharmacist's role.	PHNs must encourage connectivity of palliative services for people living in the community through addressing the themes identified in this study, ensuring the sustainability of services.
The responsibility of delivering palliative care sits across acute, primary, and aged care services, with funding models creating irrational incentives that obstruct the delivery of timely, safe and reasonable care.	Funders must recognise the multidisciplinary nature of palliative care services when developing community-based projects and account for the range of barriers we have identified.
Abbreviations: Primary Health Network (PHN).	

Publication Four

Common terminal phase symptoms include pain, dyspnoea, anxiety, terminal restlessness, nausea and noisy breathing. This study identified the proportion of community pharmacies across two Australian states stocking medicines useful in managing terminal phase symptoms, while exploring factors considered predictive of pharmacies carrying these medicines. Community pharmacies from across the states of New South Wales (NSW) and South Australia (SA)were concurrently mailed a survey. Respondents were asked questions relating to medicines stocked, expiry date of stock, awareness of people with palliative care needs and demographic characteristics of the pharmacy. A 'prepared pharmacy' was defined as a pharmacy that held medicines useful in the management of terminal phase symptoms. The proportion of prepared pharmacies across NSW and SA was 21.9%. Multiple logistic regression demonstrated eight predictors of prepared pharmacies, of which awareness of people with palliative needs using their service was the strongest. One-fifth of community pharmacies carry formulations useful in managing terminal phase symptoms. The main factor associated with this was awareness of people with palliative needs using the pharmacy. Strategies that engage with pharmacists in anticipation of the terminal phase are critical, supporting people with palliative needs to remain at home to die, if desired.

Box 4. Abstract of Publication Four

In remaining in the home environment, people rely on ORGANISATIONs with which they already have an established relationship, including the general practice and community pharmacy. With multiple options to choose from, individuals living in the same area will naturally select the general practice and community pharmacy to support their needs using various criteria such as cost, convenience and ability to connect.[173] These individual choices result in different combinations of prescribers and pharmacists coming together to deliver care. While this does not typically impact care, the nuances of collaborating in rapidly changing circumstances can be challenging for all involved. GPs and pharmacists can be unaccustomed to collaborating in the terminal phase.

In distributing the questionnaire over two Australian jurisdictions, the study underpinning Publication Four intended to ascertain the proportion of community pharmacies stocking formulations helpful in treating symptoms in the dying.[81] In addition, it sought to understand which issues influence the stocking of these medications. With only clinicians in SA being subject to the List, there was an opportunity to examine if this standardised approach to care helped improve access to medications by improving collaboration between clinicians.

In Publication Four, the use of the List in SA explains the differences between the range of medications kept in community pharmacies across the two Australian jurisdictions. This research differs from previously published studies in that it compares two cohorts of community pharmacies in jurisdictions with a different approach to terminal care.[78]

Table 8. Findings and Recommendations from Publication Four

Finding	**Recommendation**
With community pharmacies in SA being more than twice as likely to carry useful formulations than their NSW counterparts, the implementation of the List in SA demonstrated that it improves access to medications through community pharmacies.	Peak professional bodies[*] should endorse and promote a core medicines list, ensuring a standardised message to prescribers and community pharmacists as to which medicines should be prescribed and stocked to facilitate timely access.
People cared for in a home-dwelling have poorer access to formulations helpful in managing terminal phase symptoms than their counterparts living in RACHs.	Aged care and nursing organisations supporting people to remain in their own homes to die should engage with the person's usual pharmacy to support interdisciplinary communication.
Where other clinicians informed the pharmacist of people with palliative needs, the pharmacy was statistically more likely to stock formulations helpful in managing terminal phase symptoms.	Prescribers and pharmacists should anticipate the terminal phase and the challenges brought about by the limited accessibility to medicines required during this phase, as people lose their ability to swallow.
Abbreviations: New South Wales (NSW); residential aged care home (RACH); South Australia (SA).	

Critical Reflection on the Publications Associated with this Chapter

Publication Three identified several factors to consider when implementing standardised medication lists to improve the care of people in the terminal phase, while Publication Four demonstrated the benefit of a standardised list in supporting community pharmacy practice.[80, 81] In mapping the findings identified from Publications Three and Four against Grembowski's conceptual model, it is evident that these publications focus on three particular domains: "*Health*

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[*] A peak body is an Australian term to describe a national group that acts on behalf of professionals or consumers by developing standards and guidelines or to advocate to government on behalf of its membership.

System", "*Contextual Factors*", and "*Social Supports*" (see Figure 5). In contrast, the findings from Publications Three and Four poorly reflect the domains of "*Person*" and "*Community Resources*".

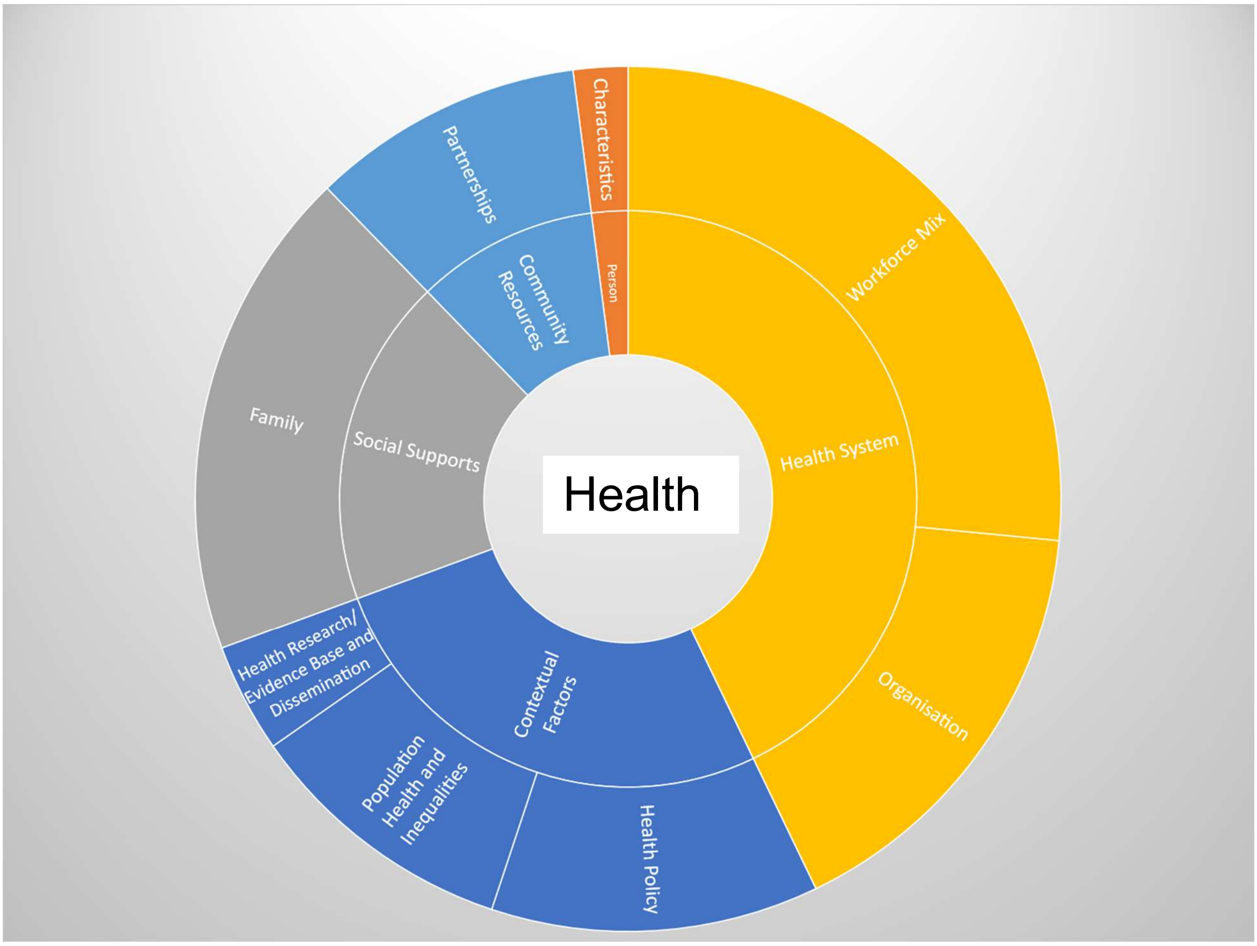

Figure 5. Plot of Publication Three and Four Findings Against the Conceptual Model

The mapping exercise showed that these publications considered all five Grembowski domains and provided several insights. Involving various disciplines in the research that underpinned Publication Three enabled a broader discussion of the various strategies employed to facilitate access to and availability of medications in managing the terminal phase. Participants tabled practical and legislative issues relating to how the List could align with these strategies. While these publications highlighted the disconnection between various policy frameworks and clinical care, it was clear that improved communication between providers was necessary. Just as SPCSs have a crucial role at a local level in establishing tools that better connect all stakeholders, there is a substantial need for a national approach to align policy, medication access, and patient needs.

Given the broad population level of the questionnaire used in Publication Four, the results could not consider the influence of local factors on the range of medications stocked. More research is required to consider the influence of local population demographics on the range of medications stocked by community pharmacies. Interestingly, the mapping exercise infrequently identified the

"*Community Resources*" domain, despite the essential role of providers of aged care services in caring for older Australians with palliative needs. Notably, people using community pharmacies without a formal link with RACHs have poorer access to formulations helpful in managing terminal phase symptoms, suggesting inequity in access, depending upon which pharmacy the person in their home-dwelling or a clustered domestic model of care uses.

Importantly, these publications mark the first consideration of the caregiver's critical role. It reflects the multidisciplinary participation within the focus groups that contributed to Publication Three and a greater professional connection with caregivers, influencing the interpretation of the data in Publication Four.

Publication Three used the List to demonstrate the complexity of caring for community-based people in the terminal phase.[80] In identifying five themes, this publication noted that the supply of medications, while grounded on sound principles, was set to fail without considering these. Publication Four confirmed the role of the List in communication between providers, particularly in the absence of transparent governance.[81] While a project plan is essential for a system-wide change, the levels of improvement seen across some community pharmacies highlight that it needs to consider factors like local interdisciplinary collaboration to guarantee sustainability. Together, Publications Three and Four showed that it is necessary to understand the complexity of the palliative care ecosystem when introducing interventions.

It was essential to identify ways of engaging all clinicians in the care ahead of when the person enters the terminal phase. While this research was not the first to tout collaborative networks as a solution for enhancing care delivery, questions remain about implementing this into the care of people with palliative needs.[119, 173, 174] Collaboration remains an essential mechanism by which organisations delivering care can at least be attentive to the issues and change.

In 2015, the Australian Government commenced funding the MedsCheck Program, which uses community pharmacists to conduct a simple medication review within the community pharmacy.[175] While it was not as detailed a review as documented within a home medicines review (HMR) or a residential medication management review (RMMR), a MedsCheck was quicker to achieve.[175] As a result of this research, all SAPS newly referred patients were referred for a MedsCheck to ensure we had an up-to-date list of their medications. It was also an opportunity for our new referrals to share information about their situation with the community pharmacist and engage with professional pharmacy services – such as home delivery or DAA services - ahead of the person's deterioration.

While Publication Four highlighted the benefit of a standardised list, it also demonstrated that conciseness was critical; as risk-averse businesses, community pharmacies needed good stock turnover to adopt them. Chapter Four introduced the standard formulation list published by the

ANZSPM.[176] While the ANZSPM list was essentially an expansion of the formulations on the SA list, it doubled the range of medications recommended. As a result of this research, the NSW CEC eventually favoured adopting the SA List over the National one; while the needs of the prescribers were significant, reducing the risk for community pharmacies was paramount.

Shortly after collaborating with the NSW CEC, the Pharmaceutical Society of Australia (PSA) commissioned an Essential Continuing Professional Education piece on Palliative Care, to which I contributed. This document described the PCP's role in supporting someone with palliative care needs and their caregiver.[177] It provided specific advice on how pharmacists in dispensing and clinical roles could identify and engage with people with palliative care needs and their caregivers.

There were also related projects where issues associated with medications management drew upon this work. In 2015, the Australian Government funded thirty-one Primary Health Networks (PHNs), replacing the Medicare Locals.[178]. As the boundaries of PHNs aligned geographically with the State-funded Local Health Networks, which govern the public hospitals and SPCSs, this provided opportunities to collaborate with projects that span the acute and primary care spaces with multiple community-based stakeholders. One such project was the Palliative Care Access to Medicines (PCAM) Project, which engaged the PSA to support the broad rollout of the List throughout metropolitan SA.

Furthermore, in 2017, the federally funded Decision Assist project launched the palliAGEDgp smartphone application - a practical resource for prescribers and pharmacists to manage care for people in the terminal phase while in a home environment.[179] While providing specific practical instructions for the prescriber about the dosing of medications, it also recommends that prescribers identify the person’s usual pharmacy and seek their support.

Significance of the Findings

Chapter Five illustrates significant and original contributions to knowledge. With the multidisciplinary team providing care distributed across multiple government-funded services and organisations, the operationalisation of the List required more than engagement with the pharmacist. This research identified the need for a multipronged approach to implementing the List. Despite its complexity in operationalising, there is merit in a standardised approach to managing terminal phase symptoms; a standardised approach offers a platform for prescribers to communicate preferences with the pharmacists in the vicinity. In the absence of a standardised approach, prescribers will interpret the evidence individually, sending unclear messages to the pharmacists with whom they need to collaborate. Additionally, given the difference between formulations stocked by community pharmacies with and without formal arrangements with RACHs, the choice of community pharmacies engaged in the person’s care may contribute to poor access to timely symptom management.

CHAPTER SIX: ENVISIONING

"If I have seen further, it is by standing on the shoulders of giants" Isaac Newton, scientist, and mathematician (1642 to 1727)

Introduction

Australia's population is ageing.[2] In 2018, Australians over 65 years of age equalled 3.8million.[180] Projections have these numbers almost doubling by 2042, to between 6.4million and 6.7million. Crucially, with more people living into old age, these projections increase the number of people expected to die and, therefore, the number of people with palliative needs.[54] Ultimately, this will place increasing pressure on healthcare services, including public hospitals.[181] The Australian Government has heavily invested in their ageing in place policy, funding aged care providers to support older Australians living and dying in the community by providing HC or RAC services.[2] Notably, organisations delivering HC and RAC services in the person's home environment – the difference is how supports are engaged to deliver care.

Many older people continue living in their own homes through the support of HC services.[182] HC services may include one or a combination of assistance with personal care (e.g., bathing), domestic support (e.g., housework), or health-related tasks (e.g., wound management).[183] While the older person and the caregiver remain responsible for the bulk of care in the home environment, they may be unprepared to manage tasks to keep them at home, including complex medication regimens. Support with these tasks is possible by working collaboratively with the nurses and aged care workers employed by the HC provider and the usual care providers, including the general practice and community pharmacy.[184] Despite the challenges of delivering HC services, Australian aged care utilisation data demonstrate trends in reduced RACH admissions and a tripling of Australians accessing HC services between 2008 and 2015.[185]

For those unable to manage well within their home-dwelling, RAC services are more appropriate.[185] RAC services are delivered in a RACH, meaning that the transition is perhaps full of anguish; the move from the family home coincides with a change in living arrangements, working with a new general practice and community pharmacy. In addition, studies indicate that more women and older, frailer people with highly complex needs receive RAC services, implying increased care needs following the death of a partner for whom they supported care in the family home.[186] Reports of significant delays in access to RAC services also indicate a greater burden on the older person, their family and possibly acute care services prior to transferring to a RACH.[187] Significantly, the family can be invisible in delivering RAC services, despite knowing the older person better than the service providers.[188]

Challenges associated with the transition to institutionalised care, the higher complexity of care needs, and caregivers' invisibility differentiate RAC from HC services.

While previous chapters have examined the pharmacist's role in delivering care for people in the terminal phase, this one examines their broader role in providing services to older people living in their home environment with palliative needs within the aged care context. This chapter will argue that PCPs are fundamental in caring for people receiving aged care services in their home environment throughout the palliative journey.

Background

Australian data indicate that multimorbidity rates are highest among older Australians.[189] Multimorbidity, defined as two or more concurrent conditions, impacts the quality of life through various physical, psychological, and cognitive function changes.[190] Studies demonstrate that older people have reduced general health, diminished ability to take care of themselves, and poor emotional and social adaptability.[191] Older Australians living with multimorbidity have impacts on overall well-being that increase their reliance on support to remain in their home environment.

Along with multimorbidity, older age is associated with polypharmacy.[189] While polypharmacy can be appropriate in older people, it can also be associated with MRPs. Prescribed and over-the-counter (OTC) medications are essential in managing troublesome symptoms in older people with palliative needs.[192] However, guidelines for managing disease struggle to account for multimorbidity, potentially prescribing unnecessary medications.[33] Typically, with a combination of multimorbidity and issues associated with ageing, various issues develop, impacting their risk of MRPs and ability to manage their medications appropriately.[193] Research shows that polypharmacy in the aged increases their exposure to MRPs and is associated with an increased risk of hospitalisation and diminishing quality of life.[194]

In addition to polypharmacy, older people are vulnerable to the inherent problems with how the palliative care ecosystem functions through increased use of services. Poor inter-clinician communication about medication changes can contribute to MRPs in this population. For example, an older person may receive prescriptions from different care providers contributing to medication complexity.[195] GPs may be unaware of all the medications a person is taking because of poor communication of medication changes by other prescribers involved in the care.[196] Furthermore, older people are at greater risk of hospitalisation due to the complexity associated with their multimorbidity.[193] Latimer surveyed GPs shortly after discharge about the information relating to medication changes made during hospitalisation and found this lacked comprehensiveness and accuracy.[197]

Pharmacists can support safe medication usage in the home environment.[52] However, recent publications envisioning the future for the Australian pharmacy profession have made multiple references to pharmacists' involvement with people obtaining RAC services without a single reference to HC services.[46, 198] While safe medication usage is equally necessary for people obtaining HC and RAC services, the published and grey literature often overlooks the pharmacist's role in supporting HC services. Given the complexity of medication issues associated with the care of older people, placing them at greater risk of MRPs in the HC setting, the lack of reference to the pharmacist's role is surprising.[199, 200] Therefore, there are opportunities to examine the contribution and value of pharmacists as critical partners with organisations delivering HC services.

Older Australians receiving aged care services in their home environment are at significant risk of MRPs due to the complexities associated with multimorbidity, polypharmacy and factors associated with the ageing process. Despite different frameworks used to deliver HC and RAC services, the pharmacist's role is critical, particularly in the last stages of life. Significantly, the role of aged care services will increase as the number of people aging increases. The publication associated with this chapter (Publication Five) identifies international published literature describing the roles and responsibilities of PCPs to support older people with palliative needs receiving HC or RAC and ascertain gaps through theming.[82]

Publication Associated with this Chapter

In 2017, as part of the Palliative Care Initiatives And Programs funding, the Australian Government supported the start of the ELDAC project.[201] The ELDAC project developed a range of services and resources for community-based multidisciplinary teams to support improved delivery of palliative care for older Australians living in their home environment.[202] While the priority for resource development focused on the needs of the aged care workforce and the GP, there was an interest in understanding the role of the allied health workforce in aged care, including the specific roles of the pharmacist.

In 2019, as an extension of my CareSearch role, I worked on the ELDAC project. At the time, the ELDAC team was conducting a review into the representation of allied health and pharmacy roles and services within their resources. Having developed web content and led the ELDAC Common Clinical Tools development, I led a rapid review of the literature to understand better the pharmacist’s role in delivering services to older people with palliative needs receiving HC or RAC. Publication Five reports on this rapid review. It aimed to identify the international published literature describing the roles and responsibilities of pharmacists working in the community supporting older people with palliative needs receiving HC or RAC, synthesising themes emerging from the data, and identifying knowledge gaps.[82] I have included the abstract (see Box 5), findings and recommendations (see Table 9) for context.

Publication Five

Globally, the number of older people requiring appropriate and safe management of medicines is growing. This review aimed to identify the roles and responsibilities of pharmacists supporting older people living in a community setting with their palliative care needs and to synthesise key themes emerging from the data, as well as any gaps in knowledge. The literature search included Medline (Ovid), Scopus, and Cinahl (Ebsco) databases. An English language limit was applied. The search included all international articles and any date of publication. Data were synthesised utilising a systematic text condensation technique and presented according to Theme, Domain, and Meaning Units. Fourteen studies met the inclusion criteria. Selected papers predominantly focused on care provided by the pharmacists supporting people receiving residential aged care services. Clinical review, supply of medicines, and clinical governance were identified as key pharmacist roles. Pharmacists' communication skills, personal behavioural approach, and positive attitude emerged as supportive characteristics for effective person-centered care. Minimal, or no information, were available related to pharmacists located in general medical practices and in Aboriginal health services sector, respectively. The multifaceted role of pharmacists presents an opportunity to provide comprehensive health care for older populations at the end of their life.

Box 5. Abstract of Publication Five

Chapter One introduced pharmaceutical care; the pharmacist's role encompasses more than just dispensing of medications.[9] Pharmaceutical care is particularly pertinent in the aged living with palliative needs within the home environment, where rapidly changing symptoms and associated medication changes contribute to an increased risk of MRPs.[37, 203] While the palliative journey differs significantly for all people living with a life-limiting illness, some touchpoints are similar. Sudbury-Riley characterises *touchpoints* as *"any point of contact between a service user and any aspect of the service"*.[204](p4) For someone with palliative needs, this will likely be associated with changes in medications and include discharge from the hospital, acceptance of HC or RAC services, and entering the terminal phase.[23, 67, 205] It makes sense to consider the PCP's role in delivering pharmaceutical care in caring for older Australians with palliative needs receiving HC or RAC services.

Publication Five establishes that pharmacists provide valuable roles for people living with a life-limiting illness obtaining HC or RAC services beyond the dispensary. For instance, they conduct medication reviews in the person's home environment. While these roles directly support the person, they also extend the skillset of the caregiver and the multidisciplinary team.

Table 9. Findings and Recommendations from Publication Five

Finding	Recommendation
The pharmacist's role in aged care is still developing. For those receiving care in their own homes, there are significant strides still to be made in how the pharmacist's role contributes to their care.	The multifaceted role of pharmacists presents an opportunity to provide comprehensive medicines management for the older population at the end of their life.
Government funding of pharmacist supply and patient-level services focuses on a transaction at a particular time.	There are growing calls for the expansion of pharmacist roles beyond dispensing and clinical reviews while streamlining funding pathways through the mechanism of pharmacist access to the MBS and PBS reimbursements.
Service provision requires the support of multiple organisations and clinicians, increasing the risk for MRPs.	There is scope within the current healthcare system to increase organisational support for pharmacists working with older populations in aged care organisations delivering RAC or HC services.
Abbreviations: home care (HC); Medicare Benefits Schedule (MBS); medication-related problem (MRP); Pharmaceutical Benefits Scheme (PBS); residential aged care (RAC).	

Critical Reflection on the Publication Associated with this Chapter

This publication identified fourteen papers from the published literature that discuss the pharmacist's role in delivering care to people with palliative needs receiving either HC or RAC services. Figure 6 shows how the findings from the rapid review map against Grembowski's *Conceptual Model of the Role of Complexity in the Care of Patients with Multiple Chronic Conditions*. Of the five Grembowski domains, a more considerable proportion of the issues identified and discussed in the rapid review focused on the *"Health System"* domain, with an equal split between the *"Workforce"* and *"Organisation"* subdomains.

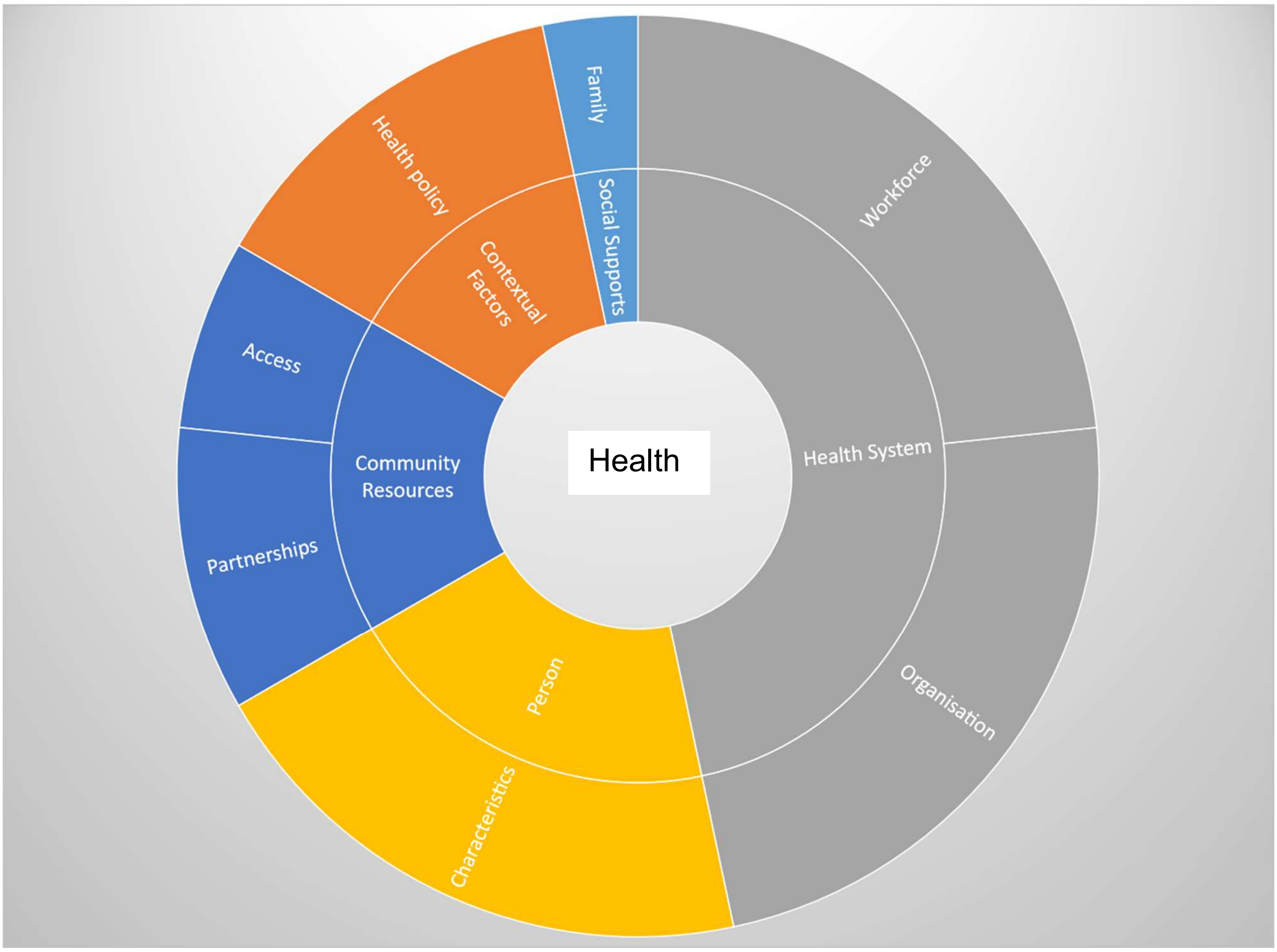

Figure 6. Plot of Publication Five Findings Against the Conceptual Model.

The spread of issues across all five Grembowski domains provides insights into the rapid review. While it focuses on the care provided to people with palliative needs receiving aged care services, the re-examination emphasises the *"Health System"* over the *"Community Resources"* domains. Given that the *"Community Resources"* domain was where I coded aged care, this finding reflects that the review focused more on the clinician's role in place of the governance structures in delivering services. Where the review referenced RACHs, the focus was on care transitions between settings, including transfer to a RACH from their home-dwelling or the hospital. Interestingly, the re-examination against the Grembowski conceptual model only mapped a handful of findings to the *"Social Supports"* domain. Given that the primary setting for conducting research has been in RAC, it is unsurprising that there was little reporting on the role of family caregivers despite their valuable role in supporting someone in their home-dwelling.

While the publications included in the review considered new and emerging roles for the PCP, such as embedded within RACHs, there was surprisingly little emphasis on the policy implications for these expanded roles. Policy drivers are critical as they guide how organisations operationalise and fund services, which the review could have discussed. Intriguingly, while articles discussed the broader role of pharmacists beyond the dispensary, these focused on developing new care models within RACHs. Just as understanding the pharmacist's role in working with RACHs is essential, organisations providing HC could adapt these learnings for their setting.

The evidence of deterioration throughout the palliative journey is well-described.[67] As the person deteriorates, changes provide multiple opportunities for the pharmacist to engage. For instance, the PCP may reconcile medications in the home shortly after discharge, educate the caregiver as things change or facilitate the disposal of unwanted medications after the person has died. Grembowski's framework helps to reimagine the findings of the rapid review by highlighting the interplay between various domains. Future opportunities to research the PCP's role in delivering support for people receiving HC services throughout the palliative journey have arisen.

This article provided an overview of the PCP's roles and responsibilities listed throughout the published literature, focusing on supporting people living with palliative needs receiving HC or RAC. It is tempting and often more natural to consider pharmacists as one collective group performing similar tasks and accessing the same funding. However, various funding pathways are needed to fund the services PCPs collectively deliver, including the PBS and the Seventh Community Pharmacy Agreement (7CPA). Furthermore, governments need to streamline these funding pathways with other aspects of good medication management, such as case conferences funded through yet another mechanism - the Medicare Benefits Schedule (MBS). Older people can fall through gaps without streamlined funding mechanisms, and ORGANISATIONs providing HC or RAC may struggle to build a business case to justify incorporating PCPs when developing services.

During the analysis, it became clear that the various pharmacist roles sometimes overlap and are strongly interdependent. As the palliative care ecosystem evolves, it will be intriguing to gauge how pharmacists working in different settings collaborate. Nevertheless, the rapid review contributes to a growing aged care literature and may be of value for related services and organisations.

In 2020, the COVID-19 pandemic confronted all Australians, resulting in the government favouring a social distancing policy. Social distancing impacted how pharmacists provided good pharmaceutical care, particularly for older Australians with palliative needs. People were discouraged from attending face-to-face appointments with their healthcare practitioners, including the GP, specialists, and PCPs, impacting their ability to be assessed medically, receive prescriptions and have prescriptions dispensed.[144] As a result, the Australian Government added new MBS items and accelerated the integration of e-Prescribing into practice.[206, 207] In addition, the Australian Government introduced changes to funding so that community pharmacies could deliver medications each month to the person's home with no out-of-pocket costs.[207] Home delivery of medications can free up the caregiver's time to invest in other tasks, mainly when the person's function decreases and the caregiver may have more hands-on demands, making tasks like collecting medications more challenging.[67] Home isolation limited access to pharmacist-led medication review services such as HMRs and RMMRS. Temporary arrangements allowed eligible PCPs to conduct these over the telephone or video conferencing mechanisms.[207] Furthermore, fear of running short of medications resulted in stockpiling and panic buying resulting in medication shortages. The Australian Government responded through the Australian Competition and Consumer Commission to cooperate with the pharmaceutical industry, ensuring that access to essential medications by community pharmacists was maintained.[207]

In 2021, the Royal Commissioners published their final report into the *Royal Commission into Aged Care Quality and Safety*.[208] Among its 148 recommendations were some relating to the use of medications in the aged. For instance, Recommendation 64 repeated calls in the literature for measures to improve access to pharmacist-led medication reviews in both the HC and RAC environments. The findings from our rapid review stress that pharmacists bring clinical experience and skills and suggest that organisations with PCPs embedded within their workforce models could work with their GPs to support the operationalisation of this recommendation into practice.

Significance of the Findings

The rapid review has identified critical points about the palliative care ecosystem as it currently stands in supporting people receiving HC or RAC and into the future. The pharmacist's role is broad; supporting the aged relies on the involvement and collaboration of multiple aspects of their skillset throughout the palliative journey. Furthermore, there is no need to limit the pharmacist's role to their dispensing functions. As their role continues to evolve, organisations take the opportunity to employ pharmacists to improve pharmaceutical care in the cohort of people who use their services. While organisations delivering RAC services are taking the lead, the literature discussing the impact of pharmacists working collaboratively with HC services is lacking. The latter is an area of untapped research potential.

Furthermore, funding models that integrate PCPs into community practice need streamlining and linking funding with a specific service or activity, which results in activities falling through the gap and being unfunded. As new roles for pharmacists develop, there need to be similar discussions at the policy level detailing how the government will fund these positions.

CHAPTER SEVEN: THE GOOD SAMARITAN

"Family is the most important thing in the world." Princess Diana, Princess of Wales (1961 to 1997)

Introduction

The literature establishes the availability of a full-time caregiver as the most necessary element of being able to die at home.[41] A caregiver includes a spouse, relative, friend, or neighbour who takes responsibility for voluntarily supporting another to attend to tasks, such as doing things around the home and getting them to appointments.[1] As the person with palliative needs experiences declining function, the range of tasks they can independently complete decreases.[67] Miller explains that caregivers respond to declining function through engagement with several informal and formal support networks critical to delivering wraparound care.[209] Furthermore, the literature describes the caregiver living with the person with palliative needs as a critical influence on the care and resources provided by an often stretched multidisciplinary team.[210]

The caregiver's role in caring for the dying within the home environment is critical for a range of activities, including the management of medications.[38, 210] The literature provides examples of training programmes designed to upskill caregivers with a range of tasks, including subcutaneous medication administration, in preparation for their role in caring for someone with palliative needs in their home.[211, 212] There is much literature discussing the issue of caregiver burden, with some authors stating that people supported by a caregiver may require increased clinical visits and equipment.[39, 40, 213, 214] It is unclear if this is in response to advocacy from the caregiver or the anxiety associated with their role.

Conversely, the caregiver's absence influences someone's ability with a life-limiting illness to be able to die in their own home; without a caregiver, it is challenging to maintain physical and psychosocial comfort.[213] When living alone, research has shown that people with a life-limiting illness draw upon an extensive range of informal supports, including friends, volunteers, neighbours, fellow churchgoers, and previous spouses.[210] In addition, there is an increased focus on using technology to provide a feeling of security. However, clinicians struggle with supporting people who live alone, with some citing that the person can often have unrealistic expectations of how they will be cared for as they deteriorate.[213] They add that there is an inability to convince them to understand the limitations of care providers.

As death approaches, the role of the caregiver in managing medications can escalate with increasingly complex processes to consider.[36] For instance, judging when to use *"as-needed"* medications is essential to managing symptoms in the dying. Just as managing medications in the home environment involves more than collecting prescriptions, the PCP provides various patient-level activities to support the caregiver.[215] These include performing medication reviews, preparing DAAs, delivering medications and disposing of them.[46] This chapter argues that caregivers require broad support in managing medications in the home environment, ensuring safe and effective symptom management of the person for whom they care. The PCP is well-positioned to deliver that support.

Background

DAAs enhance medication adherence by simplifying the management of solid oral medications.[216] For caregivers that live separate from the person to whom they provide support, DAAs may assist in planning for the week by flagging which medications are in short supply in the home; it is filled a week in advance. Furthermore, they can also help identify medications that the person failed to administer. Outsourcing the preparation of a DAA to a PCP is also possible, freeing up the caregiver's time to do other tasks. However, the literature also describes various limitations.[217] First, while a DAA can accommodate changes to medications, delays in getting it repacked can result in dosing discrepancies. Second, the quality of the prescribing may drop when the PCP packs the DAA as they tend to contact the prescriber directly to arrange ongoing prescriptions. As a result, the prescriber may continue medications without reviewing the person's needs. Third, formulations can be unsuitable for packaging in DAAs due to being unstable when stored outside of their original packaging. Fourth, errors by the person packing the DAA can result in discrepancies. Fifth, people can lose familiarity with their medications if they no longer see the original packaging. Sixth, cognitive and arthritic changes at end-of-life make handling the DAAs challenging.

An HMR provides a full assessment of a person's medicines in their home and which a specifically trained pharmacist conducts.[6] Crucially, it requires a referral from a medical officer, including their GP, specialist or hospital doctor. Medication reviews seek to improve the management of medications in the home environment through a one-on-one appointment with the pharmacist. In addition, given the anticipated deterioration of the person, HMRs provide an excellent opportunity for the pharmacist to engage with the person's caregiver. Engagement could support the caregiver's understanding of what the medications are used for, reconciling changes to medication following a hospital admission, and understanding how to manage medications when swallowing issues occur.[215, 218]

As prescribers make constant changes to medication throughout the palliative journey, some medications in the home may no longer be required.[32] Unwanted medications in homes and their inappropriate disposal create varied risks for all adults, children and animals in the household, resulting from deliberate or accidental misuse.[219] For people with palliative needs, this may increase the risks for MRPs, especially if the prescriber has failed to clarify changes or multiple people handle the medications. Returning unwanted medications to community pharmacies ensures they are disposed of by high-temperature incineration.[220] For caregivers, returning unwanted medications to the community pharmacy can reduce confusion with complicated medication regimes or assist in removing medications after the person has died.

People with palliative needs receiving care in their home-dwelling need support to remain there, making the caregiver's role critical. While support in managing medications is one of many critical roles, a range of valuable resources exist, enabling caregivers to manage medications confidently and dynamically throughout the palliative journey.[221]. The publication associated with this chapter (Publication Six) specifies a subcategory of caregivers from SA who acknowledged that they would have appreciated more assistance in managing medications for someone with a life-limiting illness.[83]

Publication Associated with this Chapter

Chapter One described how caregivers find medication management challenging when faced with clinical deterioration. The challenges were quite apparent as the clinical role at SAPS developed. For example, it was not unusual for me to visit someone's home and spend the time supporting the caregiver, leaving the person they cared for to rest. On the other hand, there was a delight in taking something they had found challenging and developing a strategy to build on the supports they already had in place. The improvements would often involve collaboration with the general practice and community pharmacy concerned in their care.

Publication Six is the focus of this chapter. It illustrates a population-based study to understand the range of caregivers who are likely to experience problems when managing the medications of a person with a terminal illness.[83] While including the publication in Appendix Six, Box 6 contains the abstract and Table 10 provides the findings and recommendations for perspective.

Publication Six

For most people, the last 12 months of life are spent living in the community, with the support of family and friends for a number of caregiving functions. Previous research has found that managing medicines is challenging for caregivers. Currently there is little information describing which caregivers may struggle with tasks associated with managing a loved one's medicines. The aim of this study was to identify factors that flag caregivers who are likely to experience problems when managing someone else's medications. The annual South Australian Health Omnibus Survey provides a face-to-face, cross-sectional, whole-of-population view of health care. Structured interviews, including questions covering palliative care and end-of-life care, were conducted with 14,625 residents in their own homes. Of the 1068 respondents who had provided care for someone who died of a terminal illness in the last five years, 7.4% identified that additional support with medicine management would have been beneficial. In addition, three factors were predictive of the need for additional support in managing medicines: aged <65 years; lower household income; and living in a metropolitan region. The findings of this study provide insights to inform the development of palliative care service models to support informal caregivers in the management of medications for people with a life-limiting illness.

Box 6. Abstract for Publication Six

Resilience is a valuable quality for caregivers of people with palliative needs. Resilience is associated with someone’s ability to manage challenges, recover, and grow, despite ongoing threats.[222] The literature describes better-prepared caregivers as having more favourable outcomes, including developing a sense of purpose and meaning, good bereavement outcomes, and closeness toward the person with the palliative needs.[41] Positive results are crucial, as the role of the caregiver will only increase as policy drivers continue to favour models that deliver care for people with palliative needs within the home environment.[23] Working dynamically, caregivers need skills to maintain their resilience, regardless of the circumstances.

Little research has centred on the characteristics of caregivers that find managing medications challenging. Publication Six differed from previously published studies as it considered the population as a whole and used multiple regression analysis to predict which caregivers would have gained from extra support in managing the medications of someone with a terminal illness.[83] Much of the palliative care literature highlights the value of clinical practices and contextual factors through the workforce lens: focusing on how caregivers conform to the multidisciplinary care team or evaluating the caregiver's unmet needs.[43, 62, 223] Understanding the characteristics of caregivers who struggle with managing someone's medications will assist governments, organisations, and clinicians build mechanisms to target services to those with the greatest need.

Table 10. Findings and Recommendations from Publication Six

Findings	Recommendation
While some caregivers request support, others may struggle without asking for help.	Clinicians need to regularly consider caregivers and assess their level of confidence in managing medications throughout their journey.
Caregivers who would have benefited from support in managing the person's medicines were from lower-income households, lived in metropolitan areas and were younger.	In a resource-limited environment, organisations should target specific subpopulations of caregivers for medication management services.
Through delivering HMRs, PCPs contribute to the care of someone with palliative needs and their caregivers.	As governments evaluate HMR programs and their evidence base strengthened, understanding caregivers' perspective for people at the end of life should be an area of particular focus.
Abbreviations: home medicines review (HMR).	

Critical Reflection on the Publication Associated with this Chapter

Through mapping the points identified in Publication Six against Grembowski's conceptual model, I demonstrate that this publication focuses on four specific domains, namely "*Health System*", "*Contextual Factors*", "*Person*", and "*Social Support*" (see Figure 7). Points relating to the "*Community Resources*" domain were absent from any discussion.

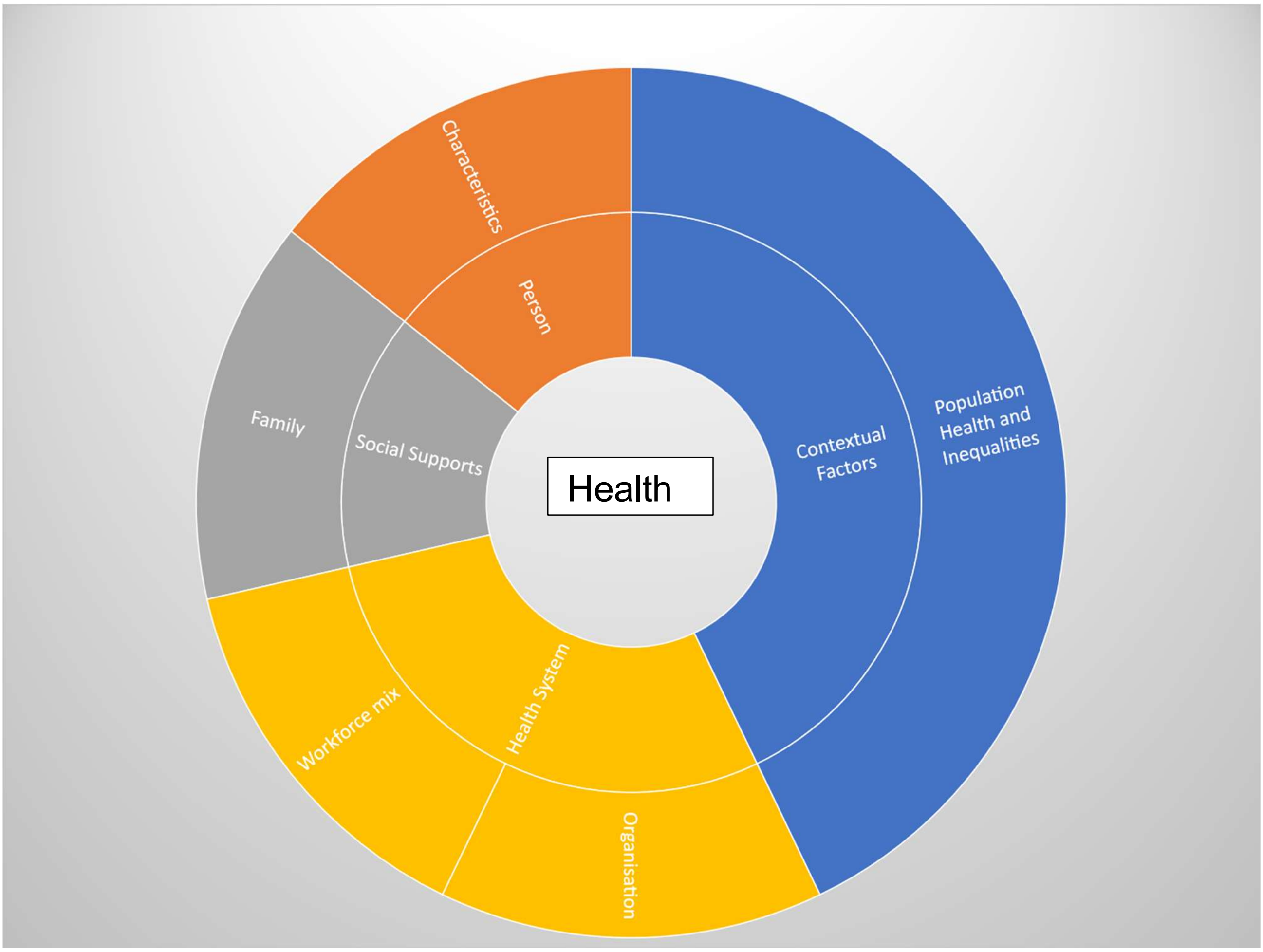

Figure 7. Plot of Publication Six Findings Against the Conceptual Model

This analysis illustrates a broader approach to the interpretation of this publication compared with those discussed previously. The lack of focus on the "*Community Resources*" domain reflects the scope of this publication. While community resources, such as the pharmaceutical industry and mass media, play significant roles in managing medications in Australia, the scope of this article provided limited opportunities to consider their influence.[51, 224, 225]. Interestingly, the issue of "*Contextual Factors*" focused entirely on the subdomain of "*Population Health & Equalities*", failing to discuss the other subdomains relating to the "*Evidence Base*" and "*Health Policy*". For instance, given the evidence supporting the Australian Government's support of care in the home as people age, a statement about the policy implications would have been valuable.[226]

The discussion articulated an argument for the involvement of pharmacists in supporting caregivers to manage medication in the home environment by including them in HMRs. There are opportunities ahead to embrace the broader functions of the PCP in the care of people with palliative needs living in the community; they do so much more than simply supplying medications through community pharmacies.[198, 227-229] While the article considers the "*Person*" domain, the scope of the article was such that it did not explore which specific aspects of the person's palliative journey the caregiver would have appreciated support in managing medications. For instance, is stress related to a particular period of the palliative journey, or is it an issue with understanding instructions from healthcare professionals?

Local developments followed from this work. As standard practice, the social worker referred all caregivers meeting the criteria identified in Publication Six for pharmacist input, including younger caregivers and those from lower household incomes. In addition, further research has commenced, using face-to-face interviews with bereaved caregivers to provide more detail on the role of the caregiver in managing medications of someone with a life-limiting illness.

In 2019, the "*Hospice in the Home*" project involving a rapid response SPCS team to visit eligible patients who had deteriorated in their homes commenced at SAPS. As the leadership group anticipated that caregivers would become overwhelmed with the number of modifications made, all caregivers were automatically referred to me to support education and counselling on good medication use.

From this body of work, there have been opportunities to contribute to a series of national projects, extending my engagement with the generalist workforce about medications for people with palliative needs. Two examples are detailed below.

In 2018, the federal government funded the Caring@home Project based on previously published work.[211] This project aimed to provide standardised resources to support the training of carers and families in drawing up and administering breakthrough subcutaneous formulations in a home-dwelling. The leadership group invited me to participate in their education steering group, to support a thorough review of the resources. In teaching complex processes, well-intentioned nurses can add their nuances in training and send inconsistent messages to caregivers. This training tool has standardised how nurses teach caregivers to administer subcutaneous medications.

In 2020, the Australian Government provided funds for the CarerHelp Project. This project provides information to caregivers on the care of those with a life-limiting illness. While this project has broader aims than the Caring@home Project, it includes information relating to managing medications earlier in the palliative journey, including medication lists. These lists are helpful for caregivers to consolidate information about medicines they are managing. This tool is valuable when attending medical appointments and presenting to the emergency department.

Even given the relative recency of this publication, emerging issues are influencing the palliative care ecosystem. For example, in 2020, the Australian Government reviewed the program rules that govern how pharmacists receive referrals and provide medication reviews for people in the home environment.[230] These changes allow for funding of the pharmacist to follow up on recommendations made in the initial medication review. Follow up is critical as medication reviews can result in multiple recommendations, which, if left to the caregiver to implement unsupported, may further contribute to MRPs. Additionally, changes to the rules extend the opportunity available to GPs to refer someone for a medication review to medical officers working in a hospital environment. As hospital admissions result in considerable changes to someone's medications, having the referral for a medication review at discharge aims to support timely reconciliation of medications in the home environment while reducing the significant risk of MRPs at this time.[197, 231]

Hospital stays can result in significant changes to a deteriorating person's medications, and there is good evidence to show that timely follow up by a pharmacist in the home environment can prevent MRPs associated with the transition from acute care.[232] In addition, creating a medication review referral by the hospital medical officer is helpful for the caregiver. While the new program rules allow the hospital-based medical officer to refer someone for a medication review directly, the referral can exclude the GP. While bypassing the GP aims to improve the timeliness of hospital-initiated medication reviews, further studies are required to see if this impacts the involvement with the GP. For caregivers supporting someone who is also deteriorating due to a life-limiting illness, the timely follow up by a pharmacist may be advantageous following significant changes in medications resulting from a hospital stay.

Significance of the Findings

This chapter illustrates significant and original contributions to knowledge about the caregiver's role in managing medications of someone with a life-limiting illness. As caregivers can fail to identify issues early, clinicians must embed standard processes to enquire if the task of managing medicines is going well. Understanding issues experienced by caregivers is significant at transitions of care, such as referral to the palliative care service or upon discharge from the hospital. In resource-poor environments, prioritising medication management services should consider urban location, low income and younger age of caregivers. Finally, as governments improve access to medication reviews in the home environment, researchers should focus on measuring the impact on the caregiver when managing the care of someone with a life-limiting illness.

CHAPTER EIGHT: DISCUSSION

“In the long history of humankind (and animal kind, too) those who learned to collaborate and improvise most effectively have prevailed.” Charles Darwin, naturalist, geologist, and biologist (1809 – 1882)

Introduction

Dying at home is preferred by most Australians, and it is where those living with life-limiting illnesses spend much of the last year of their life.[140] Indeed, people with palliative needs and their caregivers need substantial support from primary care providers, including PCPs, to facilitate this.[233] Furthermore, the substantial risk of MRPs in this population confirms the expanding opportunity for services provided by PCPs in contemporary palliative care practice.[32] However, the six publications that make up this PhD PP demonstrate that the pharmacist’s total and coordinated involvement in providing pharmaceutical care is often not ideal when caring for people with palliative needs. The system works in ways that disrupt their collaborative involvement in care.[78-83]

This chapter examines the cumulative meaning of the studies as described in this thesis. As reported in the thesis, the Grembowski conceptual model highlighted the interplay between different system elements. In reviewing these collectively, three insights into the system have arisen, which I discuss below. Indeed, while these insights have come about by looking through the lens of medication management, they have broader implications. So additionally, I discuss the practical and research implications, indicating how other authors have approached similar challenges.

Throughout this thesis, two issues ran deeply: change within a complex ecosystem and the use of Grembowski’s conceptual model as a research framework. I reflect on these. Finally, I provide the significance of the findings discussed in this chapter.

Background

I conducted the research associated with this thesis while working within an SPCS and at CareSearch. As a clinician-researcher, I recognised clinical challenges and applied various research methods to understand these in detail. The six publications associated with this thesis are part of a broader body of work, including peer-reviewed articles, vocational pieces, blogs, and conference presentations, dealing with the challenges associated with medication management for people with palliative needs living in the community.[78-83, 179, 218, 234-244] While each of the six publications had an individual value, collectively, they highlight the significance of the need to examine the roles of pharmacists, caregivers, and medications in enabling care of the dying in the home environment.

This thesis has enabled a detailed examination of the role of pharmacists, caregivers, and medications to support people with palliative needs while in their home environment. It has also created an opportunity to apply a systems lens that has brought to light broader insights into the mechanics of the palliative care ecosystem: an ecosystem with complexity at its heart. Grembowski's *Conceptual Model of Complexity in Caring for Patients with Multiple Chronic Conditions* (see Figure 2, Chapter Two) provided a framework to understand the complexity of the palliative care ecosystem.[101]

By undertaking this work, it has been possible to reinforce the original significance of the individual studies with new contributions to knowledge. Furthermore, this structured review and critical reflection have highlighted issues and considerations in undertaking research as a clinician-researcher and provided future research and dissemination directions.

Thesis Findings

Deconstructing the published papers against the conceptual model identified the interplay between the domains. For instance, while the evidence base provides good support as to which medications help manage terminal phase symptoms, these may not be listed on the PBS, increasing the out-of-pocket costs when purchased through a community pharmacy. In collectively reviewing these tensions, patterns appeared, and through collating and sorting these, three clear overarching themes emerged. The first theme considered challenges associated with funding models when applied to the delivery of palliative care services, resulting in unintended consequences for the people providing and receiving care. The second theme identified challenges in communicating clinical information, resulting in care disorganisation and the inability of community pharmacists to anticipate needs. Finally, a third theme involving challenges in providing standardised approaches emerged. In some instances, this lack of a standardised approach contributed to MRPs; in others, it highlighted the potential of unmet needs.

Challenges of Funding Models

In Australia, the federal government funds organisations to deliver most primary care services, including those which support people approaching the end of their life.[2] This research identified that while governments design funding models to improve access and affordability of primary care services, the opposite can happen within the context of palliative care.[78-83] The initial findings and considerations against Grembowski's model suggest that while these challenges concern pharmacists, substantial implications exist for people with palliative needs and their caregivers. Understanding how funding models perform across the palliative care ecosystem is necessary to ensure appropriate process and service planning while preventing structural disadvantages for specific populations. Government policy should consider the financial constraints of delivering home-based services for people living with a life-limiting illness and the organisations responsible for delivering them.

Business processes and funding rules can influence access to services when activity breaches predetermined caps.[49] Typically, governments will establish limits to the service provision by organisations to prevent overservicing.[2] Hence, when organisations apply the funding rules to people with palliative needs, this may limit who is eligible for, or how organisations offer, the service, resulting in increased expenses passed on to the consumer as out-of-pocket costs. In practice, the person or caregiver will usually be responsible for these out-of-pocket costs as the organisation completes the service.[2] This research has demonstrated that caring for people with palliative needs in the home environment is associated with increased out-of-pocket expenses.

In a recent rapid review on the cost-effectiveness of palliative care services, the authors found limited evidence relating to the consumer experience of financial constraints associated with the community-based palliative care model.[245] Without robust research into the financial distress of caregivers, measures of incidence and burden will continue to remain speculative.

Just as this research found that caregivers had financial implications for caring for someone in the home environment, commercial considerations can also impact community pharmacies. Decisions to stock or not stock, to provide services or not, are at their discretion, with impacts felt by the consumer.[246] Indeed, as generalists, the services provided for people with palliative needs are not the primary source of income for many community pharmacies, creating discord between clinical responsibilities and commercial needs. With some authors linking poor medication turnover with weak commercial performance and mediocre financial proficiency, some may be unwilling to carry stock to meet urgent but unanticipated medication needs on the chance they will be required.[247] However, the research associated with this thesis identified a range of drivers which led to the community pharmacy stocking a broader range of medications helpful in managing terminal phase symptoms, including a formal relationship with a RACH and the development and promotion of the List.

Given the complexity of managing medications within a multidisciplinary team, a fee-for-service model can be problematic. For example, the PCP needs a referral to conduct an RMMR within a RACH. Should the pharmacist recommend the rationalising of various medications that provide more harm than benefit, the current transactional model includes a payment to the pharmacist upon completion of the medication review and the writing of the RMMR report, regardless of the GP agreeing to apply the recommendations and RACH nursing staff receiving updates.[37] The GP can essentially block an independent review of their own prescribing, either by not referring the resident in the first place or not agreeing to accept the pharmacist's recommendations. Partially completed activities and vetoing of pharmaceutical care result from the current process of funding patient-level pharmacy services using a transactional model.

While traditional models, where pharmacists work remotely from the multidisciplinary team dispensing and supplying medications, remain necessary, globally, organisations are developing new models of care.[46, 248] Researchers suggest that organisations such as RACHs could integrate the pharmacist into the organisation structure, providing pharmaceutical care that is not prescriber dependent.[37, 249] These models situate the pharmacist within the organisation; being physically present, the pharmacist is more accessible to the team. Furthermore, embedded pharmacists have an opportunity to deliver comprehensive organisation-wide activities, such as education for staff, auditing, and consulting with other organisations, including community pharmacies, without restricting their activities to individual services linked with funding, such as RMMRs. However, integrating pharmacists into non-traditional workplaces such as general practice, RACHs or Aboriginal Controlled Health Care Organisations requires governments to establish new funding structures or for the organisation to fund the appointment themselves.[21]

An alternate model is performance-based payments (PBPs), which cover "*a range of funding models, from payment for quality-linked inputs to more complicated outcome-based models that link the level of remuneration with outcome measures*".[246](p503) While not always straightforward to implement, these models have improved the delivery of quality care while reducing costs and are regarded more positively than traditional funding approaches; measures underpinning them better reflect the costs associated with delivering the necessary quality of care. In Australia, the *Quality Use Of Medicines Program* is an example of a PBP model established with the support of the Pharmacy Guild Australia and the Federal Government.[198] The government funds the community pharmacy to support the RACH in various ways. Examples include meeting and maintaining medication management accreditation standards, evaluating, and guiding medication storage requirements, and collectively assessing adherence to medications by the RACH residents. Could the QUM program be expanded to support pharmacists in overcoming some of the funding tensions they experience, such as the expiry of medications?

Challenges with Clinical Communication

Good medication management for people with palliative needs requires multidisciplinary support, and clinical communication is key to delivering this.[70, 250] The importance of clinical communication across the multidisciplinary team, the person with palliative needs, and the caregiver are featured in the six publications.[78-83] Comparing the findings from the six publications against Grembowski's model, multiple instances of good clinical communication arose, including healthcare teams ensuring that PCPs were aware of someone with palliative needs and purposely involving caregivers when performing HMRs. In each example, team members ensured the rest of the team was aware of current and anticipated palliative needs to deliver good medication management ahead of the person's deterioration. Government policies should consider the challenges associated with good clinical communication in delivering care across multiple government and private organisations, as they support organisations in developing appropriate tools.

The literature describes two issues that predominantly influence clinical communication for PCPs and ultimately how they provide pharmaceutical care: the team dynamics, and the separate workspace, physically removed from the rest of the team.[173, 251] As teams develop around services that the person usually uses, such as the community pharmacy and general practice, teams need to navigate the nuances in communicating, impacting how these groups work collaboratively. Indeed, only engaging with the person's usual community pharmacy when subcutaneous formulations are urgently required is fraught with risk. In practice, where the community pharmacist suddenly learns about someone's imminent death, it is unreasonable to expect them to respond without forethought. This research has demonstrated that caring for people with palliative needs in the home environment requires planning, which is only possible through good clinical communication.

A collective review of the articles suggests that PCPs could further engage with caregivers to improve medication management within the home. For instance, clinical communication could happen in the home environment as part of an HMR, or in the community pharmacy, either as the pharmacist counsels on appropriate medication use or when the caregiver returns unwanted medications for disposal. However, this poses one fundamental question: how can the pharmacist identify the person's caregiver(s) in the first instance? It is unusual for the PCP to engage with them proactively. Despite evidence describing the importance of clinical communication with the caregiver to improve their preparedness and resilience as the person with palliative needs deteriorates, the pharmacist usually only responds to issues raised by the care team or the caregiver.[41, 222] Facilitating the PCP's role in connecting with the caregiver in advance of the terminal phase may enhance the caregiver's capability in providing medication management in the home.[43, 252]

Case conferences provide a mechanism to address communication issues and involve caregivers in the multidisciplinary team.[43] These are meetings between clinicians, the person with the life-limiting illness, and their caregiver. The GP arranges the case conference to discuss various issues, including care goals, approach to deterioration, and the caregiver's own needs.[253] While there have been recent changes to the funding of case conferences in Australia, enabling different allied health disciplines to attend, the pharmacist is omitted from this list, meaning they need to volunteer their time to attend.[254] With pharmacists already offering their time for free to complete various tasks, this will discourage them from participating.[229]

In addition to this body of work discussing opportunities for clinical communication between pharmacists and caregivers, the publications also examined the impact of interdisciplinary information sharing. Despite PCPs usually providing services remotely or in a visitation capacity, these published papers demonstrated that effective communication with the rest of the team occurred at times, allowing for care planning into the terminal phase. The published literature shows that interdisciplinary clinical communication flourishes when team members meet.[233] Telehealth has proven helpful throughout the COVID-19 pandemic.[207] In moving forward, telehealth will likely continue to provide an essential care element, particularly throughout rural Australia, where the community pharmacy contracted to deliver services to a RACH may not even be located in the same town.

Challenges of Providing Standardised Approaches to Care

An increasing expectation is that people will receive safe, appropriate, and effective care, regardless of their circumstances.[255] Indeed, the publications that make up the body of work identified variable practices in delivering services across the palliative care ecosystem, impacting the pharmacist, the person, and their caregiver.[78-83] Mapping the findings from the six publications against Grembowski's conceptual model confirmed that inappropriate care resulted from *unwarranted clinical variation*. Sutherland defines unwarranted clinical variation as *“patient care that differs in ways that are not a direct and proportionate response to available evidence; or to the healthcare needs and informed choices of patients”*.[12](p688) He adds that it *“is primarily concerned with the appropriateness of care—whether the right care is provided in the right way and in the right amount to address patients’ needs and expectations”*.(p688)

It is important to note that while service variability may reflect the specific circumstances and needs of the person living with a life-limiting illness, unwarranted clinical variation indicates that the person is not receiving appropriate care.[1] So, it makes sense that understanding the causes of unwarranted clinical variation across the palliative care ecosystem is necessary to reduce the risks associated with MRPs. The evidence base should consider the nuances of this population by validating the enablers for care consistency for all people living with a life-limiting illness and their caregivers. As medication experts, pharmacists have proven valuable in improving the appropriateness of care by reducing MRPs within the home environment.[159, 256, 257] While some variability may be necessary, integrating the pharmacist into the interdisciplinary team can improve the appropriateness of care.

The findings advocate adopting a family-centred approach when supporting people with a life-limiting illness to remain in the community. Just as caregivers vary in their demand for support in managing medications, organisations and clinicians can overlook identifying caregivers' needs as their focus is on caring for those with palliative needs.[43, 83] It is easy to see how this can happen given that managing medications is often incremental, starting with simple tasks and quickly escalating when the person cared for deteriorates. A recently published review adds that individual caregivers have different thresholds for coping with the challenges associated with their role.[69] Numerous factors relating to the caregivers receiving support, and the organisations and clinicians charged with the care, contribute to the level of engagement from caregivers.

Vermorgen also proposes that appointing a care coordinator enhances caregiver involvement with care.[43] Ding makes the case of how well positioned the GP is for this role.[258] While this role can establish expectations and assist with planning by flagging issues associated with deterioration, Ugalde notes that this should also include referral to support services.[253, 259] Furthermore, GPs can use validated clinical instruments, such as the Carer Support Needs Assessment Tool (CSNAT), to identify issues that the caregiver may experience in the home environment, including the *"giving"* of medications.[221] While this may be a great instrument to flag a PCP referral, it only questions what support caregivers require currently. The CSNAT is likely to overlook the needs of caregivers who are currently managing well but may need support in the future.

GPs note that limited time is a barrier to delivering good palliative care; thus, referral to support services is critical.[260] Given the different thresholds that caregivers have and the rapidly changing circumstances, caregivers should be flagged to the PCP early in the disease trajectory to proactively connect them to develop strategies for managing the risk of MRPs in the home environment. For instance, it is sensible to proactively involve the caregiver in a pharmacist-led HMR for the person they care for early in the palliative journey.

As with caregivers, organisations also approach the delivery of palliative care services inconsistently, with this thesis providing examples. For instance, in comparing organisations delivering HC and RAC services, the latter was more likely to describe the engagement of pharmacists in clinical components of care. Chapter One discussed that people with palliative needs are vulnerable to MRPs, so taking a different approach to care based on whether they receive HC or RAC services seems irrational. Given that people receiving HC are also likely to have an informal caregiver, the PCP's role in providing pharmaceutical care in this environment is vital.[41, 69]

Governments from across the globe have developed feedback mechanisms using benchmarking data to understand clinical care variation and enhance clinician observance of guidelines.[71] For instance, the Commission has developed the *Australian Atlas for Healthcare Variation* series to capture the appropriateness and effectiveness of various clinical indicators associated with good patient outcomes nationally.[255] The Fourth of this series includes data on clinical indicators such as polypharmacy and the proportion of the aged receiving a government-funded medication review.[261] Since the healthcare system routinely collects this information, making it publicly available can show variation across the country while prompting clinicians to ask why this variation might be happening.[261] PCPs have a unique role in interpreting data that considers medication-related issues, and, as medication experts, they play a role in developing strategies to manage this variation.

What are the Implications of these Insights?

By considering the role of pharmacists, caregivers, and medications in supporting people living with life-limiting illnesses in their home environment, this research has provided a window into the opportunities and challenges in delivering pharmaceutical care.[78-83] While the opportunities offer practical implications, the challenges demonstrate that more research is necessary to improve how organisations provide and governments fund services within the Australian context.

Implications for those Receiving Care

People living with cancer, organ failure or dementia encounter distinct challenges while living in their home environment. As they deteriorate, connecting with the organisations they have established relationships with as a significant source of information and support makes sense. Just as people living with a life-limiting illness face distinct journeys, so do their caregivers. In addition to providing direct practical care, emotional support, and liaising with health and aged care services, caregivers have a critical role in managing medications.[162] While managing medications in the home environment significantly connects people with palliative needs and their caregivers with the formal care system, this research demonstrated that nuances for this population could be disruptive, with consequences on the costs, timeliness and quality of the care provided.

It can be challenging for someone experiencing the palliative journey to foresee or even process how the experience will evolve. Indeed, building processes that regularly connect the person and their caregiver with the clinicians they know, and trust, will ensure that they have timely access to information, tools, and assistance while allowing for reinforcement of key messages. This thesis provided multiple examples where the PCP provides pharmaceutical care for the dying. These included reconciling medications in the home environment upon discharge from the hospital, providing subcutaneous medications in the terminal phase, and safely disposing of unwanted medications upon the person's death. In addition to the clinical and supply functions, the PCP can advocate for the person, ensuring that the multidisciplinary team considers the medication-related costs associated with care.

The early identification of people living with a life-limiting illness and their caregivers by PCPs is critical, given that rapidly changing symptoms and associated medication changes contribute to an increased risk of MRPs. Indeed, early identification ensures they can support the pharmaceutical care of the dying, which is both anticipated and timely. However, this thesis demonstrated that the PCP’s early identification of the person and their caregiver depends upon clear communication from other organisations partnering in their care, such as the person's general practice or aged care provider. Therefore, tools and strategies that contribute to effective communication between the organisations providing care, such as case conferences and care coordination, need to be embedded into practice at the point when clinicians recognise end-of-life.

Implications for those Providing Care

Pharmacists working in the community face distinct challenges when supporting people with life-limiting illness and their caregivers. In addition to providing clinical services, pharmacists need to be attentive to the commercial needs of the organisation within which they work. While pharmacists face challenges, so do the various community-based clinicians charged with prescribing, administering, and monitoring medications. In addition, keeping up with and communicating the person's needs to all clinicians in the multidisciplinary team is challenging as the person's circumstances change. Just as pharmacists and other clinicians have a vital role in managing medications, this research demonstrated that nuances in delivering clinical services for people with palliative needs and their caregivers could be disruptive, with consequences on their ability to respond to rapidly changing circumstances.

While each person’s journey is unique, there are parallels, including recognised contact points between them and the organisations delivering care. This thesis discussed various contact points, such as transitioning between settings and entering the terminal phase, where the involvement of the PCP assisted in mitigating the risks associated with MRPs. Indeed, organisations supporting people and their caregivers through the palliative journey can anticipate these contact points and design services around these. Given the leadership that SPCSs provide to organisations throughout their local communities, it is reasonable to expect them to take a leading role in supporting all clinicians to embed evidence-based medication management processes that anticipate the needs of people with palliative needs and their caregivers.

Research shows that clinicians often miss early communication cues when providing palliative care.[43] Contributing to this is that the multidisciplinary team delivering care may not have previous experience working together to resolve rapidly changing care needs in a home environment. Instead, teams often come together based upon the services that the person with the life-limiting illness usually uses. There has been increasing government interest in developing systems to facilitate more timely interdisciplinary communication.[262-264] Embedding the routine use of technology such as the MHR into clinical practice can improve timely interdisciplinary communication of patient-specific information, particularly in people with constant and rapidly changing needs.[157]

Implications for those Funding or Directing Care

The Australian Government funds primary care organisations to deliver services that support people with palliative needs to remain in their home environment. In addition, they collaborate with national organisations representing the voice of clinicians or consumers in developing various policy documents and standards that guide public and private services in the approach to care.[45] This thesis provided instances where these government actions have led to unintended consequences; tensions exist between clinical, funding or policy directions within the context of delivering care for people with palliative needs and their caregivers. Just as the Australian Government funds primary care organisations to deliver services, the state and territory governments fund the SPCSs to support home-based palliative care. In addition to funding the care provided through SPCSs, state and territory governments subsidise the cost of medications through hospital pharmacies.[265] While all levels of government have built significant infrastructure to guide the delivery of services supporting the care of people with palliative needs through policy and funding, this thesis identified how this could contribute to tensions. It also identified gaps.

A thread running through this thesis is the interplay between the clinical and commercial aspects of working in a community pharmacy. So, while this thesis demonstrates the crucial role of PCPs in supporting those living with palliative needs and their caregivers, funding leavers need to adapt to accommodate the issues raised throughout this thesis. Therefore, an honest question – and opportunity – to be explored in the current policy environment is what role can the current funding models play in supporting PCPs to support the care of people with palliative needs and their caregivers? For instance, does the Australian government-funded QUM program have a broader role to play? As it stands, this is limited to community pharmacies with established links to RACHs. Could the QUM program fund all community pharmacies to stock various subcutaneous medications, thus removing the burden on community pharmacies to wear the cost of expired stock?

Integration is challenging in a system that incentivises task-specific activities. New funding models may offer diverse ways to promote service integration, subsidise activity that is currently unfunded or improve the clinical independence of PCPs. These could complement existing funding models, such as those that fund the delivery of a specific task. For instance, the MBS funds multidisciplinary case conferences, encouraging medical officers to coordinate arrangements with three or more providers, offering different services and opportunities to collaborate through ongoing chronic disease management.[254] Developing financial incentives for PCP participation within the multidisciplinary case conference would improve their integration into the care team.

Just as awareness of connection points is necessary for service organisations, national organisations representing the voice of clinicians and consumers could also benefit from reviewing the critical points connecting the users of palliative care services with the organisations that deliver them. Understanding these connection points is critical to building better standards of care and resources to support clinicians and organisations in delivering care.[204] This thesis indicates that community pharmacists cannot anticipate which medications to stock and miss the cues in how they could be involved in the care. However, access to critical medications through community pharmacies increased in developing the List, indicating it contributes to better-coordinated care. In articulating the connection points, practice standards could provide nationally consistent quality indicators that support all PCPs, regardless of the settings in which they work, to operationalise pharmaceutical care across the palliative care ecosystem.

Implications for those Researching Care

The process of undertaking the original studies and the subsequent analysis and reflection has identified critical gaps in how pharmacists and caregivers manage medications for people with palliative needs living in their home environment. Further research could enhance the understanding of the palliative care ecosystem and should address the range of service features that influence integration. Based on what this thesis has identified, further research relating to the following twelve areas could improve understanding of these gaps.

1. Further research is necessary to understand the financial implications for caregivers in managing medications for people with palliative needs in the home environment. While this research identified out-of-pocket costs associated with purchasing medications helpful in the terminal phase and that caregivers on a lower income would benefit from more support in managing medications, it is unclear the importance of these findings for families, particularly those with financial stresses.
2. There is an opportunity to investigate the role of the Australian government-funded QUM program in managing some of the issues identified throughout this thesis. For example, could the funding model be expanded to fund the PCP's involvement with the person's nominated caregiver or to subsidise a specific list of medications to be carried by all community pharmacies for then the person deteriorates into the terminal phase?
3. Research into the broader use of PBPs in delivering pharmaceutical care for the dying could help determine the range of circumstances that mitigate MRPs in this population. For instance, linking pharmacist-led medication reviews with broader outcome data such as reduced admissions to hospitals or reduced polypharmacy could pave the way for PCPs to take the initiative in identifying and mitigating MRPs.
4. Research into how the multidisciplinary care team members identify and communicate medication-related risks appropriately and proactively with the caregiver could demonstrate improved confidence in managing medications in the home. While this research identified that some caregivers could have benefited from support in managing medications, it is unclear how

to recognise their needs earlier in the palliative journey. Furthermore, the involvement of PCP in this approach to care is critical.

5. Future research can explore whether case conferences are an appropriate means to improve collaboration between caregivers, pharmacists, and the rest of the multidisciplinary team in providing palliative care in the home environment. In addition, this research would require a costing analysis, as the role of PCPs in case conferences is currently unfunded.
6. Researchers need to consider the advantages and barriers to using telehealth communication, which promotes direct involvement of the pharmacist in interdisciplinary collaboration. In addition, given that pharmacists currently provide the bulk of their services either remotely or in a visitation capacity, organisations need to understand if telehealth processes can improve the timely involvement of the PCP in supporting people with palliative needs.
7. There is the opportunity to investigate the outcomes of funding pharmacist employment in non-traditional workplaces, such as organisations that provide aged care services and general practice. These need to compare against traditional models, such as medical officer referred medication reviews, and examine if they provide better opportunities to challenge poor prescribing quickly.
8. As circumstances change with deteriorating function, further research is required to understand the role of caregiver assessment instruments in predicting future burdens in the face of deterioration. Given that the caregiver's role extends beyond administering medications, such instruments need to identify risks associated with their ability to perform duties such as accessing medications, managing changes to medication schedules and monitoring symptoms. Furthermore, for resource-poor organisations, research may uncover if certain caregiver traits necessitate immediate involvement of the PCP and, thus, rationalise their involvement.
9. Research into the enablers and barriers to care coordination across the palliative care ecosystem could determine better models of multidisciplinary involvement. In addition, given the critical role that medications play, the research must assess the care coordinator’s engagement with the person’s usual pharmacist.
10. This thesis has identified that additional research into the impact of pharmacists in providing pharmaceutical care for older Australians with palliative needs receiving HC is necessary. Given that the funding for pharmacists within aged care organisations is lacking, this research must consider the cost implications of this model.
11. Research is necessary to provide a more detailed understanding of how multidisciplinary teams form in supporting people living with a life-limiting illness. Given the role of medications in managing symptoms, this ought to include general practice, organisations providing aged care services and community pharmacies. In addition, such research needs to account for how teams communicate and consider how collaboration functions over vast distances, as expected in more remote parts of the country.

12. Given the importance of benchmarking in reducing unwarranted clinical variation, researchers need to determine clinically appropriate benchmarks in managing medications for people with palliative needs in the home environment. In addition, this research should involve governments, national bodies representing the voice of clinicians or consumers and universities.

This thesis identified challenges in receiving, delivering, funding, and directing services that deliver pharmaceutical care for the dying. With other disciplines working across similar environments facing comparable challenges, the findings from this thesis will challenge the provision of palliative services more broadly.

Reflections

I commenced this PhD PP after a decade of conducting and publishing research into the role of pharmacists, caregivers, and medications. This PhD PP provided an opportunity to re-examine the six publications in greater detail while providing new insights into the pharmaceutical care for the dying. While this was important, re-examining these six publications provided so much more. Before I conclude this thesis, I must share two reflections on this journey, relating to change within a complex ecosystem and using Grembowski's conceptual model as a research framework.

Change Within a Complex Ecosystem

At the heart of this thesis was the concept of the palliative care ecosystem. It provided an analytical lens to view the roles of pharmacists, caregivers, and medications in caring for the dying within the home environment. This thesis discussed that ecosystems are complex and characterised by dynamic and interdependent connections that evolve with time.[74] Indeed, it recognised that change in the "real-world" needs to embrace the qualities of complex systems, including uncertainty, unpredictability, and evolution.

Like all complex systems, the palliative care ecosystem will continue to evolve. There is clear evidence of this with the development of new roles, such as death doulas, and new policy frameworks, like those required to operationalise voluntary assisted dying legislation.[266, 267] Yet, much of the approach to current research considers service delivery as a traditional linear process rather than a complex one.[74] Indeed, this has important implications for research into interventions designed to improve current practice. In producing research that fits the *"real-world"*, researchers need to shift from examining the quality of the individual components to that of their interaction. Furthermore, the role of the evidence-base in convincing much of the need for change will be critical.

Grembowski’s Conceptual Model as a Research Framework

I used Grembowski's conceptual model to formally examine the inherent tensions as represented across the six included publications. Mapping the tensions identified through each of the publications helped identify and categorise the challenges in delivering pharmaceutical care to the dying. I conveyed the weight of representation of the five Grembowski domains and twelve subdomains as a series of concentric circles throughout chapters Four, Five, Six and Seven. These concentric circles helped me consider how various parts of the ecosystem - those receiving, providing, funding, and researching care - view this interplay and provided critical insights into the meanings of the six original published papers. Indeed, this process assisted in developing a clear and descriptive argument for change.

When initially authoring the articles, I wrote from a specific perspective: a perspective set in a specific time and level of experience. While this reflected the circumstances that were important to me as a clinician-researcher, there were other perspectives to consider. Mapping the findings against Grembowski's conceptual model helped me explore these alternate perspectives while considering how resources and funding models had developed since the initial publication of the six articles. This formal technique provided space to reflect on the complexity of the ecosystem and how far the palliative care ecosystem has evolved.

Through all of the positive aspects of using the model in this examination, there was one issue that I struggled to place within the model: functional decline. Murali took the approach that function is an outcome and remodelled the framework to account for this.[102] In doing so, she lost the idea that functional decline contributes to the needs-services gap. I would suggest a more pragmatic approach by adding it to a subdomain of the *"Person"* domain, thus improving the model's applicability; chronic disease also influences a person's ability to function.

Significance of the Findings

Writing the discussion chapter has demonstrated how these publications collectively contribute to new insights into the role of pharmacists, caregivers, and medications in supporting the dying to remain in their home environment. This process has resulted in a better understanding of pharmaceutical care for the dying. First, there are financial implications to providing services within a system that relies heavily on a partnership between publicly and privately funded services, impacting most users and providers of palliative services. Indeed, this can result in inequities in accessing and making available medications. Second, integrating services in the community is challenging, particularly when the person's needs are rapidly changing. In the absence of a planned approach, clinicians sometimes need to respond urgently. While the usual communication channels are appropriate, they can often add to the fragmentation, resulting in trying times for all involved. Third, variable practices send inconsistent messages to the remainder of the multidisciplinary team. Given the demographics of the people receiving palliative care, community pharmacists often have close working relationships with them and their families. The heartache of being unable to anticipate a person's needs is brutal, particularly in a challenging, fast-changing situation. Fourth, Australia has well-developed health and aged care systems with a range of resources helpful in managing the care of people with palliative needs who wish to remain in the community setting. However, sometimes these resources do not align with best practices. This thesis has described a variety of ways that this impacts care. Fifth, with identifying failings within the healthcare and aged care systems, clinicians and researchers require an innovative approach drawing upon the international published literature to inform the direction while embedding a clear research agenda. Sixth, with the palliative care ecosystem underpinned by complexity, the future focus needs to be on improving the interaction between its components to engage change. Failure to do so will result in wasted resources and effort. Finally, using Grembowski's conceptual model has provided a fantastic means to explore the tensions inherent across the palliative care ecosystem. Using this conceptual model has been integral to developing a deeper understanding of the challenges we must all consider going forward.

CHAPTER NINE: CONCLUSION

“Our ultimate goal, after all, is not a good death but a good life to the very end.” Atul Gawande, surgeon, writer, and public health researcher (1965 – present)

Selected for their insight into distinct challenges of service delivery, each of the six publications underpinning this PhD PP examined issues relating to the role and contribution of pharmacists in the pharmaceutical care of the dying for those living in the community. Critical reflection and analysis through a complexity lens highlighted social, behavioural, environmental, and medical factors influencing specific aspects of operationalising care. While these publications made a significant and original contribution to the published literature, they have also contributed to the broader developments within the Australian healthcare and aged care systems.

This thesis aimed to examine the interrelated roles of pharmacists, caregivers, and medications in caring for the dying within the community. Using a conceptual model, it examined the contribution and significance of these previously published articles and the complexity of managing people with palliative needs. Consequently, these six publications collectively provide significant insights into the PCP's role in the pharmaceutical care of the dying. Furthermore, by applying a systems lens, this thesis uncovered a broader understanding of the mechanics of the palliative care ecosystem: an ecosystem with complexity at its heart.

This thesis has identified considerable opportunities and challenges in operationalising pharmaceutical care for the dying. These are related to funding models, clinical communication, and standardisation of care. In addition, the complex challenges faced by people with palliative needs demand that the people who use, provide, fund and direct services solve these collaboratively. In palliative care, this entails working across traditional workplace boundaries and with people with distinct values and viewpoints. How they collaborate is just as crucial to success as what they accomplish. In identifying these opportunities and challenges, this thesis has identified immediate improvements in practice using available resources. However, this thesis also acknowledged the need for further robust research to understand these opportunities and challenges better.

PCPs can significantly support caregivers in managing medications for people living with a life-limiting illness in the home environment. This thesis considered this role throughout. Unfortunately, caregivers can find managing medications burdensome; it is new and complex, often involving non-traditional routes of administration. The insights discussed in this thesis demonstrate that caregivers' needs will be a predominant focus that influences how the palliative care ecosystem evolves.

On a personal note, I conducted this research while employed as a clinician-researcher in an SPCS and at CareSearch. Developing research in the *"real-world"* provided various challenges discussed throughout this thesis. Upon reflection, writing this PhD PP helped to understand the role of the clinician-researcher as a bridge between the *"real-world"* clinical issues and appropriately robust research methods. Importantly, as the role of the clinician-researcher was not a formal one, the clinical workplace did not offer structure and guidance to improve research capability, as would be the case in an academic journey. Instead, stumbling upon good mentors helped navigate ethical constraints and conflicts in balancing the clinical and research commitments. I wonder if programs that encouraged my development as a clinician-researcher would have helped provide opportunities to discuss with other clinician-researchers, facilitating the skills required to be effective in this role?

If dying in the home environment continues to be supported by the government and favoured by the population, there are implications for how organisations deliver services that need addressing; the complexity and demand for palliative care in the home environment are increasing. Using a centralised, top-down approach will not fix the systemic challenges identified within this thesis. Instead, real reform will only be possible if leaders at the local level are empowered to influence change. Conspicuously, they need the tools to support coordinated approaches to care. So, in finishing, will leaders across the palliative care ecosystem advocate for a system that allows for this?

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APPENDIX 1: PUBLICATION ONE

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I was the first and corresponding author for Publication One and was primarily responsible for the manuscript's conception, design, drafting, revision, and final approval. My contribution to the publication was 80% research design, 80% data collection and analysis, and 80% writing and editing.

I have provided the co-authorship declaration separately to this thesis.

Community pharmacists: a forgotten resource for palliative care

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ABSTRACT

Timely access to medicines within the community is important for palliative patients where their preferred place of care is the home environment. The objective of this observational study is to establish baseline data to quantify the issue of poor access to medicines for symptom control in the last few days of life. The list of 13 medicines was generated from medicine use within a metropolitan palliative care unit. A survey was designed to determine which of these 13 medicines community pharmacies stock, the expiry date of this stock, awareness of palliative care patients by community pharmacists and basic demographic characteristics of the community pharmacies. Surveys were distributed, by post, to all community pharmacies in South Australia. The response rate was 23.7%, and was representative of all socioeconomic areas. Each pharmacy stocked a median of 3 medicines (range 0–12) with 1 in 8 pharmacies having none of the 13 medicines listed in the survey. When the data was combined to identify the range of medicines from all pharmacies within a geographical postcode region, the median number of medicines increased to 5 medicines per postcode. Just over 1 in 5 pharmacies reported learning about the palliative status of a patient through another health practitioner. Community pharmacies remain an underused resource to support timely access to medicines for community-based palliative patients. Palliative care services and government agencies can develop new strategies for better access to medicines that will benefit community patients and their carers.

INTRODUCTION

Good symptom control combined with advanced planning is crucial in achieving a greater likelihood of palliative care patients remaining in their preferred place of care for longer.[1] Whether the setting of care is a residential aged care facility, an acute hospital ward, or at home, appropriate levels of support—including medicine availability—must be in place to provide a successful outcome.[2] Models have been developed in palliative care, allowing prompt symptom control through physical and pharmacological interventions for patients.[3] The literature describes the unique challenges of providing care in the home environment, including difficulty in timely accessing prescribed medicines.[4 5] This is particularly relevant in the terminal phase of life where distressing symptoms can appear unexpectedly.

Symptoms experienced by patients in the terminal phase may include one or more of: fatigue, dyspnoea, pain, nausea, delirium, agitation and noisy secretions.[6] These symptoms may begin suddenly or have gradual onset. The ability to manage these symptoms promptly is important in reducing patient and carer distress: quality of life remains the central goal in palliative care. The terminal phase can also be associated with decreased energy levels, reduced ability to swallow and impaired mental state, thus limiting the choice of routes for administering medicines.[7]

The Pharmaceutical Benefits Scheme (PBS) was introduced in Australia in 1948 to subsidise the cost of a range of medicines at the time of dispensing to patients. The patient pays a fixed contribution and the remainder is subsidised by the Federal Government. Some medicines' costs are below the fixed contribution threshold. While the PBS is broad in scope, it is a finite list: some parenteral opioids used in palliative care, such as fentanyl and oxycodone, are unsubsidised. If these medicines are required for people at home and dispensed through their community pharmacy the patient pays the full cost of the medicine. Inpatients within public hospitals receive medicines during their admission without charge. Consequently, there may be a financial incentive for an inpatient admission over community-based care, if patients are unable to cover the costs of the relatively small group of medicines that remain unsubsidised.

In 2004, a specific palliative care section of the PBS was introduced as part of a range of initiatives aimed at improving access to quality palliative care within the community.[8–10] This section allows larger quantities of medicines, such as opioids. The patient must be identified as palliative, in order to access this expanded list of subsidised medicines.

This study was designed to provide objective baseline data to identify gaps that may exist in the timely access to palliative medicines for patients being cared for within the community and consequently recommend strategies for improvement.

The primary outcome measured is the likelihood of prompt access to a range of medicines used to treat common terminal symptoms through community pharmacies.

METHODS

The study cohort comprised all (455) registered community pharmacies in South Australia. The business names and addresses of the pharmacies were obtained from the Pharmacy Regulation Authority SA (PRASA).

To assess the level of relevant medicines currently stocked for end-of-life symptom management within South Australian community pharmacies, a Terminal Phase Medicines (TPM) list was constructed (see box 1). The lead author, a palliative care pharmacist, developed this in consultation with a multidisciplinary group of colleagues. The TPM list was simply intended to provide for a range of medicines and formulations that are prescribed for this patient group.

The list of medicines was selected through a review of discharge prescription data within a local inpatient palliative care unit. A systematic approach was used to develop a short list that illustrated the range of medicines that could be used for symptom control in the last few days of life and may need to be accessed through a community pharmacy. The process of reviewing the list of discharge prescription data took into account the medicines:

- Where evidence existed for pharmacological management of symptoms commonly observed in the terminal phase of a palliative illness;
- Which were registered in Australia;
- That could be administered as either an oral liquid or subcutaneous injection, to account for the dysphagia expected in this patient population.

Where several concentrations existed for the same formulation, the most commonly prescribed item was selected.

A survey (see box 2) was compiled (full survey is available from the primary author) with the purpose of:

- Establishing the likelihood of community pharmacies having medicines from the TPM list in their pharmacy;
- Establish the range of the shelf life of the stock held;
- Identifying level of awareness of palliative care patients or their carers using their service; and
- Identifying demographic characteristics of the pharmacy.

Suggested responses with check boxes were used to prompt for most of the information. These suggested responses were gathered from informal conversations with community pharmacy colleagues. Some open questions were used where necessary. Open questions were evaluated for common themes.

All questions were reviewed by peers to provide objectivity.

Box 1 Terminal Phase Medicines list

Clonazepam 1 mg injection*
Clonazepam 2.5 mg/mL oral drops*
Dexamethasone 4 mg/mL injection*
Fentanyl 100μg/2 mL injection
Haloperidol 5 mg/mL injection*
Hydromorphone 10 mg/mL injection*
Hyoscine Butylbromide 20 mg/mL injection*
Hyoscine Hydrobromide 400 μg/mL injection
Metoclopramide 10 mg/2 mL injection*
Midazolam 5 mg/mL injection
Morphine 10 mg/mL injection*
Morphine 10 mg/mL oral mixture*
Oxycodone 10 mg/mL injection
*Subsidised by the Australian Pharmaceutical Benefits Scheme

Box 2 Summary of Community Pharmacy Survey

Demographics of the pharmacy
- Role of the person completing the survey;
- Postcode of where pharmacy is located;
- Number of pharmacists (full time equivalents) working at the pharmacy;
- Pharmacy usual opening hours; and
- Clinical and supply services offered by the pharmacy.

Awareness of palliative patients
- Knowledge of how many palliative patients had used the pharmacy over the previous 12 months;
- How they became aware of palliative status; and
- The range of issues affecting timely access to these medicines.

Access to stock
- Date of completing the survey;
- Existence of medicines from the Terminal Phase Medicines list in their dispensary; and
- Shortest expiry date of each item held within the pharmacy.

Willingness to be part of an email distribution list

All 455 community pharmacies in South Australia were mailed a personally signed covering letter, the survey, and a return addressed envelope, as suggested by the Dillman Total Design Survey Method.[11] Responders were also offered a facsimile number to which to return the completed survey.

To ensure anonymity of the pharmacies involved, each community pharmacy was allocated an individual code. Once the survey was returned, the data were entered into a secure results database.

All responding pharmacies were allocated to a decile (constructed by dividing the postcodes in South Australia into state-based deciles of Seifa score) of the Socio-Economic Index for Areas (Seifa), Index of Relative Socio-Economic Disadvantage 2006 based on the postcode identified.[12]

No reminders were sent out.

All data were statistically analysed through Stata V.12 software (StataCorp 2011. Stata Statistical Software: Release V.12. College Station, Texas, USA: StataCorp LP). Continuous data was compared using a two-sample Wilcoxon rank-sum (Mann-Whitney) test. Categorical data was compared with a χ^2 test.

RESULTS

Participating pharmacies

A total of 455 surveys were mailed and 12 were returned without opening. Of the remaining 443 pharmacies, 105 (23.7%) completed surveys were returned using the reply address envelope supplied to them. No surveys were returned by fax.

All respondents identified themselves as registered pharmacists (see table 1).

Responding pharmacies had a median of two pharmacists on staff (range 1–10) and participated in a range of services, including preparing dose administration aids (92.4%), Home Medicines Reviews (91.4%) and home delivery service (76.2%). Selected pharmacies offered an after-hours or on-call service (17.1%), provided medicines for a local hospital (15.2%) or provided a clinical service for a local hospital (12.4%).

Forty-two (40.0%) responses came from pharmacies with a rural postcode and 63 (60.0%) from metropolitan Adelaide.

Because surveys were received from a broad range of socioeconomic areas, the data were considered to be sufficiently geographically representative of all pharmacies in South Australia and no follow-up letters were sent out.

Table 1 Identified role of person completing the survey

Role of person completing survey	Number of responses
Proprietor	44
Pharmacy manager	34
Staff pharmacist	26
Locum	1
Pharmacy intern	0
Technician	0

Current stock holdings from the TPM list

Each pharmacy stocked a median of three medicines (range 0–12) from the TPM list (see figure 1). Thirteen (12.3%) pharmacies had none of the medicines on the list.

The percentage of responding pharmacies stocking each medicine is shown in figure 2. The four most commonly held medicines, metoclopramide 10 mg/2 mL injection (73%), morphine 10 mg/mL injection (51%), morphine 10 mg/mL oral solution (43%) and haloperidol 5 mg/mL injection (41%), are all listed on the PBS.

Medicines least likely to be found in a community pharmacy were: oxycodone 10 mg/mL injection (6%) and hydromorphone 10 mg/mL injection (4%).

Data was collected from 73 (22.9%) separate postcodes across South Australia. When the availability of medicines from the TPM list was measured from all pharmacies within a specific postcode, the median number increased from three medicines per pharmacy to five medicines per postcode region.

Metropolitan community pharmacies held a median of 2.5 medicines (range 0–12) from the TPM list. This was significantly lower ($p=0.0063$) than the median of five medicines (range 0–11) held in rural pharmacies.

While none of the pharmacies surveyed held every medicine from the list, 102 (97.1%) pharmacists acknowledged they would employ multiple strategies to source the item, if they did not stock it. The most common strategy (77.2%) to source the item immediately was to contact another pharmacy, on the patient's behalf. A smaller proportion of pharmacists indicated they would contact the doctor on the patient's behalf, to recommend a change in medicine (20.0%), or to recommend a change in strength of the medicine (25.7%). Only two pharmacists indicated they would tell the customer that the medicine was unavailable and then purchase the item through their regular ordering arrangements (which may take a day or so to arrive).

Awareness of palliative patients using the pharmacy

Ninety-one (86.7%) pharmacists surveyed were aware of at least one palliative patient or carer using their business over the previous 12 months. However, only 22 (21.0%) reported learning about the palliative status of a patient through another health practitioner. This latter group held a median of 5.5 medicines from the TPM list (range 0–11). This was statistically higher ($p=0.0057$) than the median of three medicines (range 0–12) held in those pharmacies that did not report learning about the palliative status of a patient through another health practitioner.

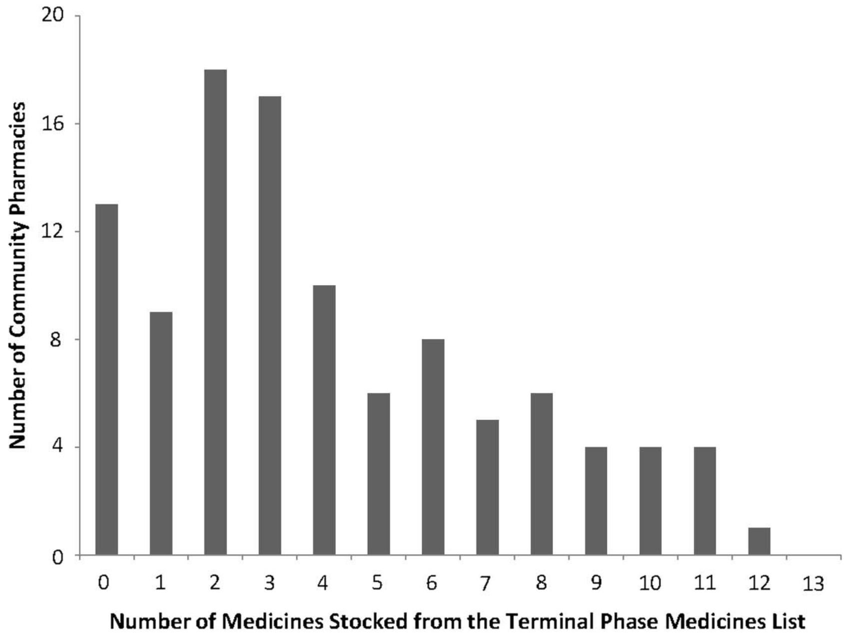

Figure 1 Number of community pharmacies with stock from the Terminal Phase Medicines list.

Compared with metropolitan pharmacists, a statistically greater number of rural pharmacists (34.2% vs 12.5%) learnt about the palliative status of a patient through another health practitioner (p=0.008).

Expiry dates

Figure 3 shows the median expiry (in months) of each medicine along with the minimum and maximum recorded months unexpired. Most items had a median expiry of greater than 12 months, with the exception of dexamethasone 4 mg/mL injection (10 months).

DISCUSSION

These findings provide an objective baseline measurement of the availability of medicines used to treat a number of common symptoms in the terminal phase through community pharmacies, and thus, the likelihood of patients being able to promptly access these medicines. Timely access to metoclopramide 10 mg/2 mL injection is possible from the majority of community pharmacies. The availability of the remaining medicines on the TPM list was limited, across the cohort of pharmacies surveyed. However, pharmacists consistently indicated that in the event they were

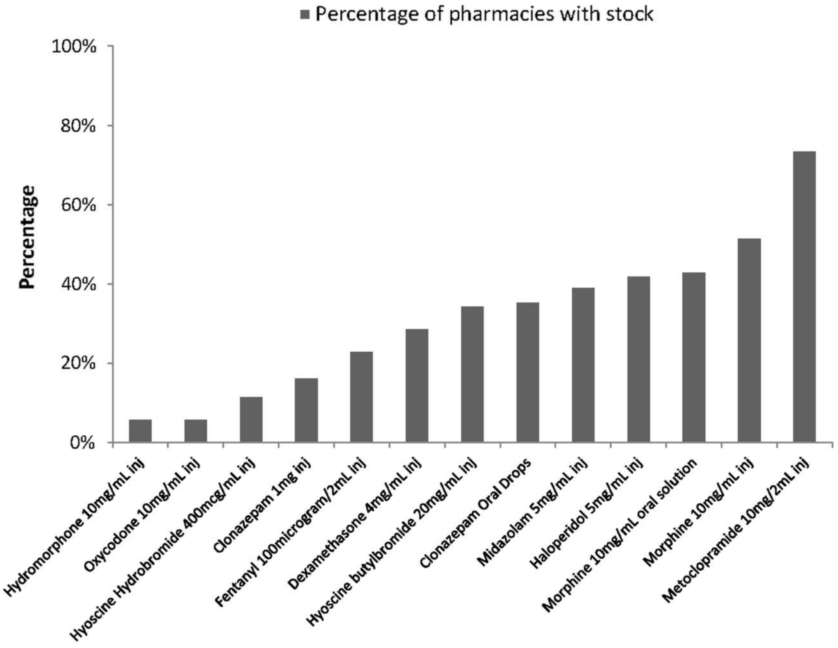

Figure 2 Proportion of pharmacies with medicines from the Terminal Phase Medicines list.

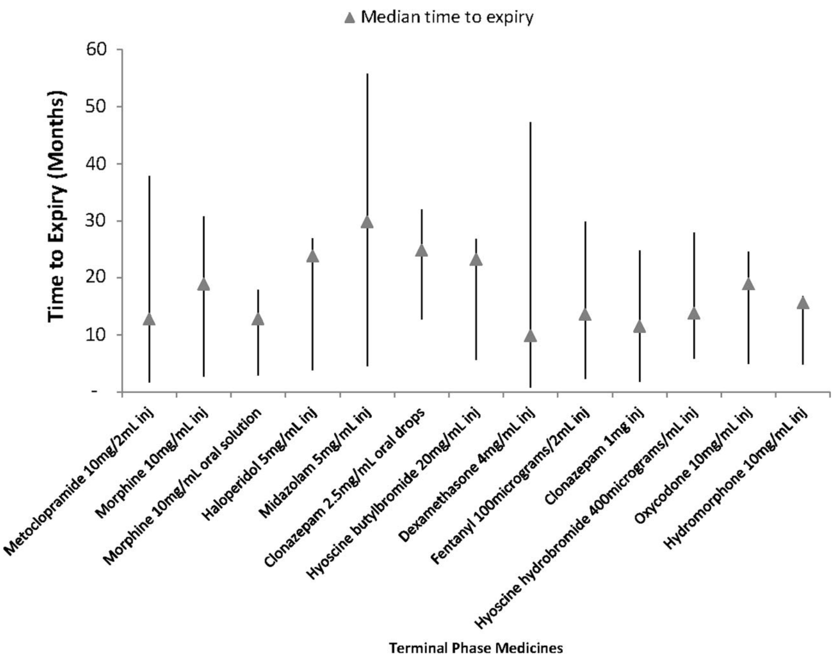

Figure 3 Median, minimum and maximum time to expiry.

unable to supply a medicine, they would contact other pharmacies within the vicinity. This finding combined with the evidence that a larger range of medicines was available across a given postcode provides support for a community pharmacy hub and spoke model. This is where a selected pharmacy within a geographical location undertakes to stock a small range of medicines under an agreement and to support other pharmacies in the geographical region to quickly access the required medicine. The focus for palliative care organisations is to work with community pharmacies and general practitioners to build geographical networks to ensure that a range of medicines are available in a timely manner. Abel *et al*[13] describe this model as circles of care.

The expiry data illustrates this group of medicines can remain in community pharmacy dispensaries for some months without going out of date and affecting stock management. There is opportunity to further improve stock turnover, and thus, the shelf life through developing strategies. This may involve the nomination of a (hub) pharmacy to carry a range of agreed medicines for a geographical area while encouraging consistent prescribing patterns through education programmes for local prescribers. In turn, this could improve the appeal for pharmacy managers to keep this small range of medicines as they are avoiding the cost and inconvenience associated with expired stock.

One in five community pharmacies acknowledged they had learnt about a palliative patient from another health practitioner. This group of pharmacies were statistically also more likely to stock medicines from the TPM list indicating that pharmacies receiving greater communication from other health practitioners are more likely to hold a greater number of medicines for palliative symptoms. Further research is warranted to investigate this association. Anticipatory discussions with the palliative patient's regular community pharmacy at an earlier point of the care journey make practical sense given the speed and unpredictability of deterioration. Community pharmacies are often geographically isolated from the healthcare team, yet are an integral stakeholder with regards to access to medicines.

Community pharmacies provide an important range of healthcare services in the community beyond their traditional supply role.[14] While the focus of this survey was to establish the capacity of community pharmacies to supply core palliative medicines in a timely fashion, other services provided by some pharmacies—including the preparing of dose administration aids and the conducting of Home Medicines Reviews—are valuable interventions for this patient group and their carers.

The TPM list developed for this survey contained 13 distinct items. It is an overview of the range of medicines that are likely to be prescribed, and was based on prescribing patterns from a metropolitan inpatient palliative care unit. It was never intended to be a complete list of medicines that could be used to treat palliative symptoms. Many of these medicines overlap in the symptoms they are designed to manage (see figure 4).

Palliative patients being managed in the community often have less complex needs than those cared for in hospices and inpatient facilities. Therefore, it is likely that the range of medicines needed within the community setting to treat terminal-phase symptoms, may

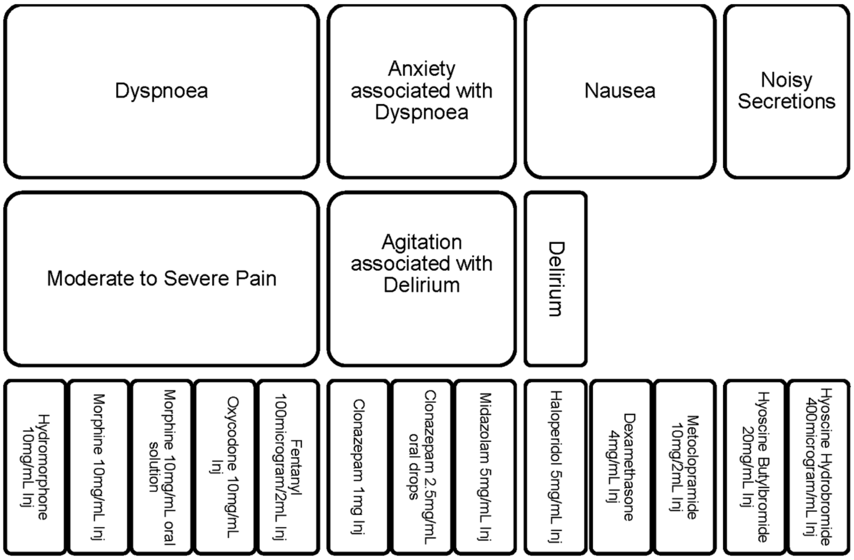

Figure 4 Overlap of symptoms managed by Terminal Phase Medicines list.

be less than required in a tertiary inpatient palliative care unit. Potentially, better engagement between community-prescribing practices and pharmacy stock holdings could be directed at a narrower range of medicines that address more than one symptom.

In Australia, consensus guidelines exist to support prescribers and pharmacists alike with regards to the appropriate medicines to prescribe and to stock for palliative symptoms.[15] These results show there is a poor fit between these guidelines and the medicines community pharmacies stock. This probably reflects diversity in prescribing practices, and the relatively small number of palliative care patients that access medicines through an individual pharmacy each year. Therefore, pharmacy managers are currently unable to reliably anticipate which medicines to make available. In practical terms, this may well lead to delays in access to medicines for the management of terminal symptoms. This observed poor fit between stock levels and prescribing practices paves the way for more structured education of community prescribers and pharmacy managers to encourage use of a narrower list of medicines for the range of terminal symptoms in non-complex community patients.

Organisations across the globe have studied the problem of timely access to palliative medicines through different lenses. Palliative medicine kits containing a small number of medicines have been used in the home as a means to anticipate symptoms and address comfort for dying patients being cared for in the community.[1 16–18]

In Australia, a range of injectable emergency drugs are provided to prescribers for use in situations where urgent access to medicines is required. This includes medicines that are useful in treating symptoms common in the terminal phase.[19] This list of medicines is available free of charge to prescribers who may order up to a specified maximum quantity of each medicine via the PBS, on a monthly basis. The prescriber can then issue this restricted range of medicines free to patients, in an emergency. This is known as the Prescriber Bag (Emergency Drug) Supply.

A succinct TPM list would be the foundation for a broad range of applications, including supporting community pharmacy hubs where pharmacies within a local geographical network can communicate between each other to coordinate timely medicine supplies. This model is likely to succeed within a metropolitan area where there is a median of 2 (range 1–17) pharmacies per postcode region. This model could also work in selected rural centres.

The Australian Government has recently invested in an electronic health (eHealth) record system that places the patient at the centre of their own healthcare. This offers the capacity for patients and their healthcare providers to securely access health information, thus improving communication between healthcare providers, with the potential for better advanced care planning and improved medicines management for community patients.

Lucey *et al*[5] performed a qualitative systems analysis of the process by which palliative patients obtain medicines. They identified a number of factors that have caused delays in accessing medicines. These include medicines not being stocked in community pharmacies, specific formulations being unavailable and medicines being unsubsidised through federally funded schemes. Our data supports their findings and quantitatively demonstrates the likelihood of accessing a range of medicines in the last few days of life.

Limitations

Medicines were selected for the TPM list based on usage within one metropolitan inpatient palliative care unit. Whether the concentrations selected for each medicine reflect community prescribing for palliative symptoms is unknown. For example, the availability of the 10 mg/mL hydromorphone injection was the lowest of all the medicines. The authors note the 10 mg/mL hydromorphone is about five times the potency of the other parenteral opioids included within the list. The results for stock levels of this medicine may have been different if the equivalent potency strength (2 mg/mL) of hydromorphone was included within the TPM list.

The study was conducted using a postal survey. As the responders were asked to use information from the pharmacy shelves—including stock availability and expiry dates—the postal survey was considered more practical to use in this instance. Irrespective of the practical intentions, postal surveys have a larger response rate to online surveys.[20]

The response rate of 23.7% achieved with one mailing of the survey is low. However, since the responses came from a wide distribution of socio-economic areas and the proportion of rural postcodes expected, this was considered an acceptable representative sample of the overall pharmacy population.

The use of a survey relies on recall which can be biased. The use of suggested responses and checked boxes within the survey to encourage information may have shifted the thinking of some respondents from actual to best practice. However, given the range of responses, it appears likely the strongest viewpoints have been reported.

While postcodes are a valuable system in arranging data and models of service delivery across a geographical region, it is important to consider that postcodes across Australia vary significantly by population and area. The largest South Australian postcode region measures 258 139 km^2 making it larger than the land area of the UK. It is unfeasible to consider a hub and spoke model in such a remote part of the country.

RECOMMENDATIONS

Health practitioners should identify the patient's usual community pharmacy and involve the pharmacist in discussions about care planning related to medicines for community-based palliative patients in advance.

Palliative care organisations should collaborate with medical, nursing and pharmacy organisations to develop an agreed core medicines list that would support symptom management in non-complex community palliative patients. It should take into consideration cost, access to government subsidies (eg, PBS), pharmacokinetics and shelf life.

Policy makers need to put in place incentives for community pharmacies to hold a small range of medicines that may be required urgently, but so infrequently, that loss of stock due to expiry is otherwise a financial burden.

CONCLUSION

Enabling palliative patients to receive care in their home environment is good public health practice. This study provides valuable evidence to enable palliative care services and government agencies to develop new strategies for better access to medicines for community patients. While there are many challenges that affect symptom control for palliative patients in their home environment, access to medicines for the relief of frequently encountered symptoms should not be one of them.

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Contributors PAT initiated the collaborative project, designed the Terminal Phase Medicines (TPM) list and the community pharmacy survey, monitored data collection for the whole trial, cleaned and analysed the data, and drafted and revised the paper. He is guarantor. JG and PH supported the design of the community pharmacy survey, analysed the data, and revised the draft paper. BM supported the design of the community pharmacy survey, and revised the draft paper. DCC supported the design of the TPM list, and revised the draft paper. DSR designed the TPM list and the community pharmacy survey, and revised the paper.

Competing interests None.

Ethics approval Ethics approval for the study was obtained from the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC).

Provenance and peer review Not commissioned; externally peer reviewed.

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APPENDIX 2: PUBLICATION TWO

Citation

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Contribution Statement

I was the first and corresponding author for Publication Two and was primarily responsible for the manuscript's conception, design, drafting, revision, and final approval. My contribution to the publication was 80% research design, 80% data collection and analysis, and 80% writing and editing.

I have provided the co-authorship declaration separately to this thesis.

Paul Tait
Bel Morris
Timothy To

Core palliative medicines: meeting the needs of non-complex community patients

Background

There are a number of challenges facing people in the last days of life who wish to receive care in their home environment. This includes timely access to medicines for symptom control.

Objective

This article outlines the development of a concise list of core medicines that can provide symptom control in non-complex patients in the last days of life. The list is based on practical criteria including evidence of efficacy, affordability, the option for parenteral administration, availability on the Pharmaceutical Benefits Scheme and the doctors' emergency drug supply list.

Discussion

A list of core medicines can facilitate timely prescribing and supply of essential medicines for end-of-life symptom management. However, the development of this list should not replace planning and routine involvement of community resources. Multidisciplinary education strategies are needed to ensure that the core medicines list is utilised effectively by doctors, pharmacists and community nurses.

Keywords

general practitioner; palliative care; pharmacies; medication systems; terminal care

Across Australia, there are approximately 64 000 palliative care patients annually and a significant proportion are cared for in the community.[1] The general practitioner, with the support of palliative care organisations and community services, is well placed to lead their care.

For patients in palliative care who wish to spend their last days at home, good symptom control and advanced care planning are essential.[2] The literature describes many challenges to providing good symptom control for people at home, including timely access to medicines,[3,4] which is especially important in the last few days of life (terminal phase) when symptoms can appear or worsen quickly without warning.[5]

Commonly encountered symptoms at the end of life have been well described and include fatigue, pain, nausea, dyspnoea, noisy breathing and delirium.[6] Australian guidelines are available for symptom management in palliative care and they offer a broad range of pharmacological choices to manage these symptoms.[7] However, this range may be unnecessary for uncomplicated community-based palliative care patients.

A Western Australian group developed a list of almost 50 medicines considered essential for symptom control in palliative care patients to guide aged care facilities and their pharmacies in the range of medicines required.[8] However, most community pharmacies find it difficult to hold all of the listed medicines and maintain a minimum stock turnover to make it sustainable to stock this range of medicines.[9]

Shorter lists of medicines for palliative care have been published in the literature.[10–12] Each of these lists has been developed as a result of prescriber surveys, focusing on familiarity of use. This methodological approach fails to acknowledge practical aspects of accessing medicines, such as national medication regulations (eg. licensing and subsidy), expense (to the patient or health care system) and sustainability for pharmacies.

In this article, we describe the development of a core medicines list, which is aimed at guiding prescribers, community nurses and pharmacists in supporting the care of patients in their homes, during the terminal phase of life.

Core medicines list development

An expert working group was convened. The group consisted of clinicians from three tertiary palliative care services in South Australia, a palliative care consultant, three palliative care

Table 1. Representative group of stakeholders
South Australian (SA) Health palliative care nurses
All SA Health palliative care physicians
All SA Health palliative care pharmacists
All SA Health directors of pharmacy departments
Representatives of Country Health SA
Representatives of SA Ambulance Service
SA Pharmacy representatives
Representatives of all SA Medicare Locals and Divisions of General Practice

Table 2. Core medicines for the terminal phase
Clonazepam 1 mg injection
Morphine 10 mg/mL injection
Haloperidol 5 mg/mL injection
Metoclopramide 10 mg/2mL injection
Hyoscine butylbromide 20 mg/mL injection

pharmacists, two nurse practitioner candidates and a tertiary palliative care service manager who chaired the group.

The expert working group commenced with a gap analysis of the Western Australian document[8] designed to guide aged care facilities.The 49 separate formulations listed in this document were reviewed against the Palliative Care Therapeutic Guidelines. This was achieved by applying the following practical criteria, based on work by Rowett et al:[13]

- evaluating the evidence for management of five symptoms commonly seen in the terminal phase of life (pain, dyspnoea, nausea, noisy breathing and delirium)
- comparing costs of each medicine (including the availability of government subsidies)
- assessing the route(s) of administration, acknowledging the frequency of dysphagia at the end of life
- considering medicines available on the Pharmaceutical Benefits Scheme (PBS) emergency drug supply (doctor's bag) list.

A draft list of medicines was distributed to a representative group of stakeholders (*Table 1*), who were invited to review the medicines and to provide literature to support any recommendations to change. This group provided feedback but no literature was presented to challenge any of the decisions made by the expert working group. *Table 2* lists the final five medicines selected.

Discussion

Given the high prevalence of dysphagia at the end of life, all of the core medicines for this project were selected for subcutaneous administration.[7]

Pain

Pain is a frequent complication of cancer and many other life-limiting illnesses. Poorly controlled pain causes significant distress and disability. Morphine is efficacious and equivalent to other opioids in the treatment of moderate-to-severe pain.[14–16] It is affordable for patients and the healthcare system. The 10 mg/mL strength was selected for the core medicines list, for safety and ease of calculation, despite the availability of 15 mg/mL and 30 mg/mL in the PBS emergency drug supply list.

Parenteral oxycodone and fentanyl were excluded as their non-PBS status made these medications expensive. Hydromorphone is subsidised through the PBS and can be used in renal failure (with dose reduction) as the kidneys account for only a small amount of the elimination of the parent drug and its metabolites.[17] These points make hydromorphone a suitable second-line agent when morphine is contraindicated. However, with a potency of about five times that of morphine, hydromorphone presents significant safety concerns for prescribers unfamiliar with its potency.

Dyspnoea

Dyspnoea, or breathlessness, is the uncomfortable sensation or awareness of breathing or needing to breathe. For some patients, anxiety may be a contributing factor that may also need to be addressed.

Opioids have a clear role in the relief of dyspnoea and morphine has the best evidence supporting its use as first-line therapy.[18] Benzodiazepines, including clonazepam and midazolam, have an important role in supporting patients with dyspnoea and its significant associated anxiety. The long half-life of clonazepam allows administration as a subcutaneous bolus once or twice a day, to deliver a sustained effect. By contrast, midazolam, which has a short half-life, requires a syringe driver or frequent subcutaneous administration to provide the equivalent outcome. Both sublingual and subcutaneous clonazepam have a quick onset of action, making clonazepam suitable for breakthrough symptoms. Dry mouth is a frequent problem at the end of life and can affect sublingual absorption; thus subcutaneous injection is the more pragmatic choice for patients in the last days of life.

Delirium

Delirium is the acute or recent development of confusion and altered consciousness occurring in a fluctuating manner. Despite no medication being registered through the Australian Therapeutics Goods Administration for the management of delirium, antipsychotics are first-line pharmacotherapy, with a few exceptions such as the use of benzodiazepines in alcohol withdrawal.[19] With no demonstrated difference in efficacy, compared with atypical antipsychotics, the typical antipsychotic haloperidol is recommended on the basis of scientific evidence, cost, availability, familiarity and option for parenteral administration.[20] Haloperidol injection, 5 mg/mL, is also available through the PBS emergency drug supply list.

If sedation is required, particularly in instances of terminal restlessness, clonazepam has a favourable pharmacokinetic profile (as outlined above) and may avoid the need for a syringe driver, which may be problematic in an agitated patient.

Nausea

Nausea, with or without vomiting, can be intermittent or persistent. Previously published data indicate that metoclopramide 10 mg/2 mL injection is already widely available through community pharmacies.[9] Thus, it is included in addition to haloperidol, which also has anti-emetic properties. Parenteral metoclopramide 10 mg/2 mL is also available through the PBS emergency drug supply list.

Noisy breathing

Noisy breathing can be present in over 40% of dying people.[21] This symptom may be more distressing for the family and treating staff than for the patients themselves. There is no evidence to show that any of the commonly used anticholinergic agents are superior to each other, or against placebo or octreotide, in the management of noisy breathing.[22] Atropine and hyoscine hydrobromide cross the blood–brain barrier and may contribute to delirium and sedation. By contrast, hyoscine butylbromide does not cross the blood–brain barrier and is available through the PBS emergency drug supply list.

For these two reasons, hyoscine butylbromide 20 mg/mL injection was selected as the preferred anticholinergic agent.

General considerations

The introduction of a core medicines list must involve multidisciplinary education programs targeted to prescribers, community nurses and pharmacists. Engagement with prescribers and pharmacists ensures that the particular medicines that are prescribed are also the ones that are stocked by community pharmacies.[23] Without these multidisciplinary discussions, there is a risk that prescribers, through personal preferences, will prescribe a range of medications that are unsustainable for community pharmacies to hold.[9] This will compromise the timely control of symptoms simply because the pharmacist is unable to anticipate which medicines to stock.

The core medicines list is a safety net for patients who deteriorate suddenly at the end of life. It is not a substitute for good advanced planning. Advanced preparation for deterioration in palliative care patients provides opportunities for establishment of the required ancillary supports from services such as palliative care, community nursing, domiciliary services, as well as engagement with the community pharmacy. It also allows for tailored prescribing, adapting to the patient's needs, taking into account established medicines for symptom control and significant comorbidities. Non-pharmacological strategies for symptom management also remain a key component of quality end-of-life care.

Recommendations

General practitioners should engage with the patient's usual community pharmacy when prescribing for symptom control at the end of life, to ensure the suitability and availability of medications. Palliative care organisations should collaborate with community-based medical, nursing and pharmacy organisations to implement a core medicines list. Policy makers need to put in place incentives for community pharmacies to hold these five core medicines to support end-of-life care in the community, in a similar model to the PBS emergency drug supply list.

Future considerations

Plans are underway in South Australia to assess the sustainability of community pharmacies stocking these medicines and to determine the factors that support this. The aim is to use the patient's usual pharmacy, where possible, to provide prompt access to symptom control. This pilot program involves training for clinicians, as prescription guidance is a key element of providing sustainable access to these medicines.

Conclusion

This list is intended to support timely access to medicines for palliative patients where their preferred place to die is in the community. It is paramount that the development of core medicines lists takes into account the practical needs of carers and patients, and is supported by a multidisciplinary education campaign to ensure prescribing mirrors medicine availability.

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APPENDIX 3: PUBLICATION THREE

Citation

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Contribution Statement

I was the first and corresponding author for Publication Three and was primarily responsible for the manuscript's conception, design, drafting, revision, and final approval. My contribution to the publication was 80% research design, 50% data collection and analysis, and 80% writing and editing.

I have provided the co-authorship declaration separately to this thesis.

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Research

Improving community access to terminal phase medicines in Australia: identification of the key considerations for the implementation of a 'core medicines list'

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Abstract. During the terminal phase, access to medicines is critical for people wishing to spend their last days of life at home. Yet, access to medicines can be problematic. The aim of this study was to report the perspectives of specialist and generalist health professionals (HPs) on the issues of community access to medicines for this vulnerable group. A qualitative descriptive study design investigated the views of HPs working in palliative care roles in South Australia. Nurses, doctors and pharmacists described their experiences of accessing medicines for management of terminal phase symptoms during semi-structured focus group discussions. Content analysis identified six themes including: 'Medication Supply', 'Education and Training', 'Caregiver Burden', 'Safety', 'Funding' and 'Clinical Governance'. Future projects should aim to address these themes when developing strategies for the management of people wishing to die at home.

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Introduction

Community-based palliative services have demonstrated that encouraging choice of place of death is associated with cost savings (Gomes *et al.* 2013). Yet, home deaths are a reality for only 14% of Australians, despite most indicating the family home as their preference (Bell *et al.* 2010; Swerissen and Duckett 2015). Comparable countries, such as Ireland and France, demonstrate significantly higher rates (Broad *et al.* 2013). Given an environment of mounting hospital-based costs for palliative care services (Australian Institute of Health and Welfare 2014), further improvements to the Australian community-based model for the dying has merit.

Good symptom control is a critical enabler for people to remain at home, including residential aged care residents (Hudson 2013). However, timely access to medicines through community pharmacies is problematic, with pharmacists unable to anticipate which injectable medicines to stock (Lucey *et al.* 2008; Tait *et al.* 2013). As such, a 'core medicines list' (the List) – comprising subcutaneous medicines used to manage symptoms commonly seen in the terminal phase (Box 1) – was developed, increasing the likelihood of these medicines being prescribed and stocked by community pharmacies (Tait *et al.* 2014). A variety of applications for similar lists of core medicines have been implemented internationally (Box 2).

Initiatives improving community-based palliative services (including access to medicines) are complicated by the variety of organisations involved and their separate governance arrangements. These challenges are poorly documented, from the perspective of the HP. The aim of this study was therefore to identify and describe the considerations for the implementation of the List to improve access to medicines for people who wish to remain in the community (including residential aged care homes) during the terminal phase.

Methods

A semi-structured focus group approach was used to identify the views of HPs on the critical points to be considered when implementing strategies aimed at improving access to medicines for the dying.

Participant recruitment (W. H. Cheung)

Health professionals were recruited using thoughtful purposive sampling, to select those who have had previous involvement with community-based palliative services and likely to be involved in the implementation of strategies supporting access to medicines. Doctors, nurses and pharmacists from both specialist palliative care and generalist settings, with awareness of the List, were invited to participate. Enrolment into each group was based upon order of response and availability. All participants were coded to ensure their comments were de-identified.

What is known about the topic?

- Many patients express a desire to remain at home during the terminal phase; however, rates of home deaths in Australia are low in comparison to countries with similar health systems.

What does this paper add?

- This paper identifies six key themes regarding the provision of medicines that providers must be mindful of during the planning and implementation of terminal care in the community setting.

Focus groups (W. H. Cheung, K. Staff, M. Wiese and P. Tait)

Focus groups included four to six participants, consisting of a heterogeneous mix of disciplines. Two researchers facilitated and documented the discussions. A semi-structured approach was implemented, with the participants discussing the role of the List and issues in applying the List to the community setting. No further guidance was provided by the facilitators during the discussion.

Focus groups were audio recorded and transcribed verbatim using Adobe Audition CS6 (Adobe Systems Inc., San Jose, CA, USA). The unedited transcripts were independently checked against the recording by two researchers for accuracy before analysis.

Data analysis (K. Staff and P. Tait)

Two researchers independently read the transcripts for each focus group, establishing a preliminary list of themes and acknowledging any preconceptions determined by the research question. They then organised data elements of the transcripts line by line to identify and assign meaning units – defined as a text fragment containing information regarding prescribing, accessing, administering or monitoring of medicines in the terminal phase (Malterud 2012). A new meaning unit was allocated when a different element was introduced into the conversation. Meaning units were allocated independently by two researchers using consensus to combine results. Thematic analysis was performed and the researchers re-examined the assignment to ensure statements were contextualised. An overview analysis of the individual focus groups determined that a high degree of inter- and intra-group thematic homogeneity existed, suggesting the data could be combined with minimal bias.

Box 1. South Australian 'Core Medicines List'

Clonazepam; 1 mg mL^{-1} injection
Morphine: 10 mg mL^{-1} injection
Haloperidol: 5 mg mL^{-1} injection
Metoclopramide: 10 mg per 2 mL injection
Hyoscine butylbromide: 20 mg mL^{-1} injection

Ethical consideration

This study was approved by the Southern Adelaide Clinical Human Research Ethics Committee (Application Number: 165.13) and the University of South Australia Human Research Ethics Committee (protocol 0000031470), in accordance with the National Health and Medical Research Council (NHMRC) National Statement.

Results

A total of 26 HPs were invited to participate in three focus groups, with 16 (62%) participants – 6 doctors, 6 pharmacists and 4 nurses – attending. Eight participants identified palliative care as their main field (Medical Specialist, MS; Pharmacist Specialist, PS; Nurse Specialist, NS), with the remainder identifying as generalists with experience in palliative care (Medical Generalist, MG; Pharmacist Generalist, PG; Nurse Generalist, NG).

In total, 187 meaning units were identified from the data, resulting in six broad themes. Table 1 defines each theme in descending frequency. The discussion around each theme was multidisciplinary and all components of the medication management cycle were raised in discussion. References to the List by participants from all professions were predominantly positive in nature.

Medication supply

Pharmacists frequently raised this theme (Fig. 1).

Box 2. Applications of a standardised medicines list

Just-in-case box
A small supply of medication commonly required for symptom management, which is stored in the patient's home 'just in case' it is needed and can only be administered by an appropriate nurse or doctor (Walker and McPherson 2010; Rosenberg *et al.* 2015).

Emergency Care Paramedic (ECP) service
Emergency Care Paramedics carry a range of medicines suitable for managing symptoms commonly observed in the terminal phase. Allows patients to betreated at home or in their home surrounds, avoiding unnecessary hospital transfer (Swetenham *et al.* 2014).

Anticipatory prescribing toolkit
Pre-emptive orders or prescriptions for common symptoms designed to enable prompt symptom relief for whenever the person deteriorates, allowing immediate implementation (Faull *et al.* 2013).

Residential aged care home imprests
Standard list of recommended medicines available through the organisation (Brisbane South Palliative Care Collaborative 2013).

Table 1. Definition of health professional-identified themes generated during the focus groups for accessing medicines in the community

Theme	Brief description
1. Medication Supply	Issues relating to systems in place to ensure medicines are available for management of symptoms anticipated in the terminal phase, while minimising medicines loss due to spoilage and expiry.
2. Education and Training	Matters relating to access to knowledge, know-how, skills and competences required by Health professionals to deliver good care to patients in the terminal phase.
3. Caregiver Burden	Activities that place a strain on the wellbeing of caregivers supporting the patient to remain at home during the terminal phase.
4. Safety	Problems affect the level of care, including iatrogenic harm.
5. Funding	Issues associated with monetary cost, inconvenience or inequity.
6. Clinical Governance	Matters relating to professional and legal accountability, as well as processes that may present barriers to healthcare service redesign.

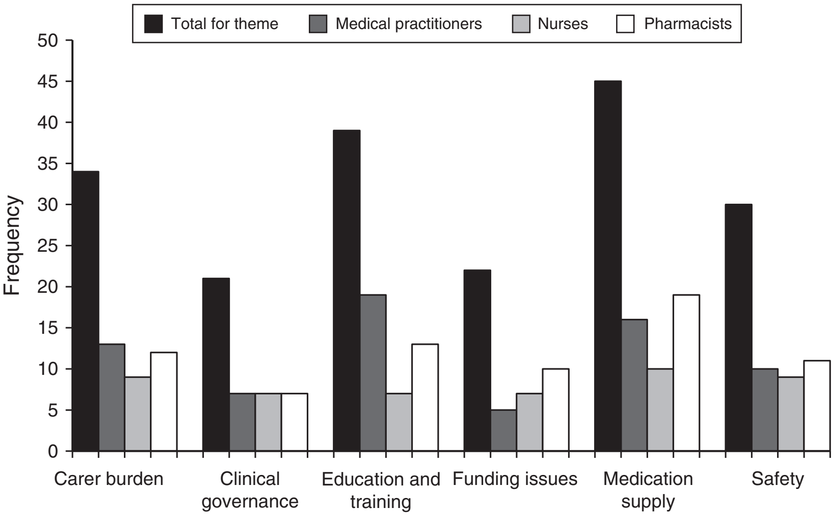

Fig. 1. Major themes identified and the frequency it was discussed during three focus groups. Data are stratified by the health professional who initiated the discussion. Number of participants in focus groups totalled 16 (6 medical practitioners, 6 pharmacists, 3 nurses), with a mixed background of general practice ($n = 8$) and palliative care speciality ($n = 8$).

The List guided pharmacists on preferential subcutaneous formulations to stock, knowing further supply can be rapidly obtained for ongoing symptom control.

> If somebody has a script for 100 ampoules of morphine 10 mg . . . you just don't have the safe space to be able to stock that [in the pharmacy] . . . so you've always got some . . . here is some to go on with . . . and then we will deliver the rest [PG].

Participants highlighted a range of applications for the List to support timely access to medicines in the terminal phase, including availability through hospitals, ambulance services, emergency doctor's bag and imprests within residential aged care homes. A complex network of systems was deemed essential to facilitate people to stay in the community. In particular, the sudden and unexpected nature of the terminal phase was regularly noted as a challenge to the timely access to medicines, particularly in rural locations.

> There is obviously a variation between metropolitan and rural nursing in terms of access to pharmacies . . . the pharmacies that are open at the time you need the medication, if it hasn't already been prescribed or at the home. . . [MS].

Education and training

Doctors frequently raised this theme (Fig. 1). The List needed to be taught in conjunction with good clinical skills: in order to appreciate the many unforeseen issues that can develop in the terminal phase. Participants acknowledged the broad remit of education programs, including: use of syringe drivers, safe disposal of sharps, prescribing guidance, advance care planning and how to anticipate needs. Engaging generalist HPs, through education (using the List as the focus), was identified as an opportunity to develop confidence in providing care.

> In my work in nursing homes, they know very well the GPs are uncomfortable with doing palliative care because they . . . under prescribe morphine . . . I guess with this [core medicines] list . . . one feels the GP needs to be brought up to speed [with information to support safe prescribing] [MG].

A range of enablers supporting access to clinical information were proposed, including the availability of short and succinct guidelines and use of smartphone technology.

Caregiver burden

All disciplines contributed equally to this theme (Fig. 1), reflecting the widely acknowledged concern for the responsibility that caregivers have in caring for people within the home. HPs agreed that a good relationship with the caregiver enhances the quality of care in the home during the terminal phase, with older and non-healthcare trained caregivers at greatest risk. Enablers for caregivers to confidently provide good end-of-life care included clear communication from HPs and good education strategies incorporating written instructions.

> The classic is giving a lot of 'PRNs' [*pro re nata* or 'as required' medications] for narcotics . . . I usually [advise carers] you give a dose, if no relief in pain in an hour repeat the dose, if there is no relief in pain, call us to get further advice. It might be that we may ask you to give the third dose, but you would not leave particularly elderly people with that decision. . . [MS].

The caregiver is often relied upon to collect all prescribed subcutaneous medicines. Delays in accessing medicines contribute to setbacks in education and training for the caregiver on how to administer them. Furthermore, this training should extend to practical issues, such as how to break open vials and description of equipment to be used.

> It is the families who have to get [the medicines] from the community pharmacy and bring it back home. And then . . . the nurse has to come around. . . And make this up then . . . and that introduces another factor, they are really busy and they can't always come at the time [they say they will] . . . there could be a window of about two hours [PS].

Resistance from caregivers to store subcutaneous medicines in the home was discussed, as they may find this a confronting reminder of their loved one's approaching death.

> The way I sell it [asking carers to fill a prescription for subcutaneous medicines] is to talk about the oral route . . . particularly for people with regular medications for symptoms . . . that we have a backup plan if they suddenly [deteriorate] . . . not only if they lose their oral route permanently, but if they are vomiting [MS].

Safety

All participants contributed to this theme, regardless of their professional background (Fig. 1). A range of concerns affecting the patient, their caregiver and HPs were expressed, including poor staffing ratios in residential aged care homes, dosing errors and risk of drug diversion or misuse by family members.

> One of the important things from the outset of this work . . . is not only about giving them [the patients] the medicines . . . but also requires we have due diligence around recovering what is not used . . . because of diversion and misuse . . . there are data that highlight that most of the diversion actually comes from family members or people who know them [SP].

Safety concerns discussed for HPs included being identified as targets when arriving at a private dwelling.

> I guess the risk for the nursing staff carrying [medicines] . . . if people in that street [are aware] and you are coming in regularly. . . [NG].

The issue of conservative prescribing practices was also discussed.

> It would be nice to see the same attitude to the risk of diversion applied to poor symptom control . . . concern about the person left in pain . . . versus the risk of administration of medication [MS].

Funding

Pharmacists frequently described funding concerns (Fig. 1). Although all agreed on the potential benefits of anticipatory prescribing, this led to robust discussion concerning cost to the consumer and there is no guarantee the medicines prescribed will be utilised. Furthermore, concerns were voiced regarding inequity of access and inconsistency of service provision, resulting from different funding models in accessing medicines through community pharmacies and public hospitals. Subsidised access to some medicines is restricted by the Pharmaceutical Benefits Scheme (PBS) rules, leaving them unsubsidised when prescribed for particular indications. Patients living in metropolitan locations were seen to have an advantage over their rural counterparts, given the ability of public hospitals to subsidise non-PBS items.

> Everyone should have access to the same medications with the same price. Just because you have a different postcode, doesn't mean you should have less access to the same supports, benefits and treatments. . . [NG].

For some, prescribing is influenced by the degree of availability through the PBS, rather than sound clinical principles.

> At the general practice level, sometimes [the PBS] influences your prescribing . . . you usually have haloperidol in preference to midazolam because of the cost. When you have a terminal illness, some families don't mind . . . but to a pensioner family . . . [the cost] can be worrying [MG].

Health professionals too accepted some of the cost, with community pharmacists absorbing the cost of expired medicines and GPs asked to prescribe outside of scheduled (and funded) activity.

Clinical governance

While working under distinct governance structures, different organisations engaged with care cooperated when delivering end-of-life care; the endorsed List was considered a means to encourage such interdisciplinary conversations. Legislative barriers to medicine access relating to the licencing of residential aged care homes to carry opioids on their imprest were identified.

Discussion

This study has identified six key themes, including: 'Medication Supply', 'Education and Training', 'Caregiver Burden', 'Safety', 'Funding' and 'Clinical Governance'. These themes need to be considered when developing strategies to improve access to terminal phase medicines. Traditionally, medicines required for those entering the terminal phase are accessed through their usual community pharmacy or local hospital. This study emphasises the need for engagement with a wider group of stakeholders.

Access to the List needs to be in conjunction with the development of clinical skills to deal with the many unforeseen issues that can develop in the terminal phase. This is vital for primary HPs who, because of infrequent exposure, may lack experience (O'Connor *et al*. 2013). Education programs need to be broad, considering the range of issues that may develop in the terminal phase (Linge-Dahl *et al*. 2015).

Medication management is a complex task frequently allocated to caregivers (Ewing and Grande 2013), with delays in accessing medicines being compounded by a lack of caregiver training and education (Payne *et al*. 2015). When multiple medicines are required, education regarding medicine administration needs to be coordinated with their physical supply (Virdun *et al*. 2015). Enablers for caregivers to confidently provide terminal phase care include clear communication from HPs and good education strategies incorporating written instructions (Payne *et al*. 2015).

The development of the PBS Palliative Care Schedule has tried to address the issue of inequality of access through the subsidy of medicines frequently used in the terminal phase. However, some of the core medicines, such as clonazepam injections, have restrictions placed upon them, limiting their subsidy. Given the multidisciplinary needs of the dying, any tools developed must consider all stakeholders with appropriate flexibility.

Strengths and limitations

We are confident that these six themes are robust, as they were consistently encountered across the focus groups. All analysis was conducted independently by two researchers, resulting in confluent outcomes.

An inherent weakness with this study design is the value placed on theme frequency, with no measure of emphasis or duration of discussion. Patients and caregivers were also excluded from the study, with concerns that HPs may influence their views. Furthermore, dominant personalities may have influenced the direction of the focus groups, particularly as the groups contained a mix of specialist and generalist practitioners.

Recommendations

Clinicians must recognise the value of partnerships with other primary health providers when caring for palliative patients in the home environment.

Primary Health Networks (PHNs) must encourage connectivity of palliative services for people living in the community through addressing these themes, ensuring sustainability of services.

Funders must recognise the multidisciplinary nature of palliative care services when developing community-based projects and account for the range of barriers we have identified.

Conclusions

Community access to medicines during the terminal phase is a complex process with multiple elements. This study reinforces the value of multidisciplinary input into terminal phase care. Furthermore, implementation of strategies enabling people to be cared for at home has significant implications for caregivers. Barriers to this result in poor outcomes for people wishing to die at home, with negative effects on GPs, residential aged care facility staff and caregivers. This aspect of care requires the attention of primary HPs, PHNs and funders, with each needing to recognise the interdisciplinary nature of the delivery of community-based palliative care, as well as the responsibilities taken on by caregivers at this critical point of care.

Conflicts of interest

The authors declare that they have no conflicts of interest.

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APPENDIX 4: PUBLICATION FOUR

Citation

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Contribution Statement

I was the first and corresponding author for Publication Four and was primarily responsible for the manuscript's conception, design, drafting, revision, and final approval. My contribution to the publication was 80% research design, 50% data collection and analysis, and 80% writing and editing.

I have provided the co-authorship declaration separately to this thesis.

Factors Affecting Access to Subcutaneous Medicines for People Dying in the Community.

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Factors Affecting Access to Subcutaneous Medicines for People Dying in the Community.

Objectives: Common terminal phase symptoms include pain, dyspnoea, anxiety, terminal restlessness, nausea and noisy breathing. This study aimed to identify the proportion of community pharmacies across two Australian states stocking medicines useful in managing terminal phase symptoms, while exploring factors considered predictive of pharmacies carrying a broad range of these medicines.

Methods: Community pharmacies from across the states of New South Wales (NSW) and South Australia (SA) were concurrently mailed a survey. Respondents were asked questions relating to medicines stock levels, the expiry date of stock, awareness of people with palliative care needs and basic demographic characteristics of the pharmacy. A 'prepared pharmacy' was defined as a pharmacy that held medicines useful in the management of pain, dyspnoea, anxiety, terminal restlessness, nausea and noisy breathing during the terminal phase of palliative care.

Results: The proportion of prepared pharmacies across NSW and SA was 21.9%. Multiple logistic regression demonstrated five objective predictors of prepared pharmacies, of which supplying medicines to residential aged care homes was the strongest. Furthermore, multiple logistic regressions demonstrated that the respondents from prepared pharmacies were 12 times more likely to be aware of palliative care patients using their service.

Conclusions: These results suggest that one fifth of community pharmacies carry formulations useful in managing care in the terminal phase. The main factor associated with stocking medicines useful in the management of terminal phase symptoms is awareness of people with palliative care needs using the pharmacy. Strategies that engage with pharmacists in anticipation of the terminal phase are critical, ensuring people with palliative needs living in the community, have timely access to medicines enabling optimum symptom control; supporting their ability to remain at home to die if desired.

Keywords: pharmacists, terminal care, pharmaceutical preparations, signs and symptoms

Background

Internationally, there is growing pressure for palliative care services, as the population ages [1]. While the last 12 months of life are spent predominantly in the community, changes in someone's condition will nevertheless contribute to multiple hospital admissions [2-3]. The experience of people living with palliative care needs highlights the demand for systems and processes supporting collaboration between clinicians working in community-based and hospital-based services [4]. Access to subcutaneous medicines for people wishing to remain in the community and the role of the community pharmacist in end-of-life care, has been studied globally. [5,6,7,8]

The Australian healthcare system is complex: two tiers of government (one federal and eight state or territory-based) predominantly share the responsibility for its funding and regulation. The Australian Federal government subsidises care provided through non-government organisations (NGOs), including community pharmacies, general practices, and aged care service providers. Important funding levers include, the Pharmaceutical Benefits Scheme (PBS), the Medicare Benefits Schedule (MBS) and Home Care Packages (HCP). Australian public hospitals are predominantly funded by the relevant state or territory-based government. Specialist Palliative Care Services (SPCSs) support people with complex palliative needs within hospital settings and provide outreach into the community. Like hospitals, they are funded at the state or territory level. For community-based patients, collaboration between clinicians working in SPCSs and NGOs is essential, despite separate funding models.

Even with these complexities, figures indicate about half of all Australians with palliative needs die either in their own home or within a Residential Aged Care Home (RACH) [9]. Evidence shows that appropriate symptom management throughout the terminal phase is a central component to being able to remain at home to die [6]. Commonly observed terminal phase symptoms include: pain, dyspnoea, anxiety, terminal restlessness, nausea and noisy breathing [10].

In 2012, a Community Pharmacy Survey was developed within one SPCS, to identify how this service could work better with community pharmacists in supporting people with palliative needs across the state of South Australia (SA) [11]. The survey included a comprehensive list of subcutaneous formulations (including alternative strengths) useful in managing symptoms commonly experienced in the terminal phase. The authors concluded that, community pharmacists throughout SA were often unable to anticipate which formulations to stock for people requiring medications in the terminal phase; leaving them underprepared when a prescription was presented for such medicines. In response, a state-based multidisciplinary working party lead the development of a core medicines list, comprising five formulations to manage terminal phase symptoms [12]. This list formed the basis of a range of education strategies for clinicians working in NGOs across SA. Data from a repeat survey in 2015 demonstrated significant improvement in availability of formulations from the core medicines list through pharmacies across SA [13].

In 2017, discussions across state borders led to recommendations to distribute the survey to community pharmacies in the state of New South Wales (NSW) [14]. To be able to compare results, the survey was distributed concurrently to community pharmacies across SA and NSW.

The objectives of distributing the survey were to identify the (1) proportion of community pharmacies stocking formulations useful in managing all six terminal phase symptoms and (2) factors associated with stocking a broad range of medicines, across two Australian states.

Methods

The development of the Survey has been described elsewhere [11]. It is a two page paper-based survey and is included in the Supplementary file.

[Insert link to supplementary file here]

The study population comprised all community pharmacies across SA and NSW. The names and addresses of all 1970 registered pharmacies operating in NSW was obtained from the Pharmacy Council of NSW. Details of all 482 registered Pharmacies from SA were obtained from Pharmacy Regulation Authority of SA. Twelve pharmacies from SA were excluded as they would not be expected to carry end-of-life medicines (e.g. a pharmacy associated with a fertility clinic). This left 470 SA pharmacies.

All 2440 pharmacies were posted a covering letter, the survey and a reply paid envelope. These were addressed to the proprietor or manager, where this information was known. Respondents could return the survey using a reply paid envelope.

Because of the large numbers of letters and surveys printed, signed and posted, the mailing of the surveys was done throughout August and September, 2018. To allow time for completing responses, surveys were accepted if received by 30 November 2018.

Each survey was allocated an individual code, allowing anonymous identification of non-responders through their postcode. The data of responders could then be compared with non-responders to identify applicability of this dataset and relevance of the findings to the broader pharmacy community.

Once the survey was returned, the data were entered into a secure results database. All fields completed by the respondent were included in the analysis. If the respondent left a field blank, this was taken as the item or service being unavailable in their pharmacy.

Pharmacies were assigned PhARIA (Pharmacy Accessibility Remoteness Index of Australia), which quantifies the degree of remoteness and accessibility (both geographic and professional), and was developed by the National Key Centre for Social Applications of Geographical Information Systems (GISCA) at the University of Adelaide, for the (then) Commonwealth Department of Health and Aged Care and the Pharmacy Guild of Australia. PhARIA continues to be maintained by the Hugo Centre for the Commonwealth Department of Health [15]. Distributions of the index between responding and nonresponding pharmacies were compared and tested. The non-significant test result would indicate the same spread of remoteness/accessibility between responding and non-responding pharmacies.

A ‘preparedness score’ (ranging from 0 to 6) was calculated for each pharmacy, using the data provided, by adding one point if they held a medicine that could manage each of the following terminal phase symptoms: pain, dyspnoea, anxiety, terminal restlessness, nausea and noisy breathing (see Table 1). A ‘preparedness score’ of 0 indicated no likelihood of finding medicines useful to manage terminal phase symptoms. For ease of comparison, pharmacies:

- scoring six points were coded ‘prepared’ as they had at least one medicine available to ameliorate each of the six commonly anticipated terminal phase symptoms;
- scoring five or less points were coded ‘underprepared’.

[Insert Table 1. near here]

Responses were assessed to identify characteristics significantly associated with being prepared.

Statistical Analysis

The distributions of the PhARIA index between responding and non-responding pharmacies, in both states, were tested using Chi-Square statistics. The non-significant test result would indicate the same spread of remoteness/accessibility between responding and non-responding pharmacies.

Descriptive statistics were used to describe the outcome and explanatory variables. The outcome of the study was preparedness, which was dichotomised into prepared and underprepared pharmacies. Categorical explanatory variables were described proportionally, while mean and standard error was used to describe continuous variables. A difference in proportions and/or an association between outcomes and explanatory variables was tested using Chi-square statistics, with continuity adjustment. Fisher exact test was applied where appropriate.

Potential predictors were individually tested in simple logistic regression models. Logistic regression models were used to identify the significant survey responses associated with prepared pharmacies. Survey responses identified as significant ($p<0.05$) were used to build a multiple logistic regression model. From the logistic regression model, an association was quantified by odds ratio and its 95% confidence interval. The confidence interval, including one, indicated an insignificant odds ratio. All possible models were assessed for: goodness of fit using Hosmer and Lemeshow statistics, coefficient of determination using Nagelkerke R^2 and Area Under The Receiver Operating Characteristic Curve.

All statistical analyses were performed using the Statistical Package for Social and Science for Windows (version 19). The level of significance used for all the tests was 0.05.

Results

A total of 2440 community pharmacies were mailed a survey. Eight surveys were returned undelivered. Seven hundred and twenty-nine (30.0%) completed surveys were returned, using the reply address envelope supplied to them. The difference in the PhARIA categories between participating and non-participating pharmacies was not significant (p=0.13). As no substantial bias between responding and non-responding pharmacies was apparent, the findings could be generalised to a total population of pharmacies in the two states. As such, no follow-up letters were mailed out.

Of the 729 respondents that provided details of their role, 329 (45.1%) identified as proprietors, 264 (36.2%) as registered pharmacists and 112 (15.4%) as managers.

Responding pharmacists worked in pharmacies with a median of two pharmacists on staff (Interquartile range (IQR) =2, 1 to 3) and offered a median of four medication management services, as specified in Table 2. These were likely to be services relating to the preparation of dose administration aids (DAAs), delivery of medicines to the person’s home, Nationally funded in-pharmacy medication reviews (known as a MedsCheck) and Nationally funded in-home medication reviews (known as a Home Medication Review).

[Insert Table 2. near here]

Community pharmacies stocked a median of three formulations (IQR=5, 1 to 6) that would be suitable to use in managing terminal phase symptoms. These were likely to be metoclopramide 10mg/2mL ampoule (59.9%), morphine 10mg/mL ampoules (42.0%) and haloperidol 5mg/mL ampoules (37.9%) (See Table 2). One hundred and seventy three (23.7%) pharmacies carried no formulations suitable to manage symptoms in the terminal phase.

Preparedness

The median calculated preparedness score was two (IQR=5, 0 to 5), indicating that half of the community pharmacies will be able to supply medicines for at least two out of a possible six terminal phase symptoms. For the purpose of comparison, 160 (21.9%) pharmacies were coded prepared as they had the maximum preparedness score. The remaining 569 (78.1%) of pharmacies were coded as underprepared.

Predictors of being prepared

Of the 18 factors reviewed, simple logistic regression identified 13 that were significant (see Table 3). Multiple logistic regression identified eight of these factors as significantly associated with prepared pharmacies. Respondents were more than 12 times likely to be prepared if they were aware of at least one palliative care patient using their pharmacy over the previous 12 months ($p=0.001$). In addition, prepared pharmacies were almost two and a half times more likely to be in SA ($p<0.001$).

[Insert Table 3. near here]

Discussion

Almost one in five community pharmacies across NSW and SA stocked sufficient formulations to manage commonly anticipated terminal phase symptoms. For caregivers living in urban areas, chances are good for accessing terminal phase medicines through their usual pharmacy, or one nearby. Those living in regional areas, without a car or access to good transport links, can experience significant disadvantage.

These findings also demonstrate predictive factors that influence the availability of medicines used to manage terminal phase symptoms, through community pharmacies.

Respondents from prepared pharmacies were 12.7 times more likely to be aware of palliative care patients using their pharmacy in the previous 12 months, giving weight to the role of a pharmacist in interdisciplinary care. Further analysis of the data is necessary to understand how respondents are made aware of people with palliative care needs. Studies from Australia and beyond have reported that pharmacists are often underutilised and unrecognised members of the palliative care health team [7]. Nevertheless, pharmacists are willing to be more involved with people experiencing palliative care needs, along with their caregivers [16].

The data also describes how respondents from prepared pharmacies behave differently. It seems that working in a prepared pharmacy empowers staff to communicate with the prescriber when presented with an issue, such as, the inability to immediately supply a medicine. When a medicine requires purchasing, extra delays result. Most caregivers faced with the possibility of delayed symptom management, while waiting for the medicines to arrive, are likely to approach another pharmacy or escalate care in order to expedite symptom control [11]. While there are many approaches to managing a request for subcutaneous medicines unstocked by the pharmacy, contacting the prescriber offers a number of opportunities to build on the multidisciplinary nature of palliative care and embed the role of the pharmacist into practice, including:

- Increasing the pharmacist's perspective on the situation so they have better understanding of the urgency of the situation (Is this medicine ordered in anticipation of a terminal phase symptom or are they imminently dying?);
- Negotiating a supply plan to accommodate escalation of doses, or simply ongoing supply;
- Improving collaboration for future requests, resulting in a shift towards anticipatory prescribing or the stocking of a standard list of medicines, by the pharmacy;
- Building relationships with prescribers so that other services, such as home delivery, home medicines review and education or disposal of unwanted medicines, become standard practice for people with palliative care needs.

Community pharmacies which supply medicines to RACHs were twice as likely to be prepared. This link is unsurprising given the overlap between aged care and palliative care. Importantly, in Australia, RACHs have formal contracts with privately owned community pharmacies.

Innovative models of providing care in home-like environments - such as clustered domestic residential aged care - have increasing uptake; these models are associated with fewer hospitalisations and better quality of life [17]. Under these models, Australians will continue to obtain funded aged care services in the home, while independently sourcing their medicines through their preferred community pharmacy, bypassing the aged care provider. Policy makers will need to consider how this will impact on how medicines useful for symptom management in the terminal phase are accessed, within this context.

Community pharmacies open for longer hours, providing home delivery services and staffed with more than two full time equivalents of pharmacists were also predictive of being prepared. It is likely that these qualities make the community pharmacy more accessible for carers of people who are dying. More research would be necessary to ascertain if this explanation was appropriate.

SA pharmacies were almost two and a half times more likely and NSW pharmacies to be prepared. This may be attributed to the promotion of a core palliative medicines list [13]. While the SA list was constructed in 2012, a broader national list was endorsed by the Australian and New Zealand Society of Palliative Medicine in 2015 [18]. Table 4 compares the two lists against the availability through the Australian PBS [19]. The PBS was introduced in Australia in 1948, to provide government subsidy to the cost of a broad range of medicines at the time of dispensing to patients. With community pharmacies stocking a median of three formulations to manage terminal phase symptoms, the smaller list from SA appears more pragmatic, when applying these lists to practice. Regardless of the size of the list, core medicines lists have been developed out of a need for people to access medicines more readily and cost effectively for terminal phase symptoms [12, 20]. There are a large number of formulations available on the Australian market to manage commonly observed terminal phase symptoms; it is unreasonable to ask community pharmacies to carry all possible formulations. A tighter standardised list of medicines can ensure the medicines that are prescribed are also the ones that are stocked, by community pharmacies or RACHs. This may be based on State-based or National guidance or through local discussions between prescribers and pharmacists. The introduction and promotion of a palliative care core medicine list in

NSW would support greater communication and collaboration within the wider palliative care multidisciplinary team. Prescribers would be able to prescribe a medicine that they know the community pharmacy is likely to stock, without adding stress to the carer.

[Insert Table 4. Near here]

Enabling people with palliative needs to receive care in their home is important. While there are many reasons for people to be transferred and cared for within acute services, access to medicines for the relief of terminal phase symptoms should be reliable and not the cause for escalation of care. Using the person's preferred pharmacy is sensible. The study findings suggest that communicating with pharmacists about people with palliative care needs can streamline access to appropriate medicines.

Limitations

This study only considered geographic representation when assessing applicability of results across the broader Australian population. There may be other factors, such as socioeconomic, or a respondent's years of experience, which may have influenced the results. The survey has not formally been validated and might have missed factors, such as the proportion of older Australians within each postcode. Survey responses were based on an individual pharmacist's recall and personal practice, which may not be representative of other pharmacists in the same pharmacy. It may also be their ideal practice as opposed to how they would respond under pressure. While a comprehensive list of medicines is included in the survey, it is possible that some expensive medicines missing from the list (e.g. ondansetron injection) are available in community pharmacies; this would change the calculated preparedness score. Finally, the terms prepared and under-prepared are constructs to distinguish between pharmacies with a broad range of medicines even though many patients will not experience all symptoms.

Implications for clinical practice

In practice this study shows that when considering access to medicines useful in managing terminal phase symptoms, planning and communication remain important.

Healthcare professionals should identify, document and communicate with the person's usual pharmacy early in their trajectory, as a simple approach to improve the pharmacist's awareness of people with palliative care needs using their services. It is important that the onus is on the healthcare professional, as it is likely they will identify more people with palliative care needs.

Generalisability

This study was conducted across two States in a resource-rich country that has universal healthcare, founded upon a network of community-based providers. Community pharmacists in Australia provide a range of medication management services, which may differ in other parts of the world.

Recommendations

Peak professional bodies should endorse and promote a core medicines list, ensuring there is a standardised message to both prescribers and community pharmacists as to which medicines should be prescribed and stocked, to facilitate timely access.

Aged care and nursing organisations supporting people to remain in their own home to die, should engage with the person's usual pharmacy, to support interdisciplinary communication.

Prescribers and pharmacists should anticipate the terminal phase and the challenges brought about by the limited accessibility to medicines required during this phase, as people lose their ability to swallow. Interdisciplinary discussions in anticipation of people entering the terminal phase are paramount, to ensure that individuals are helped in a timely manner.

Conclusion

Our survey results articulate a number of factors associated with community pharmacies stocking medicines useful in the management of terminal phase symptoms. Community-based pharmacies can play an important role in managing terminal phase symptoms, through timely access to medicines. Pharmacist awareness of people with palliative care needs using their pharmacy appears to be a crucial factor; one which can be improved. Translating partnership models that currently exist between RACHs and community pharmacies, are important as health systems evolve to support people dying at home or home-like environments. By strengthening partnerships across communities, businesses and government – with policy support and adequate funding models – it is possible to improve community access to medicines useful in the management of terminal phase symptoms.

Authorship

Substantial contribution to the concept or design of the work – KS, NM, PT

Acquisition, analysis or interpretation of data – all authors

Drafted the article or revised it critically for important intellectual content – all authors

Approved the version to be published – all authors

Have participated sufficiently in the work to take public responsibility for appropriate portions of the content – all authors

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Ethics Approval

The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC) reviewed the project and determined it does not require ethical review or approval, as this is a quality improvement project. Ethics for conducting the study in NSW was obtained from the South Eastern Sydney Local Health District Human Ethics Committee in accordance with NSW Health Guideline GL2007_020 Human Research

Ethics Committees - Quality Improvement and Ethics Review: A Practice Guide for NSW.

Competing Interest

None declared.

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Table 1. Relationship between symptoms and formulations listed within the survey to calculate the preparedness score

Terminal Phase Symptom	Medicine	Score
Anxiety	Clonazepam 1mg/mL Ampoules Clonazepam 2.5mg/mL Oral Drops Midazolam 5mg/mL Ampoules, or alternative concentrations	1
Pain	Fentanyl 100mcg/2mL Ampoules, or alternative concentrations Hydromorphone 10mg/mL Ampoules, or alternative concentrations Morphine Sulfate 10mg/mL Ampoules, or alternative concentrations Morphine Hydrochloride 10mg/mL Oral mixture, or alternative concentrations Oxycodone Hydrochloride 10mg/mL Ampoules, or alternative concentrations	1
Dyspnoea	Fentanyl 100mcg/2mL Ampoules, or alternative concentrations Hydromorphone 10mg/mL Ampoules, or alternative concentrations Morphine Sulfate 10mg/mL Ampoules, or alternative concentrations Morphine Hydrochloride 10mg/mL Oral mixture, or alternative concentrations Oxycodone Hydrochloride 10mg/mL Ampoules, or alternative concentrations	1
Terminal Restlessness	Haloperidol 5mg/mL Ampoules Clonazepam 1mg/mL Ampoules Clonazepam 2.5mg/mL Oral Drops Midazolam 5mg/mL Ampoules, or alternative concentrations	1
Nausea	Metoclopramide 10mg/2mL Ampoules Haloperidol 5mg/mL Ampoules Dexamethasone Sod.Phos. 4mg/mL Ampoules, or alternative concentrations	1
Noisy Breathing	Hyoscine Hydrobromide 400mcg/mL Ampoules Hyoscine Butylbromide 20mg/mL Ampoules	1

Table 2. Proportion of pharmacies providing medicine management services and terminal phase medicines (n (%))

Pharmacy Service	Total (Proportion) of All Pharmacies (n=729)
After-hours/ On-call service	115 (15.8)
RACH (Clinical service)	120 (16.5)
RACH (Supply service)	243 (33.3)
DDA service	681 (93.4)
Home delivery service	590 (80.9)
HMR service	518 (71.1)
Hospital (Clinical)	32 (4.4)
Hospital (Supply)	59 (8.1)
MedsCheck	588 (80.7)
RMMR	130 (17.8)
Clonazepam 1mg Ampoules	94 (12.9)
Clonazepam 2.5mg/mL Oral Drops	250 (34.3)
Dexamethasone Sod.Phos. 4mg/mL Ampoules	165 (22.6)
Fentanyl 100microgram/2mL Ampoules	65 (8.9)
Haloperidol 5mg/mL Ampoules	276 (37.9)
Hydromorphone 10mg/mL Ampoules	105 (14.4)
Hyoscine Butylbromide 20mg/mL Ampoules	245 (33.6)
Hyoscine Hydrobromide 400mcg/mL Ampoules	25 (3.4)
Metoclopramide 10mg/2mL Ampoules	437 (59.9)
Midazolam 5mg/mL Ampoules	306 (42.0)
Morphine Hydrochloride 10mg/mL Oral mixture	254 (34.8)
Morphine Sulfate 10mg/mL Ampoules	303 (41.6)
Oxycodone Hydrochloride 10mg/mL Ampoules	26 (3.6)

DDA – dose administration aid, HMR – home medication review, RMMR – residential medication management review, RACH – residential aged care home

Table 3. Predictors of Respondents working in Prepared Pharmacies (n (%))

Variable	Characteristic	Prepared	Underprepared	Simple logistic regression		Multiple logistic regression	
				Odds Ratio (95% confidence interval)	p-value (F-test)	Adjusted odds ratio (95% confidence interval)	p-value (F-test)
Awareness of people using pharmacy in the previous 12 months	None	2 (1.9)	102 (98.1)	1.0			
	Aware of at least 1 customer with palliative needs	188 (30.1)	437 (69.9)	21.9 (5.3 – 89.8)	p<0.001	12.7 (3.0 – 53.5)	p=0.001
If the prescribed formulation was not stocked, respondent would:							
Tell the carer they were unable to supply item	No	175 (26.2)	493 (73.8)	1.0			
	Yes	15 (24.6)	46 (75.4)	0.9 (0.5 – 1.7)	p=0.78		
Contact prescriber to recommend an alternative concentration	No	112 (20.0)	449 (80.0)	1.0			
	Yes	78 (46.4)	90 (53.6)	3.5 (2.4 – 5.0)	p<0.001	1.6 (1.0 – 2.7)	p=0.047
Contact prescriber to recommend an alternative medicine	No	119 (20.3)	466 (79.7)	1.0			
	Yes	71 (49.3)	73 (50.7)	3.8 (2.6 – 5.6)	p<0.001	2.0 (1.2 – 3.4)	p=0.007
Contact the distributor urgently to arrange prompt delivery of medicines	No	140 (24.8)	425 (75.2)	1.0			
	Yes	50 (30.5)	114 (69.5)	1.3 (0.9 – 2.0)	p=0.14		
Place an order with their distributor to arrange delivery of medicines, for the next working day	No	84 (28.9)	207 (71.1)	1.0			
	Yes	106 (24.2)	332 (75.8)	0.8 (0.6 – 1.1)	p=0.16		
Contact another pharmacy to arrange urgent	No	40 (22.6)	137 (77.4)	1.0			
	Yes	150	402 (72.8)	1.3 (0.9 –	p=0.23		

supply of medicines		(27.2)		1.9)			
PhARIA	1	144 (25.2)	428 (74.8)	1.0			
	2,3,4,5,6	46 (29.3)	111 (70.7)	0.8 (0.5 – 1.2)	p=0.30		
Australian State	NSW	139 (23.8)	445 (76.2)	1.0			
	SA	51 (35.2)	94 (64.8)	1.7 (1.2 – 2.6)	p=0.006	2.4 (1.5 – 3.8)	p<0.001
Number of pharmacist in pharmacy	0.0 to 2.0 FTE	110 (21.8)	394 (78.2)	1.0			
	2.01 to 11.0 FTE	77 (37.7)	127 (62.3)	2.2 (1.5 – 3.1)	p<0.001	2.0 (1.3 – 2.9)	p=0.001
Medication management services							
Provide an after-hours or on-call service	No	131 (21.3)	483 (78.7)	1.0			
	Yes	59 (51.3)	56 (48.7)	3.9 (2.6 – 5.9)	p<0.001	2.3 (1.4 – 3.7)	p=0.001
Provide a clinical service to a RACH	No	125 (20.5)	484 (79.5)	1.0			
	Yes	65 (54.2)	55 (45.8)	4.6 (3.0 – 6.9)	p<0.001		
Provide a medicines distribution service to a RACH	No	82 (16.9)	404 (83.1)	1.0			
	Yes	108 (44.4)	135 (55.6)	3.9 (2.8 – 5.6)	p<0.001	2.1 (1.4 – 3.2)	p<0.001
Provide a DAA service	No	6 (12.5)	42 (87.5)	1.0			
	Yes	184 (27.0)	497 (73.0)	2.6 (1.1 – 6.2)	p=0.03		
Offer a home delivery service	No	19 (13.7)	120 (86.3)	1.0			
	Yes	171 (29.0)	419 (71.0)	2.6 (1.5 – 4.3)	p<0.001	1.9 (1.0 – 3.4)	p=0.04
Provide a HMR service	No	37 (17.5)	174 (82.5)	1.0			
	Yes	153 (29.5)	365 (70.5)	2.0 (1.3 – 2.9)	p=0.001		
Provide a clinical service to a hospital	No	176 (25.3)	521 (74.7)	1.0			
	Yes	14 (43.8)	18 (56.3)	2.3 (1.1 – 4.7)	p=0.02		
Provide	No	171	499 (74.5)	1.0			

medicines distribution service to a hospital		(25.5)					
	Yes	19 (32.2)	40 (67.8)	1.4 (0.8 – 2.4)	p=0.26		
Offer MedsCheck services	No	33 (23.4)	108 (76.6)	1.0			
	Yes	157 (26.7)	431 (73.3)	1.2 (0.8 – 1.8)	p=0.42		
Provide an RMMR service	No	136 (22.7)	463 (77.3)	1.0			
	Yes	54 (41.5)	76 (58.5)	2.4 (1.6 – 3.6)	p<0.001		
DAA – dose administration aid, HMR – home medication review, RMMR – residential medication management review, PhARIA - Pharmacy Accessibility Remoteness Index of Australia , RACH – residential aged care home							

Table 4. Comparison between SA ore Medicines List, ANZSPM terminal phase Medicines list and PBS availability

Formulation	Core Medicines List from SA	ANZSPM Terminal Phase Medicines	Australian PBS
Clonazepam 2.5mg/mL Oral Drops	No	Yes	Yes (restrictions apply)
Clonazepam 1mg/mL Ampoules	Yes	Yes	Yes (restrictions apply)
Fentanyl 100microgram/2mL Ampoules	No	Yes	No
Haloperidol 5mg/mL Ampoules	Yes	Yes	Yes
Hydromorphone 2mg/mL Ampoules	No	Yes	Yes
Hyoscine butylbromide 20mg/mL Ampoules	Yes	Yes	Yes
Metoclopramide 10mg/2mL Ampoules	Yes	Yes	Yes
Midazolam 5mg/mL Ampoules	No	Yes	No
Morphine sulfate 10mg/mL Ampoules	Yes	Yes	Yes
Morphine 30mg/mL Ampoules	No	Yes	Yes

ANZSPM - Australian and New Zealand Society of Palliative Medicine, PBS - Pharmaceutical Benefits Scheme

APPENDIX 5: PUBLICATION FIVE

Citation

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I have provided the co-authorship declaration separately to this thesis.

pharmacy

MDPI

Review

The Roles and Responsibilities of Community Pharmacists Supporting Older People with Palliative Care Needs: A Rapid Review of the Literature

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Abstract: Globally, the number of older people requiring appropriate and safe management of medicines is growing. This review aimed to identify the roles and responsibilities of pharmacists supporting older people living in a community setting with their palliative care needs and to synthesise key themes emerging from the data, as well as any gaps in knowledge. The literature search included Medline (Ovid), Scopus, and Cinahl (Ebsco) databases. An English language limit was applied. The search included all international articles and any date of publication. Data were synthesised utilizing a systematic text condensation technique and presented according to Theme, Domain, and Meaning Units. Fourteen studies met the inclusion criteria. Selected papers predominantly focused on care provided by the pharmacists supporting people receiving residential aged care services. Clinical review, supply of medicines, and clinical governance were identified as key pharmacist roles. Pharmacists' communication skills, personal behavioural approach, and positive attitude emerged as supportive characteristics for effective person-centered care. Minimal, or no information, were available related to pharmacists located in general medical practices and in Aboriginal health services sector, respectively. The multifaceted role of pharmacists presents an opportunity to provide comprehensive health care for older populations at the end of their life.

Keywords: palliative care; residential aged care; community pharmacist; medication review; multidisciplinary team

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1. Introduction

As the population ages, the number of older Australians with palliative care needs is increasing [1]. Multimorbidity is common and this typically contributes to significant polypharmacy [2]. While polypharmacy can be appropriate, there is considerable evidence for its ability to cause harm, which is preventable [3]. Clearly, appropriate and safe management of medicines is an important aspect of care for older people [4]. Yet, there are several points of weakness in the medication management process which can contribute to poor outcomes [5,6]. In partnership with the multidisciplinary team, community pharmacists are ideal people to facilitate good medicines management for older people, built upon their clinical expertise and existing relationships with people they service, their carers, and the broader healthcare workforce [7,8]. The 2019 report *"PHARMACISTS IN 2023: For patients, for our profession, for Australia's health system"* describes the broad remit of Australian pharmacists. It outlines some of the non-dispensing roles that community pharmacists have with care teams such as advising on medicine management, medicine safety, and the rational use of medicines in a cost-effective manner [9].

While changes in an older person's condition can contribute to multiple hospital admissions, the last 12 months of an older person's life is spent predominantly in the community [10,11]. They may receive care through:

- Home Care (HC) services—where the person receives care in their home dwelling; or
- Residential Aged Care (RAC) services—where the individual is provided care within a Residential Aged Care Home (RACH).

In Australia, a multidisciplinary approach to care is dependent on a range of Non-Government Organisations (NGO) working together, including general medical practices, aged care providers, Aboriginal health services, and dispensing pharmacy services. NGOs predominantly deliver care that is subsidised using National funding levers, including the Medicare Benefits Schedule (MBS), 6th Community Pharmacy Agreement (6CPA), Pharmaceutical Benefits Scheme (PBS), and Home Care Packages Program (HCPP). Within this complex, multi-faceted Australian healthcare system, rational use of medication management services for older people is provided by the primary healthcare services and aged care organisations collaboratively via referrals between pharmacists and general medical practitioners [12].

Although structures exist to facilitate pharmacist involvement in care, we are unaware of any extensive research discussing the full spectrum of their roles and responsibilities, specifically relating to the care of older people receiving HC or RAC toward the end of their life [13]. This rapid review aimed to identify international published literature that describes the roles and responsibilities of community pharmacists supporting older people receiving HC or RAC with their palliative care needs, to synthesise key themes emerging from the data, as well as identify any gaps in knowledge.

2. Materials and Methods

This rapid review applied a streamlined systematic review method [14,15]. Scientific peer reviewed journal articles were retrieved through searching in electronic databases. The search strategy was developed and tested in Medline (Ovid) with the help of a Health Librarian (SH). Broad text words and MeSH headings were used with relevance to palliative care, aged care in a community setting, and the role of a pharmacist. An English language limit was applied due to time and resource constraints. No date limit was applied. Furthermore, searches included articles from any country. Once the search was finalised and run in Medline (Ovid), it was then translated and run in Scopus and Cinahl (Ebsco) on the 23 July 2019.

The full search strategies for each database are detailed in online only Supplementary Tables S1–S3. The search results for each database were uploaded to Endnote X9.2 reference management software and deduplicated [16]. Journal articles were then imported into the web-based software program Covidence for screening and data extraction [17].

2.1. Inclusion Criteria

Criteria for inclusion weref developed—these are summarised in Table 1.

Two reviewers (SH and PT) independently assessed titles and abstracts against the priori inclusion criteria outlined in Table 1. Where eligibility was unclear based on the title and abstract screening, the full text article was retrieved and assessed. Any disagreements on eligibility for inclusion were resolved by discussions with a third reviewer (JT), if necessary.

The full-text articles identified from the title and abstract screening were independently assessed by two reviewers (AC and PT), using the inclusion criteria before selecting for final data extraction and synthesis. Reference lists of the included studies were not examined to identify additional articles. A range of published literature were included, such as papers of experimental and quasi-experimental primary studies, review papers, program evaluation reports, expert commentaries, and surveys.

Studies were excluded if they lacked discussion of the role of the pharmacist, had no specific focus on older people, or were describing care in an acute hospital care setting (including discharge planning).

Table 1. Criteria for title and abstract screening, and full-text review of the included papers.

No.	Criterion	Description
1.	Population of interest	Pharmacists practising predominantly in dispensing or non-dispensing role.
2.	Settings of interest	Community setting comprising dispensing pharmacy, general medical practice, residential aged care facility, Aboriginal health services, and peoples' own home.
3.	Phenomenon of interest	Roles and responsibilities of community pharmacists supporting older people aged 65 years and over and their carer living in the community with palliative care needs.
4.	Types of studies	Quantitative or qualitative studies, including peer-reviewed journal articles and grey literature documents. Studies were selected if they reported one or more of the inclusion criteria (i.e., 1–3) outlined above.

2.2. Data Extraction

A data extraction tool was developed using Microsoft Excel and tested with three randomly selected articles. Two researchers (PT and AC) extracted the following data: (1) study characteristics, (2) summary description, and (3) Data Elements. Study characteristics pertained to author, study year, study design, study setting, country, and level of evidence. The assessment of "level of evidence" employed an adaptation of the Johns Hopkins Model of Evidence-Based Practice [18]. The levels of evidence in papers were organised into five categories (Table 2), where Level I represents the strongest quality of the evidence [18]. Summary description included brief information on what the study contains. Data Elements included the roles and responsibilities of community pharmacists identified in the full text screening.

Table 2. Evidence type used in appraising the quality of the evidence of included papers.

Level Type	Description
Level I	Experimental, randomized controlled trial (RCT), systematic review RTCs with or without meta-analysis
Level II	Quasi-experimental studies, systematic review of a combination of RCTs and quasi-experimental studies, or quasi-experimental studies only, with or without meta-analysis
Level III	Nonexperimental, systematic review of RCTs, quasi-experimental with/without meta-analysis, qualitative, qualitative systematic review with/without meta-synthesis
Level IV	Respected authorities' opinions, nationally recognized expert committee or consensus panel reports based on scientific evidence
Level V	Literature reviews, quality improvement, program evaluation, financial evaluation, case reports, nationally recognized expert(s) opinion based on experiential evidence

2.3. Synthesis of Data

Synthesis of data was conducted in sequential steps utilizing a systematic text condensation technique [19].

Two researchers (AC and PT) independently read each of the full text papers to establish a preliminary list of Themes. The researchers then reviewed each of the included papers, line by line, to identify Data Elements. A Data Element was defined as a text fragment that described a certain idea (e.g., pharmacist providing medicines useful in symptom management for pain for a resident in aged care home). Common Data Elements were combined into a single Meaning Unit (e.g., supply of medicines to a RACH). Domains emerged out of the Data Elements through linking similar Meaning Units into groups (e.g., medicine supply). Domains were then mapped into relevant Themes.

Assignment of Data Elements into Meaning Units and Domains were performed independently by two researchers and the results were combined with consensus. An overview analysis of the coded Data Elements by individual researchers (AC and PT) determined that a high degree of inter- and intra-group thematic homogeneity existed, suggesting that the data could be combined with minimal bias.

3. Results

3.1. Literature Search, Screening, and Selection of Papers

Figure 1 shows search results in a PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Flow Diagram and the findings are reported following the PRISMA checklist (Supplementary Table S4). The electronic database search identified a total of 382 citations. After removing duplicates, the title and abstract screening of 246 citations identified 28 potential papers for full text review. Eligibility assessment resulted in 14 papers [20–33] meeting the inclusion criteria and being selected for final data extraction and synthesis.

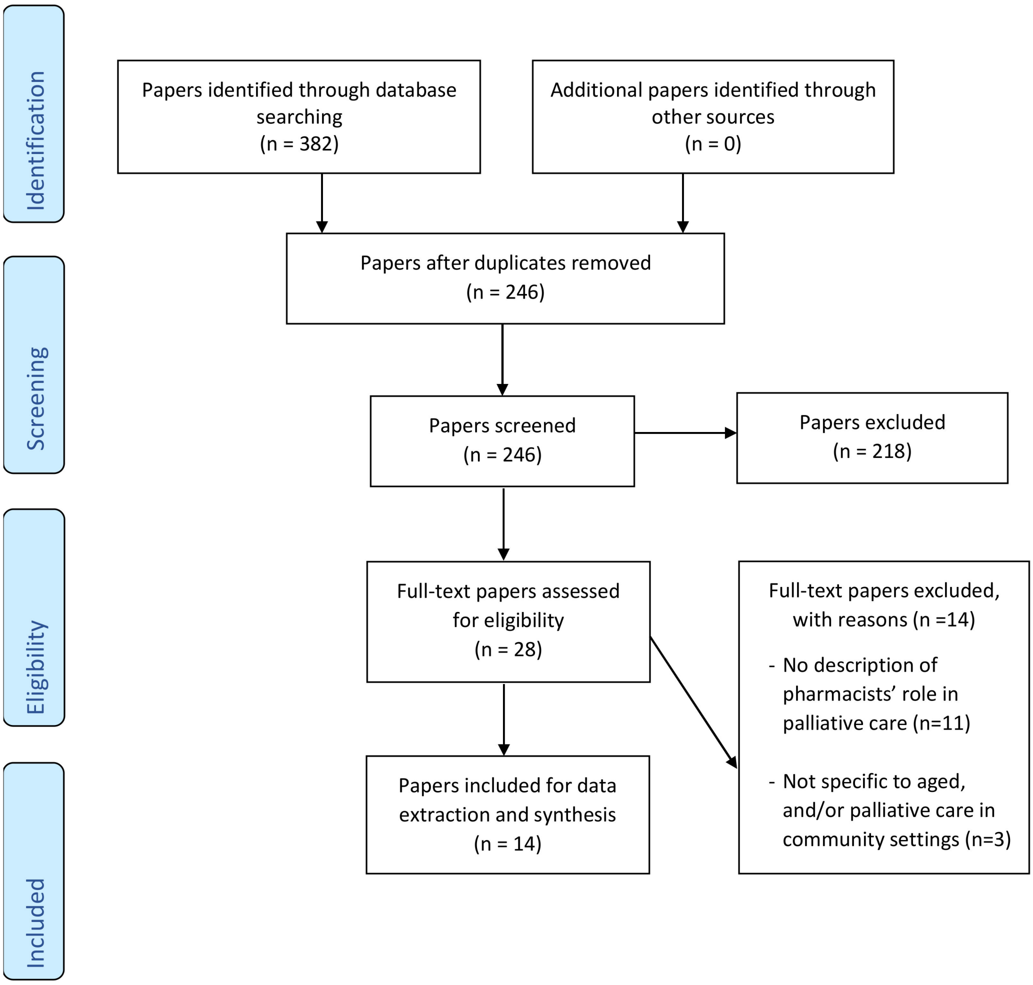

Figure 1. PRISMA Flow Diagram describing the paper selection process.

3.2. Characteristics of the Selected Papers

Further characteristics of included papers are provided in Table 3. Of the 14 included papers, seven were conducted in the United States of America (USA) [21,26–28,30–32], four in Australia [22,23,25,33], two in the United Kingdom (UK) [20,29], and one in Canada [24]. Six of the 14 papers [20–22,26,30,31] described pharmacists' role predominantly for people receiving RAC services. Three papers [23,24,27] discussed pharmacists' role in caring for older people receiving HC services. The remaining five papers discussed care for people receiving either RAC or HC services [25,28,29,32,33].

Among the included papers, the levels of evidence varied [18]. Seven papers [20,22,23,25,26,32,33] were classified at the Level III evidence level. These included three papers [20,26,32] which systematically reviewed and synthesised best practice clinical interventions and four papers used observational qualitative research spanning across semi-structured interviews [22,23], focus groups [25], and surveys [33]. The remaining seven papers [21,24,27–31] were classified at the Level V evidence level. These included three expert commentaries [21,24,29], two case studies [27,28], one comprehensive literature review [31], and one [30] describing a pilot phase of a "quality improvement" intervention. The levels of evidence were comparable for papers focusing on receipt of either RAC or HC services.

3.3. Data Extraction

In total, 196 Data Elements were identified from the 14 selected papers (see Table 3). These were combined in 37 Meaning Units and 8 Domains. Three broad Themes relating to the roles and responsibilities of community pharmacists with older people living in the community were determined (see Table 4):

(1) Type of care delivery;
(2) Work context of the pharmacist; and
(3) Supportive professional and personal characteristics as soft skills.

Table 3. Characteristics, level of evidence, count of data elements, and summary description of selected papers.

Author, Year	Title	Study Design	Setting	Country	Level of Evidence	Count of Data Elements	Summary Description
Burns, 2014 [20]	New horizons in care home medicine	Systematic review of experimental, quasi experimental, and non-experimental studies	Residential Aged Care Home (RACH)	UK	Level III	8	Reviews role of RACH staff including pharmacists in integrated models of care supporting better outcomes for older people.
Crecelius, 2006 [21]	Pain Control: No Time to Rest on Our Laurels	Expert opinion	RACH	USA	Level V	7	Provides expert commentary on pain management for older people living in RACH environments
Disalvo, 2019 [22]	Pharmacists' perspectives on medication reviews for long-term care residents with advanced dementia: a qualitative study	Qualitative study using semi-structured interview	RACH	Australia	Level III	29	Explores pharmacist perspectives of the Australian Government funded residential medication management review and its role improving the quality and safety of prescribing for people with advanced dementia.
Elliott, 2016 [23]	Medicines Management, Medication Errors and Adverse Medication Events in Older People Referred to a Community Nursing Service: A Retrospective Observational Study	Retrospective records audit and telephone interview	Home Care	Australia	Level III	12	Explores the characteristics of older people referred for medicines management support, type of support provided, medication errors, and Adverse Drug Reactions.
Hays, 1984 [24]	Home Care of the Frail Elderly And the Terminally Ill	Expert opinion	Home Care	UK	Level V	5	Discusses general principles of managing elderly and terminally ill patients in a home environment.
Kuruvilla, 2018 [25]	Medication management for community palliative care patients and the role of a specialist palliative care pharmacist: A qualitative exploration of consumer and health care professional perspectives	Qualitative study using focus group	Both RACH and Home Care	Australia	Level III	20	Explores the gaps in the current model of community palliative care services on medication management and the role of a pharmacist in addressing these.
LaMantia, 2010 [26]	Interventions to Improve Transitional Care Between Nursing Homes and Hospitals: A Systematic Review	Systematic review of experimental, quasi experimental, and non-experimental studies	RACH	USA	Level III	7	Identifies and evaluates interventions to improve the communication of accurate and appropriate medication lists and advance directives for older people who transition between a RACH and a hospital.

Table 3. *Cont.*

Author, Year	Title	Study Design	Setting	Country	Level of Evidence	Count of Data Elements	Summary Description
Martin, 2011 [27]	There's No Place Like Home: A Pharmacist Fills the Need	Case report	Home Care	USA	Level V	14	Describes the practice of a pharmacist working with older people receiving home care.
Meade, 2006 [28]	Innovative Services for Assisted Living, Hospice, and the Community	Case report	Both RACH and Home Care	USA	Level V	29	Describes the practice of a pharmacist who provides medication management services to older people living in a RACH or receiving home care.
Noyce, 1990 [29]	Intramural and extramural health care in the United Kingdom	Expert opinion	Both RACH and Home Care	UK	Level V	8	Describes the factors that determine whether health care in the United Kingdom is provided in hospital, at home, or through intermediate or shared care arrangements.
Prukowski, 2017 [30]	The DE-PHARM Project: A Pharmacist-Driven Deprescribing Initiative in a Nursing Facility	Quality improvement intervention study	RACH	USA	Level V	10	Assesses the acceptance of recommendations from the pharmacist to the primary care team regarding the discontinuation of medications used for the management of comorbid diagnoses.
Tait, 2017 [33]	Improving community access to terminal phase medicines through the implementation of a "Core Medicines List" in South Australian community pharmacies	Qualitative study using repeat survey	Both RACH and Home Care	Australia	Level III	14	Identifies changes in community access to medicines for managing symptoms in the terminal phase following the development of a "Core Medicines List".
Tamura, 2012 [31]	Outcomes of Polypharmacy in Nursing Home Residents	Comprehensive literature review	RACH	USA	Level V	13	Reviews the outcomes of polypharmacy in RACHs.
Tija, 2013 [32]	Studies to Reduce Unnecessary Medication Use in Frail Older Adults: A Systematic Review	Systematic review of experimental, quasi experimental, and non-experimental studies	Both RACH and Home Care	USA	Level III	20	Identifies interventions that reduce the use of unnecessary medications in frail older adults and patients approaching end of life.

Table 4. Taxonomy of the themes identified and illustrated with key roles and responsibilities of the pharmacists that emerged from the literature synthesis.

Theme (n = 3)	**% (n) of Data Elements**	**Definition**	**Domain (n = 8)**	**Meaning Unit (n = 37)**
Type of care delivery	72% (n = 140)	Pharmacists support the medicines management of people living with palliative care needs directly with the patients themselves and indirectly by improving the performance of the organisation.	Clinical review	Reconciling medications; Deprescribing; Guiding the adjustment of medication doses; Identifying medication related problems; Assessing appropriateness and safety of prescribed medications;
			Supply of medicines	Stocking subcutaneous injections; Dispensing; Returning of unwanted medicines; Delivering Medicines to the home; Supplying medicines to a residential aged care home; Offering a dose administration aid service; Providing medicines information; Counselling and educational intervention
			Clinical governance	Participating on Medicines Advisory Committees in residential aged care home; Educating nursing workforce including carers; Auditing of medications; Developing policies and guidelines
Work setting of the pharmacist	20% (n = 40)	Pharmacists collaborate with multidisciplinary workforce to achieve optimal results in patient care.	Community Pharmacy	Clarifying prescriptions with prescribers; Improving access to subcutaneous medicines; Participating in case conferences; Discussing medication review findings
			Residential Aged Care Homes	Reviewing medicines on admission; Participating in multidisciplinary medication reviews; Participating in case conferences; Understanding patient's goals of care; Supplying medicines to RACH imprest stock
			General Medical Practice	Offering a clinical resource; Providing medicines information; Improving efficiency of medication reviews
Supportive professional and personal characteristics as soft skills	8% (n = 16)	Pharmacists use soft skills in their role to assist and provide support to patients with their medication management.	Soft skills in supporting person-centred care	Advocating; Following-up
			Soft skills in dealing with clinician prescribers	Framing of recommendations; Building trusting relationships; Developing creative communication approaches; Demonstrating a positive and helpful attitude; Communicating in a clear and honest manner; Facilitating referrals

3.3.1. Theme One: Type of Care Delivery

The selected articles examined various pharmacist-led services for older people with palliative care needs. These included clinical review, supply of medicines, and contribution to clinical governance.

Clinical review

The bulk of the 14 papers discussed the pharmacist's involvement in direct person-centred care involving a one-on-one clinical review. While this often involved the older person, some papers discussed inclusion of their carer [25,27,29]. The clinical reviews were conducted in people receiving both HC and RAC services. These included individualised medicines management such as medication reconciliation [23,26,27], recommendation of changes to medication doses [22,30], identifying medication related problems, and ensuring safety and appropriateness of prescribed medications [28,31,32]. Other activities described within a clinical review involved deprescribing of medicines that were no longer required, including analgesia and sedatives [20,21,27,30,31].

A number of key barriers to providing pharmacist-led clinical reviews were identified including: inadequate remuneration [22]; involvement of multiple prescribers [23]; poor processes for information sharing between providers [23]; unrealistic family expectations [22]; and poor health literacy among the population [25].

Supply of medicines

Responsibilities relating to supply of medicines featured in a few of the included papers, with references to people in receipt of HC and RAC services. This Theme comprised activities related to ordering and stocking of medicines [25]; dispensing [28]; delivery of medicines [28]; providing medicines information and counselling [21,25,29,33]; disposing unwanted medicines [27]; and provision of medicines in dose administration aids [27–29]. Some papers focused on the supply of medicines in the last days of life and the issues relating to poor access to subcutaneous medicines as the oral route is lost [25,33].

Clinical governance

Pharmacist roles also involved indirect care through broader engagement at the organisational level [22,23,28,31–33]. These papers focused on people receiving RAC services and discussed favourable organisation-wide changes—both clinical and financial—resulting from pharmacist involvement. Pharmacist advisors to a Medicines Advisory Committee (MAC) assisted in the development, promotion, monitoring, review, and evaluation of medication management policies, guidelines, and procedures and thus influenced the health and quality of life for all people cared for by the organisation. Other cited examples of pharmacists in indirect roles involved the provision of education to the nursing workforce around medicines and auditing of medication usage, resulting in cost savings [22,32]. Barriers to pharmacist involvement at the organizational level were inadequate remuneration.

3.3.2. Theme Two: Work Setting of the Pharmacist

Ten of the papers described pharmacists working in a range of work settings, including Community Pharmacy, Residential Aged Care Homes (RACH), and General Medical Practice [20,22,23,25,27,28,30–33]. Each work setting offered different opportunities for the pharmacist to engage with the multidisciplinary workforce. These papers discussed a range of disciplines that pharmacists worked alongside, including general practitioners (GP), specialists in pain management and palliative care, allied health professionals, nurses, and medical administrators. No studies discussed the role of pharmacists within Aboriginal health services.

Community Pharmacy

Aside from their dispensing role, pharmacists working in community pharmacy also provide direct medication management support for those receiving HC services through informal connections with local GPs. Barriers to care are related to community pharmacies being geographically isolated from prescribers. Selected papers illustrated activities that maintain the pharmacist's connection with the local healthcare teams, including:

- Real time liaison with GPs as part of case conferencing [22];
- Clarification of information relating to the prescription, including changes to the packing of dose administration aids [23]; and
- Anticipating which subcutaneous medicines to stock that are useful in managing symptoms expected in the last days of life [25].

These connections were led by the person's acute needs and were often driven at an individual clinician level.

Residential Aged Care Homes

Many papers described the pharmacist's clinical role or function of supply of medicines to the organization within a context of a formal arrangement or contract between the organisation providing RAC services and the individual pharmacist or pharmacy. As such, the role of the pharmacist within a multidisciplinary team was largely process driven, providing consistent care across the organisation, impacting on all people living in the organization. The clinical role of the pharmacist in this setting—such as the "medication review"—is performed in consultation with onsite nurses and GPs. In one paper, this role extended to communication and handover of medicines information at critical transitions of care such as admission to the RACH [26].

General Medical Practice

One study described how pharmacists working in a general medical practice setting improved timeliness and quality in how medication reviews were conducted [22]. Employing pharmacists within the general medical practice setting provided an opportunity to develop screening criteria for medicines prescribed by the GPs, such as checking medication lists for drug interactions, identifying duplication of therapy, and identifying problematic side effects; and facilitating external referral pathways. Pharmacists based at a general medical practice were also recognised as a resource for practice staff and community, with their timely provision of medicines information enabling effective coordination of home medication reviews for older people living in their home.

3.3.3. Theme Three: Supportive Professional and Personal Characteristics as Soft Skills

Four [22,27,28,32] of the 14 papers highlighted the importance of having supportive professional and personal characteristics. These supportive characteristics demonstrate soft skills of pharmacists, such as communication skills, personal behavioural approach to other clinicians, and positive attitude for the pharmacist workforce towards effective person-centered care. The supportive characteristics identified in the review were categorised into two levels: (1) Soft skills in supporting person-centered care (the people they provide services for as well as their carers) and (2) Soft skills in working with clinician prescribers.

Soft skills in supporting person-centered care

Pharmacists advocate for and follow up on behalf of the people they provide services for (as well as their carers), ensuring better clinical outcomes. Examples of these skills include:

- Advocating with prescribers (e.g., GPs and specialists) to change medicines or doses and/or deprescribe medicines that maybe are unnecessary [30]; and

- Following-up with people after a home visit to monitor how changes to medicines are going and answer any medication-related questions [27].

Soft skills in working with clinician prescribers

Key skills of the community pharmacist workforce that enable building effective working relationships with a range of clinicians included creative communication and people skills. Examples of these skills are:

- Writing medication review recommendations as a "medication management plan" to make it more acceptable and relevant for GPs to provide feedback [22];
- Supporting and maintaining trusting relationships with a multidisciplinary team of practitioners [22];
- Demonstrating a positive and helpful attitude to medication prescribers and other clinicians [22];
- Communicating with medication prescribers in a clear and honest manner [22]; and
- Following-up with medication prescribers if no response to medication reviews outcome reports are received [32].

4. Discussion

This rapid review has identified several matters relating to the roles and responsibilities of the pharmacist workforce supporting older people living in a community setting with palliative care needs. Despite diversity in the health care systems across the USA, Canada, UK, and Australia from where the studies were generated, similar themes across the literature were observed.

Reviewed papers predominantly focused on care provided by the pharmacist for people receiving RAC services; only a few examined the role of pharmacists with older people receiving HC services. This may be explained by the complex health and social care needs of people receiving RAC services. Services established for delivery of RAC are also likely to have more formal systems and processes in place as a result of contractual arrangements, making this aspect of care easier to review and assess. In contrast, HC service provision is less visible due to informal processes and relationships between individuals.

The findings observed in this rapid review suggest that a pharmacist's role (in developed countries) continues to evolve beyond their traditional medication dispensing responsibilities, with pharmacists stepping away from the dispensary and gaining larger significance in RAC services and General Medical Practices. A focus on the clinical role of pharmacists when working with older people in the community—including guidance on deprescribing, monitoring of medicines use, and detecting adverse drug events—is particularly important considering the growing prevalence of age-related multimorbidity resulting in polypharmacy and the increasing number of older populations receiving RAC and HC services.

In Australia, existing government-funded programs support pharmacists conducting clinical reviews, including: MedsChecks, home medicines reviews (HMRs), and residential medication management reviews (RMMRs) [12]. Such programs aim to prevent adverse drug reactions, improving clinical care and reducing unnecessary usage of medicines [34]. As well as providing direct clinical outcomes, medication reviews improve communication between pharmacists and the multidisciplinary team. As such, existing government funding levers may provide a useful instrument to involve pharmacists within aged care organisations. In 2018, the Australian government funded almost half a million medication reviews across the entire population, with 22% as RMMRs, 16% as HMRs, and the remaining 62% as MedsChecks [35]. With over 3.6 million Australians aged 65 years or more [36], there is a significant capacity for expanding the number of funded medication reviews by accredited pharmacists in older people each year. The Australian Government has recently relaxed the referral process for HMRs and RMMRs, permitting any Medical Practitioner to refer a patient for a medication review [37,38].

This review also identified organizational wide benefits of involving pharmacists from involvement on MACs to the conducting of audits or guideline reviews. While articles discussing this broader role for pharmacists were limited to organisations providing RAC services, NGOs such as those providing HC services could learn from the RAC experience, particularly in light of the Royal Commission into Aged Care [39]. The Royal Commission has identified several concerns—including poorly executed palliative care and excessive use of sedatives—where pharmacists could play critical roles in the development of safeguards, ensuring good medication management for all older people [40]. Furthermore, the soft skills inherent in the pharmacist workforce may augment the more formal processes that support good management of medicines within organisations. The Pharmaceutical Society of Australia (PSA) National Competency Standards Framework for Pharmacists In Australia supports pharmacists' role in multidisciplinary teams by saying pharmacists "show a commitment to interprofessional practice" [41]. Consideration of the diverse role of the pharmacist and their broader benefits to the multidisciplinary aged care workforce, including GPs and those delivering HC services, should be studied.

The pharmacist's role within the multidisciplinary team—supporting the care of older people—has been established: contributing to the improvement in health outcomes by working with others to provide medication management in older people who take multiple medications within a context of complex health care needs [42–44]. Roles of pharmacists within the context of multidisciplinary palliative care may strengthen the evidence base for good medicines management where RAC and HC services are delivered [45].

Implications for Policy and Practice in Aged Care

Health care services provided to older Australians are delivered by multiple providers across primary, secondary, and tertiary health care services. These services are often fragmented, with poor information sharing at points of transition. In addition, polypharmacy is inherent in the older population, making them more vulnerable to several risks, including adverse drug reactions and drug interactions. As such, pharmacists have a significant opportunity to contribute to and ensure appropriate and timely provision of medication and ensure that medication advice is available for all older Australians [46]. There are growing calls for the expansion of pharmacist roles beyond dispensing and clinical reviews while streamlining funding pathways through the mechanism of pharmacist access to the MBS and PBS reimbursements [47]. These expanded roles may serve to free up valuable GP time to manage more complex or acute medical problems, leading to a reduction in delays in essential end of life care for all older Australians [47].

5. Limitations

This rapid review was a resource constraint and time bound analysis. We applied a search strategy involving only three databases, focusing on indexed English language literature. Due to the streamlined search approach, relevant papers indexed in other databases and non-English literature would have been missed. The search approach adopted in this rapid review, however, is in line with existing rapid reviews that reported to have searched a minimum of two databases to retrieve literature and synthesise data [48].

The rapid review only located papers of level III and level V evidence. There were no papers graded at Level I, suggesting that scientifically strong papers in this area may be lacking. The lack of papers classified into the Level I category may also have been due to our specific research question and search strategies. The review question applied in this study sought a snapshot of the evidence exploring pharmacist's role in supporting the older population with palliative care needs. Therefore, intervention studies assessing the effectiveness of the roles of community pharmacists within the context of multidisciplinary palliative care may have been missed due to our streamlined research question and search strategies.

Further, this review resulted into relevant papers being sourced predominantly from developed countries, including the USA, Canada, UK, and Australia. As such, the health care settings in developing and less developed countries may not reflect the same health system structure and practices. In other countries, the community pharmacist role may not be as well established and they may not have the same roles and responsibilities identified in this review. Hence, the results generated from this review may not be generalisable in developing and less developed health care settings.

6. Conclusions

The roles and responsibilities of community pharmacists continue to evolve. The multifaceted role of pharmacists presents an opportunity to provide comprehensive medicines management for the older population at the end of their life. There is scope within the current health care system to increase organisational support for pharmacists working with older populations in aged care organisations delivering RAC or HC services. This is likely to facilitate better management of medication and improved care on discharge from the acute sector for older people with palliative care needs. Further studies should aim to build the level of evidence relating to the effectiveness of pharmacist roles in supporting people living with palliative care needs in the community.

Supplementary Materials: The following are available online at http://www.mdpi.com/2226-4787/8/3/143/s1, Table S1. Database(s): Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) (Search conducted: 19 July 2019). Table S2. Database: Cinahl (Ebsco) (Search conducted: 23 July 2019). Table S3. Database: Scopus (Search conducted: 23 July 2019). Table S4. Completed PRISMA checklist.

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APPENDIX 6: PUBLICATION SIX

Citation

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Contribution Statement

I was the first and corresponding author for Publication Six and was primarily responsible for the manuscript's design, drafting, revision, and final approval. My contribution to the publication was 0% research design, 30% data collection and analysis, and 80% writing and editing.

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What Are the Factors Identifying Caregivers Who Need Help in Managing Medications for Palliative Care Patients at Home? A Population Survey

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Abstract

Background: For most people, the last 12 months of life are spent living in the community, with the support of family and friends for a number of caregiving functions. Previous research has found that managing medicines is challenging for caregivers. Currently there is little information describing which caregivers may struggle with tasks associated with managing a loved one's medicines.
Aim: The aim of this study was to identify factors that flag caregivers who are likely to experience problems when managing someone else's medications.
Setting/Participants: The annual South Australian Health Omnibus Survey provides a face-to-face, cross-sectional, whole-of-population view of health care. Structured interviews, including questions covering palliative care and end-of-life care, were conducted with 14,625 residents in their own homes.
Results: Of the 1068 respondents who had provided care for someone who died of a terminal illness in the last five years, 7.4% identified that additional support with medicine management would have been beneficial. In addition, three factors were predictive of the need for additional support in managing medicines: aged <65 years; lower household income; and living in a metropolitan region.
Conclusion: The findings of this study provide insights to inform the development of palliative care service models to support informal caregivers in the management of medications for people with a life-limiting illness.

Keywords: caregivers; medication therapy management; needs assessment; palliative care; surveys and questionnaires

Background

Good symptom control at the end of life is valued by patients, family, and friends providing care, and health professionals above all else.[1,2] For most people, this will include prescribed medications, which generally increase in number as death approaches.[3] This includes a combination of medications for long-term comorbidities and medications for symptom control.[4,5] The proportion of people with palliative care needs who are on 10 or more medications is very high,[4,5] putting these patients at substantial risk of drug–drug and drug–host harms.[6]

More than 95% of care in the last year of life occurs in the community[7,8] and relies heavily on the presence and active engagement of families and friends to provide that care.[9,10] This results in a large number of relatively untrained individuals who administer medications to people with life-limiting illnesses. At a community level, it is really important that we support caregivers as they take on this difficult and challenging role.[11] This is particularly important as caregivers may fulfill this role several times in their life despite little preparation and often with poor evaluation of their ability or willingness to provide this care.[9,10]

Over 80% of caregivers of hospice patients report managing and administering medications to relieve patients' pain and other distressing symptoms.[12] Yet, many caregivers have

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unmet needs and require preparation for the role, with ongoing information, education, and personal support to assist them.[13]

Medication management relates to all practices used to manage the provision of medicines and can involve their purchase, administration, and monitoring.[14] For patients, medication management can be confusing and complicated; medications are often changed and doses altered, especially if the dosage is based on fluctuating severity of symptoms or other clinical findings.[12,15] For caregivers, managing the administration of medications for another person has additional challenges.[16,17] Medication management creates intense and ongoing responsibilities for caregivers that increase as the patient progresses through the illness and loses the capacity to contribute to his or her own medication management. Furthermore, the complexity of care provided in the community continues to increase with much more expected of caregivers in medication management than ever before, including the administration of subcutaneous medications and the need to make judgments about the use of ''as-needed'' (pro re nata) medications.[18,19] The medications used for symptom control have a range of potentially serious side effects, especially if given differently than prescribed.

Currently, there is little information about how caregivers perceive the task of managing medications for a palliative care patient.[20] Consequently, it is important to identify possible factors that flag caregivers who require additional support in managing medications.

Aim

The aim of this study was to determine whether there are any clinico-demographic factors that identify caregivers who perceive they need additional support in managing medicines. The null hypothesis was that there would be no characteristics that could help identify this group of caregivers. If any characteristics were identified, these findings could be used to develop and implement resources about medication management, focused on the unmet needs of these caregivers.

Methods

Survey design

The South Australian Health Omnibus Survey (HOS) is an annual, face-to-face, cross-sectional, whole-of-population, multistage, systematic clustered area sampling survey. It is run by a commercial research organization that provides deidentified data for researchers on a user-pays basis. Approximately 200 questions (including those covering palliative and end-of-life care) are asked annually, of which only the demographic questions remain constant.

Interviews are conducted by trained interviewers in participants' homes and last between 60 and 90 minutes. This approach provides a way of assessing the population rather than people identified only by health services with whom they have had contact.

Setting and subjects

The Australian state of South Australia has a population of $\sim$1.74 million people (6.9% of the Australian population), the majority of whom live in the state capital.[21] The HOS is carried out between September and December each year. The HOS is piloted with 50 respondents from the general community annually. The methodology has been described in detail elsewhere.[22]

A stratified sampling method by the size of a nonmetropolitan town identifies a representative cohort from metropolitan and country towns (with populations of more than 1000) with more than 5000 properties approached annually.

The units of randomization are (1) census collection districts (CCDs) and (2) the starting point within the CCDs. From the starting point in each CCD, there is a skip pattern of every 10th property. Properties approached may be houses, businesses, properties with other uses, or vacant land. Hotels, hospitals, caravan parks, and aged care facilities are excluded from the sample.

For dwellings, interviewers return up to six times if no one responded before acknowledging that they were unable to make contact. Participation rates are calculated on the number of potential participants with whom contact is made, and therefore, the denominator is fewer than the total number of properties approached. For example, if the property identified was a commercial property, or a vacant block of land, these were not included in the denominator of the participation rate.

One interview was conducted in each household with the person aged ≥15 years who most recently had a birthday. If that person was unwilling to participate, and another member of the household was unable to replace them, then that household was classified as declining participation.

For this particular study, having established that the person had provided care for someone who died of a terminal illness in the last five years, respondents were asked ''…if additional support would have been helpful.'' One potential response was a perceived need for help with medication management.

Data quality

All data were double entered with a supervisor, following up missing responses by telephone. In addition, 10% of each interviewer's respondents were recontacted to confirm their eligibility and ensure consistency of responses by reanswering a selected number of questions. Data were anonymized and then released to researchers.

Statistical analysis

Data were weighted to the 2010 Estimated Residential Population for South Australia by five-year age groups, sex, rurality, and household size.

Data analyses were conducted using SPSS for Windows Version 19.0. (2011; SPSS Chicago, IL). A p-value of 0.05 was accepted as the threshold for statistical significance, and adjusted by the Bonferroni correction for multiple comparisons ($p \leq 0.004$). Simple descriptive statistics were presented together with a multivariable regression seeking to identify any distinguishing characteristics for the subgroup of caregivers who identified that they perceived the need for more help with medication management. Included in the regression model was a combination of factors that were significant in univariable outcomes and those that were biologically plausible, including factors relating socioeconomic status and age (given the relationship to health literacy) and rurality (given differing levels of community clinical support).

Sensitivity analysis

To confirm the magnitude and direction of key findings, analyses were rerun with unweighted data.

Results

Among the population of 14,625 interviewed (2002, 2003, 2005–2007), 1085 (7.3%) respondents identified that they had provided day-to-day hands-on or intermittent hands-on care for ''someone close to them'' with a life-limiting illness during the previous five years (Table 1). Seventy-nine (7.4%) of these respondents identified that additional support with medication management would have been helpful. Key parameters that sought to identify characteristics of caregivers who perceived that they required additional help managing medications included the following: demographic characteristics; caregiving profile; characteristics of the deceased care recipient and palliative care service use (Table 1).

In univariate analyses, caregivers who lived in metropolitan areas were more likely to identify unmet needs in medication management compared with caregivers who were living in rural areas (8.6% and 4.1%, respectively; $p = 0.007$).

TABLE 1. CHARACTERISTICS OF CAREGIVERS AND NEED FOR ADDITIONAL SUPPORT WITH MEDICATIONS FROM A SURVEY OF 3000 PEOPLE RANDOMLY SELECTED EACH YEAR IN SOUTH AUSTRALIA

	Additional support needed with medications			
Characteristic	*No* (n = *1006)*	*Yes* (n = *79)*	*Total*	p *Value*
Age group (years)				
<65	798 (92.5)	65 (7.5)	863	0.531
65+	208 (93.7)	14 (6.3)	222	
Gender				
Male	373 (94.0)	24 (6.0)	397	0.265
Female	633 (92.1)	54 (7.9)	687	
Country of birth				
ESB	909 (92.9)	69 (7.1)	978	0.554[d]
NESB	97 (91.5)	9 (8.5)	106	
Work status				
Work full-time or part-time	439 (91.6)	40 (8.4)	479	0.403
Unemployed, home duties, student, and other	355 (93.2)	26 (6.8)	381	
Educational attainment				
Did not complete school, high school only, or still studying	456 (92.1)	39 (7.9)	495	0.429
Trade qualification, certificate, diploma, or higher	549 (93.4)	39 (6.6)	588	
Household income (per year)[a]				
Up to $60,000	556 (91.7)	50 (8.3)	606	0.093
$60,001 or more	321 (94.7)	18 (5.3)	339	
Rurality				
Metropolitan	678 (91.4)	64 (8.6)	742	0.007
Nonmetropolitan	328 (95.9)	14 (4.1)	342	
SEIFA				
Low SEIFA score	429 (92.5)	35 (7.5)	464	0.702
High SEIFA score	577 (93.1)	43 (6.9)	620	
Most involved level of care				
Daily ''hands-on'' care	423 (92.8)	33 (7.2)	456	0.964
Intermittent ''hands-on'' care	583 (92.8)	45 (7.2)	628	
Place of death[b]				
Home	80 (94.1)	5 (5.9)	85	0.584[d]
Elsewhere	326 (95.3)	16 (4.7)	342	
Palliative care services accessed				
Yes	615 (93.3)	44 (6.7)	659	0.410
No/don't know	391 (92.0)	34 (8.0)	425	
Care again[c]				
Yes	282 (94.3)	17 (5.7)	299	0.596[d]
Maybe/no	73 (92.4)	6 (7.6)	79	

Five years of data.
Values are numbers (percentages).
[a] A large proportion of respondents declined to provide this answer.
[b] Only asked in years 2005–2006.
[c] Only asked in years 2006–2007.
[d] Fisher's exact test.
NESB, non-English-speaking background; ESB, English-speaking background; SEIFA, Socioeconomic Index for Areas—an index of relative socioeconomic disadvantage and is based on the postcode provided by recipients.

This was the only difference identified between the groups. It is relevant to note that accessing a palliative care service made no difference between groups, and death at home similarly did not differ between groups.

In multivariate analyses, factors included in the model comprised the following: caregivers' ages; caregivers' sex; country of birth; the caregiver's (estimated) household income (noting that this may change as the result of the death of someone else in the household); rurality; most involved level of care (daily or intermittent hands-on care); and whether the caregiver identified that a palliative care service was used (Table 2). The fit of the model was adequate (Hosmer and Lemeshow $p = 0.114$) with the Nagelkerke R^2 being 4.3%.

Three factors were predictive of the need for additional support in medication management: a person younger than 65 years (odds ratio [OR] 0.982 [95% confidence intervals, CIs] 0.967–0.998); lower household income (OR 1.820 [95%CI 1.017–3.260]); and living in the metropolitan region (OR 2.425 [95%CI 1.263–4.656]).

Discussion

This study identifies a subgroup of caregivers supporting people at the end of life who subsequently indicated that would have liked more help managing medications. Three factors create a composite picture of a caregiver more likely to identify the need for assistance: a person younger than 65 years, from a lower income household, and living in a metropolitan region. This is an important finding that should be considered from the time a patient is referred to palliative care, and their caregiver(s) are identified. Consideration needs to be given to the systematic training and ongoing support that need to be in place for such caregivers.

People aged <65 years in general are likely to be working and have competing commitments such as caring for children.[23,24] They may also be living separately to the patient, particularly if they are caring for a parent. Financial stress for caregivers has been discussed in the literature.[25] In palliative care, the frequent changing of medications, formulations, and routes of administration creates a significant financial burden for the families of people being cared for in the community.[25] Being in a lower income household may potentially mean that difficult choices relating to household costs—including the purchase of medicines—are required if there is insufficient money.

People living in metropolitan areas are less likely to have strong communities supporting them when compared with nonmetropolitan areas.[26]

Palliative care services have a responsibility to assess caregivers' level of competence and confidence in managing medications for the patient from the time of initiating referral right through to the time of death. All caregivers need careful assessment, with particular emphasis on caregivers whose characteristics are defined by this study. Complexity and responsibility of caregivers' medication management increase as death approaches often with increasing numbers of medications,[3] new routes of medication administration, changing doses, and the requirement for ''as-needed'' medications.[18,19] The latter requires caregivers to make complex clinical decisions for which they are often ill-prepared.

Palliative care is often provided to people who frequently have a higher risk of medication misadventure due to the following:

- Polypharmacy associated with multimorbidity.
- Frequent transitions between health care settings.
- Multiple prescribers engaged with their care.
- Extensive changes to their medications (e.g., dose changes, switching formulations, ceasing of medications as clinical conditions change).
- Presence of worsening end-organ failure.

This creates an environment that is frequently changing for the person managing someone else's medications.

TABLE 2. REGRESSION MODEL FOR PREDICTORS OF PERCEIVED NEED FOR ADDITIONAL SUPPORT IN MEDICATION MANAGEMENT FOR CAREGIVERS WHO HAD PROVIDED CARE FOR SOMEONE AT THE END OF LIFE

		95% Confidence interval		
Factors	*Odds ratio*	*Lower*	*Upper*	p *Value*
Caregivers' age	0.982	0.967	0.998	0.031
Caregivers' sex				
Female	1.000			
Male	0.842	0.492	1.441	0.530
Country of birth				
NESB	1.000			
ESB	1.028	0.446	2.367	0.949
Estimated household income				
>$60,000	1.000			
≤$60,000	1.820	1.017	3.260	0.044
Rurality				
Nonmetropolitan	1.000			
Metropolitan	2.425	1.263	4.656	0.008
Most intense level of care				
Intermittent hands-on care	1.000			
Day-to-day hands-on care	1.089	0.649	1.826	0.747
Use of a palliative care service				
No (or unknown)	1.000			
Yes	0.954	0.572	1.593	0.858

Assuming responsibility for the management of medications for another person is stressful, even when caregivers are supported in taking on the role. Given the large number of medications that people take at the end of life and the fact that the overall number increases as death approaches, and is associated with frequent changes,[3] it would be understandable if some caregivers found the process of managing someone else's medications stressful.

Strengths of the study

Given that respondents are contacted independently of involvement with a health service, it is likely that this is a relatively representative population, reflecting the experiences of a wide range of caregivers supporting people at the end of life.

Limitations of the study

Limitations of this study include that no one younger than 15 years was able to be interviewed; it is known that people younger than 15 years do provide care to people at the end of life.[27] This is especially important, given this study identified that caregivers younger than 65 years were more likely to have unmet needs in managing medicines.

People living in towns with a population <1000 were excluded as the HOS was not conducted in these areas. This excluded people living in remote parts of the state.

The study excludes (and is therefore blind to) the increasing proportion of the population living in caravan parks, including the so-called gray nomads who, because of age, are more likely to need palliative care yet are less likely to have local support networks.

The data were collected 15 years ago, but given the absence of any data on this topic, it was felt important to create an understanding of some robust data to inform further work in this important area of hospice/palliative clinical care.

Implications for clinical practice

In practice, this study shows that when considering medication management, clinicians need to consider caregivers and assess their level of confidence in managing medications. This is particularly important given the wide range of people called upon to provide care at the end of life. Each caregiver's perspective on medication management should be reviewed regularly, especially as new medications are added, routes of administration change, the intensity of care increases, and clinical assessments are required if 'as-needed' medications are introduced.[18]

Targeting specific subpopulations of caregivers (such as those with a lower income), for medication management services, may provide a pragmatic approach in a resource-limited environment.

A key health professional in the clinical care team for providing education and ongoing support for caregivers providing medication management is the pharmacist. In Australia, Home Medication Reviews (HMRs) provide one model for engaging with patients and their caregivers within the home environment: reviewing medications; providing education; and creating a mechanism for ongoing support.[28] As HMR programs are evaluated and their evidence base strengthened, understanding the perspective of caregivers for people at the end of life should be an area of particular focus.

Implications for future research

Having established the baseline rate of 1 in 13 people identifying that additional support would have been useful, future surveys can explore the level of medication decision making expected, especially for ''as-needed'' medications. This includes clinical assessment skills to inform ''as-needed'' medications or where the dose of regular medications needs to be adjusted. Understanding this by classes of medication and routes of administration will be important in future qualitative and quantitative work. Another question of interest will be whether caregivers who themselves are on regular medications are more likely to be able to manage someone else's medications with more confidence. Finally, an objective prospective evaluation of the competence of caregivers to manage medications would build logically on the foundation created by this study, especially for people who perceived no need for additional support.

This initial survey was not designed to identify the consequences of feeling unsupported in managing medications. Such work now needs to be undertaken. Does this contribute to avoidable hospital admissions? Is symptom control poorer when a caregiver is less confident? Are compliance rates for medication administration affected when caregivers feel unsupported? Such work will need to involve longitudinal data collection in future research.

Generalizability

This study was conducted in one jurisdiction in a resource-rich country that has universal health care and a health system in the community built strongly around general practitioners. Community pharmacists in Australia are trained to deliver advice on medications also and their support of caregivers may differ in other parts of the world.

Ethics and Consent

The HOS receives annual South Australian Department of Health Research approval. Verbal consent was obtained from all participants before commencing an interview and continued participation was accepted as ongoing consent.

Data Sharing

Data are available on request from bona fide researchers.

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Author Disclosure Statement

No competing financial interests exist.

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APPENDIX 7: PUBLICATIONS AND OTHER MATERIAL ARISING FROM THIS RESEARCH

Peer Reviewed Publications

Tait, P., Chakraborty, A., Jones, K., & Tieman, J. (2021). What Is the Community Pharmacists' Role in Supporting Older Australians with Palliative Care Needs? Healthcare (Basel), 9(5), 489.

Tait, P., Chakraborty, A., & Tieman, J. (2020). The Roles and Responsibilities of Community Pharmacists Supporting Older People with Palliative Care Needs: A Rapid Review of the Literature. Pharmacy, 8(3), 143.

Tait, P., Sheehy, K., Sindhusake, D., & Muscillo, N. (2020). Factors affecting access to subcutaneous medicines for people dying in the community. Progress in Palliative Care, 28(5), 326-333.

Tait, P., Cuthbertson, E., & Currow, D. (2020). What Are the Factors Identifying Caregivers Who Need Help in Managing Medications for Palliative Care Patients at Home? A Population Survey. Journal of Palliative Medicine, 23(8), 184-1089.

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Listed Other Material

2022 RePADD Vlog: Pharmaceutical Care of the Dying

2021 Report: Rawlings D, Devery K, Tieman J, Tait P, Chakraborty A. Rapid review of the literature on end-of life care. Sydney: ACSQHC; 2021.

2021 ConPharm: Annual Consultant Pharmacy Seminar

Oral Presentation: Bereaved Carers Views On Medicines Management: Learnings For The Accredited Pharmacist

2021 CareSearch Blog: Palliation from the PBS Prescriber Bag

2020 CareSearch Blog: Five tips to facilitate good medicines management during the coronavirus pandemic

2019 CareSearch Blog: Symptom Management in the Terminal Phase: Turning Challenges into Opportunities

2018 National Medicines Symposium 2018

Three poster presentations: Pharmacist Reconciliation Initiative: MedsCheck at End-of-Life (PRIME), Symptoms and Medicines: A Portal to Good Quality Australian Palliative Care Medicines Information, and Rational use of medicines for people who are imminently dying.

2018 Caring@home Blog: Four ways to improve medicines management at the end of life

2018 ELDAC Blog: Pharmacists: The Medicines Experts

2018 qiCommunity Webinar: Managing the prescribing of medicines in the last days of life

2017 14th Australian Rural Health Conference

Oral presentation: An evaluation of doctor's experiences with the palliAGEDgp smartphone app

2017 Purple Pen Podcast: Palliative Care with Paul Tait

2016 Caring@home Blog: Four ways to improve medicines management at the end of life

2016 2016 Primary Health Care Research Conference

Oral presentation: palliAGED: Developing an innovative tool supporting evidence-based palliative care delivery by GPs

2016 National Medicines Symposium 2016

Oral Presentation: palliAGEDgp: Developing an innovative tool supporting evidence-based palliative care delivery by GPs

Poster presentation: Information resources for healthcare professionals in primary care: Improving access through information technology

2016 2016 Australian Pain Society 36th Annual Scientific Meeting

Co-Chair and organiser: Pharmacological Management in Pain - Morning Half Day Workshop

2016 ELDAC Blog: 5 tips for opioid prescribing in palliative patients

2015 13th Australian Palliative Care Conference

Two oral presentations: Smart Phone Apps & General Practitioners: A Portable Solution for Community Care, and The Approach To End-Of-Life Care: A Community Pharmacy's Perspective

Poster presentation: Case Conferencing For Palliative Patients Do Specialist Palliative Services Have A Role?

2015 Palliative Care Perspectives Blog: Five quick tips for prescribing medicines in the last days of life

2014 Society of Hospital Pharmacists of (SHPA): Medicines Management 2014

Oral Presentation: Meeting the challenges of Shifting Needs: The Palliative Paradigm

2014 South Australian Palliative Care Conference

Oral Presentation: A Pilot Retrospective Audit of Aged-Care Prescribing during the Last Three Months of a Resident's Life

2013 ConPharm: Annual Consultant Pharmacy Seminar

Oral Presentation: The role of the accredited pharmacist in palliative care

2013 4th International Society of Advance Care Planning and End of Life Conference

Oral Presentation: Development of an End-Of-Life Core Medicines List for Community Patients