

**MEASURING AND VALUING QUALITY OF CARE
FOR OLDER ADULTS IN SUBACUTE SETTINGS:
A HEALTH ECONOMICS PERSPECTIVE**

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SUMMARY

Ageing populations are predicted to increase demand for health and aged care services markedly during the coming decades. In addition older adults increasingly have rising expectations regarding the quality of the care they receive. This thesis aimed to investigate, from a health economics perspective, mechanisms for examining the quality of care of older adults in subacute care settings. Quality of care was examined through an investigation of process (the way in which subacute care services are delivered) and outcome (the measurement and valuation of the quality of life of older adults receiving subacute care). The thesis also aimed to compare the quality of life experienced by a subacute sample to that of a general population sample.

Eighty-six adults aged 65 years and over and receiving subacute outpatient day rehabilitation or residential Transition Care in Adelaide, South Australia participated in face-to-face interviews in which they completed validated instruments to measure their capability-based quality of life (ICECAP-O), health-related quality of life (EQ-5D-3L) and quality of care transitions (CTM-3). The respondents also completed a discrete choice experiment in which they were presented with alternative configurations of rehabilitation programs and asked to choose which programs they would prefer to receive. To generate population norms for the ICECAP-O and the EQ-5D-3L and to facilitate comparisons of the quality of life of the subacute care sample with the general population, a total of 1,174 Australians aged 65 years and over participated in face-to-face interviews or online questionnaires to complete the ICECAP-O or EQ-5D-3L.

The thesis identified a limited use of preference-based instruments to date in measuring quality of life in subacute care. The subacute care recipients reported upon in this thesis exhibited higher levels of capability-based quality of life in general than health-related quality of life. As expected, when compared with that of the general population the subacute care recipient group were found to have lower levels of quality of life.

However in general, the differences in EQ-5D-3L values between the subacute care recipients and the general population was more pronounced than those for the ICECAP-O. The subacute care recipients reported experiencing high quality transitions between health care settings, with the quality of care transitions being more strongly correlated with capability-based quality of life than health-related quality of life. Analysis of the subacute care recipients' preferences for the process of care using discrete choice experiment methodology indicated that similar aspects of care were important to both the outpatient day rehabilitation and residential Transition Care recipients. Strong preferences were evident for a shared decision-making approach and for the use of electronic medical records to transfer information between health and aged care settings.

In summary, the empirical findings from this thesis highlight the strong relationships between process and outcome for older adults receiving subacute care. Health, quality of life and the quality of care transitions were found to be inter-related. Older adults also demonstrated the ability to participate in the assessment of quality of care through application of discrete choice experiment methodology with the clear identification of preferences for aspects of subacute care that they value.

PUBLICATIONS ARISING FROM THIS RESEARCH

Refereed Manuscripts

1. Couzner L, Crotty M, Walker R, Ratcliffe J. Examining older patient preferences for quality of care in postacute Transition Care and day rehabilitation programs. *Health* 2013;5(6A2):128-35.
2. Couzner L, Crotty M, Norman R, Ratcliffe J. A comparison of the EQ-5D-3L and ICECAP-O in an older post-acute patient population relative to the general population. *Appl Hlth Econ Health Policy*. 2013;11(4):415-25.
3. Couzner L, Ratcliffe J, Lester L, Flynn T, Crotty M. Measuring and valuing quality of life for public health research: application of the ICECAP-O capability index in the Australian general population. *Int J Public Health*. 2013;58(3):367-76
4. Couzner L, Ratcliffe J, Crotty M. The relationship between quality of life, health and care transition: an empirical comparison in an older post-acute population. *Health and Quality of Life Outcomes*. *Health Qual Life Outcomes*. 2012;10(69).

Conference Abstracts

1. Couzner L, Ratcliffe J, Walker R, Crotty M. Patient preferences for rehabilitation therapy: A discrete choice analysis. Health Services & Policy Research Conference; Adelaide, Australia, December 2011.
2. Couzner L, Ratcliffe J, Crotty M. More general than specific? Measuring and valuing quality of life of older people receiving post-acute rehabilitation and Transition Care. International Society for Quality of Life Research 18th Annual Conference; Denver, Colorado, October 2011.
3. Couzner L, Ratcliffe J, Crotty M. An assessment of the practicality and validity of the ICECAP-O Index of Capability in Transition Care and clinical rehabilitation programmes for older people. 9th Asia/Oceania Regional Congress of Gerontology and Geriatrics; Melbourne, Australia, October 2011.
4. Couzner L, Ratcliffe J, Lester L, Flynn T, Crotty M. South Australia – Does it really give you such a ‘Brilliant Blend’? Findings from the application of the ICECAP-O to measure and value quality of life in a general population sample. Australian Health Economics Society Meeting; Sydney, Australia, October 2010.

DECLARATION

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

Although the concept for the studies presented here was conceived prior to my candidature, I was involved in the design of the research study including the completion and submission of ethics approval applications. The questions for the Discrete Choice Experiment were selected in consultation with my supervisors and experienced geriatricians. The statistical design was developed by Dr Leonie Burgess who has extensive experience in this area.

Upon commencement of the studies, I was responsible for screening potential patient participants for eligibility and conducting the data collection interviews. Although some of this was performed by research nurses, I undertook the majority of the screening and data collection duties. The data from the general population samples was collected and provided by Dr Richard Norman in addition to the Health Omnibus Survey. However I was responsible for the submission of the questions to the Health Omnibus Survey.

I was responsible for the entry of all data. I received assistance to analyse the data pertaining to the discrete choice experiment from Dr Laurence Lester who is an experienced econometrician, and co-author on the resulting publication. The remainder

of the original data reported on in the thesis was analysed by myself with guidance from my supervisors when necessary regarding the interpretation of the results.

In regard to the literature reviews, I developed the search strategies following consultation with a medical librarian. I was responsible for running the search strategies, screening the results, obtaining copies of the relevant studies and contacting authors for additional information where required. I then conducted the analysis, and in the case of the quality of life literature review, received guidance from one of my supervisors relating to the conversion of instrument scores. In regard to the systematic review on outcome utility measurement, assistance with the data analysis was received from Professor Richard Woodman.

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LIST OF ABBREVIATIONS

ASCOT – Adult Social Care Outcomes Toolkit

CBA – Cost benefit analysis

CEA – Cost effectiveness analysis

CTM-3 – Care Transition Measure

CUA – Cost utility analysis

DCE – Discrete Choice Experiment

EQ-5D-3L –EuroQol 5 dimension 3 level

FIM – Functional Index Measure

HRQoL – Health-related quality of life

HUI – Health Utility Index

ICECAP-A - ICEpop CAPability measure for Adults

ICECAP-O –ICEpop CAPability measure for Older people

MAUI – Multi-attribute utility instrument

MMSE – Mini Mental State Examination

OPQOL – Older Person’s Quality of Life questionnaire

PROMs – Patient Reported Outcome Measure

QALY – Quality adjusted life year

QWB – Quality of Well-Being Scale

SG – Standard gamble

TTO – Time trade-off

VAS – Visual analogue scale

WTA – Willingness to accept

WTP – Willingness to pay

Chapter 1

Introduction and rationale for thesis

1.1 Introduction

A recent report from the Australian Government's Treasury Department has called for a reform on health spending to ensure the best quality health services can be provided to meet the needs of the ageing population with the resources available.¹ While the need for the Australian health system to provide cost-effective services has been widely acknowledged for some time, it has also been recognised that ideally this should be undertaken in a way that does not minimise the quality of care provided to recipients. The escalating pressure faced by health systems in relation to the allocation of scarce health care resources highlights the importance of economic evaluations of health and social care interventions in informing such decisions.²

Significant increases are predicted in the proportions of older adults (aged 65 years and above) living in the community both within Australia and internationally.³ To ensure that future decisions regarding policy, programs and human resources incorporate the needs and preferences of older adults themselves, it is important that new methods are introduced which facilitate the active involvement of older adults in transforming the health system.

1.1.1 Subacute care

Subacute care services, sometimes referred to as post-acute care, play a varied, but important role within the Australian health care system. Rather than being driven by a patient's diagnosis, subacute care is driven by the goals the patient would like to achieve and their individual functional status including physical and cognitive abilities.⁴⁻⁶ Consider, for example, two patients admitted to acute care settings following a stroke. While the first patient is discharged home the following week, the second

patient is transferred to a rehabilitation unit because her movement and speech remains limited and she is unable to perform activities of daily living such as feeding herself. Although both of these patients have the same diagnosis, it is the second patient's functional ability that determined her need for subacute care, rather than her diagnosis of stroke.⁴ The primary goals in the provision of subacute care are to improve the functional abilities and quality of life of patients, in order to enable patients to live as independently as possible, for as long as possible.^{4, 7}

An Australian casemix classification reported there to be five clinically distinct case types within subacute care: palliative care, maintenance care, psychogeriatric care, geriatric evaluation and management (GEM) and rehabilitation.⁸ Subacute care is typically provided by a multidisciplinary team of health professionals which include, but is not limited to, doctors, nurses, physiotherapists, occupational therapists, speech pathologists, social workers and psychologists.^{4, 7} Although subacute patients typically require less surgery and diagnostic tests than acute patients, subacute patients often require a more intensive level of care from allied health professionals. Additionally, subacute care requires increased communication and coordination between health professionals and patients' families, and also with other health services as subacute patients are likely to require ongoing care following discharge from the subacute care setting.⁴ Hospital length of stays for patients receiving subacute care also tend to be longer than those of patients receiving acute care, with a typical rehabilitation hospital admission being two weeks or longer in duration. Because of this, despite subacute care patients accounting for only 2.5% of Australian patients, they occupy 13% of public hospital beds.⁴

The priority being placed on subacute care in Australia was demonstrated by the signing of a National Partnership Agreement on Hospital and Health Workforce Reform (NPA HHWR). This agreement committed up to A\$500 million to states and territories in 2008-2009 with the aim of increasing the number and quality of subacute care services both in hospitals and in the community by 5 percent annually between 2009-2010 and 2012-2013.⁷

1.1.2 Subacute care for older adults

As a population group, older adults have the highest hospital admission rates in Australia, with the average length of stay for hospital episodes also increasing with age.³ Services such as rehabilitation and Transition Care are expected to play an increasingly important role in the overall health care for older adults, assisting in recovery from an acute episode of illness, the management of chronic conditions and the development and maintenance of functional independence.⁹⁻¹² Subacute health care additionally reduces the pressure placed on acute care services, allowing patients who no longer require an intense level of care to be transferred to a more appropriate setting.

Transition Care

An emerging approach to meeting the subacute care needs of older adults both in Australia and internationally is Transition Care. This model of care is designed for older adults who are at the interface of the acute, and residential care settings.¹³ The implementation of the Australian National Transition Care Program was announced in 2004 to reduce the length of inappropriate hospital stays and premature admission to residential aged care facilities. The program is targeted at older adults at the end of an inpatient hospitalisation who are not eligible for hospital rehabilitation services, but

who require further care in order to complete their recovery, optimise their level of functioning and make arrangements for long term care if necessary.¹⁴ The program is goal-oriented, but time-limited, with the average duration being seven weeks. A maximum of 12 weeks is permitted, however an additional extension of six weeks may be provided under particular circumstances for a total possible program duration of 18 weeks.¹³ The Australian National Transition Care Program is jointly funded by the Commonwealth and State/Territory Governments and can be provided in either an inpatient or community setting. The services provided are determined by individual need and can include low intensity rehabilitation, medication support, case management, nursing and personal care.¹³ Prior to commencing Transition Care, patients are required to be medically stable and approved for Transition Care by an Aged Care Assessment Team.¹⁴ A recent evaluation of the Australian Transition Care program demonstrated that Transition Care provided in the community could reduce both hospital readmissions and transfers to residential care settings.¹⁵ Additionally, the Australian Transition Care Program has been shown to improve patients' functional status, and have high levels of acceptability among health professionals, patients and their families. However, as a relatively new model of care, its increased implementation will need to be accompanied by further evaluations in terms of cost and patient outcomes.^{13, 16}

Geriatric Rehabilitation

In the Australian context, the majority of subacute care provided is in the form of rehabilitation.¹⁷ As defined by The Australasian Faculty of Rehabilitation Medicine, rehabilitation, for the purpose of this thesis refers to:

A service which “aims to assist people with loss of function or ability due to injury or disease to attain the highest possible level of independence (physically, psychologically, socially and economically) following that incident or illness. This is achieved through a combined and co-ordinated use of medical, nursing and allied health professional skills. The process involves individual assessment, treatment, regular review, discharge planning, community integration and follow-up of people referred to that service.”¹⁸ (p.2)

In South Australia, rehabilitation is provided in a range of settings including inpatient settings, centre-based day rehabilitation and in patients’ homes. Inpatient rehabilitation is typically the most intense level of care, while centre-based day rehabilitation tends to provide low to moderate therapy in which patients reside in their own homes and attend the centre two to five times per week for half a day.⁶ Hospital in the home also provides therapy to individuals who do not require inpatient care, however this therapy occurs in the patient’s home rather than them attending a rehabilitation centre.⁶

Increases in the utilisation of rehabilitation services within Australia have largely been attributed to the ageing population.¹⁹ Recent data shows that the number of inpatient rehabilitation episodes in Australia has increased by 6% between 2014 and 2015, accompanied by a 7% increase in ambulatory (outpatient) rehabilitation episodes in the same period.^{20, 21} The average age of patients receiving inpatient rehabilitation has increased from 72 years in 2000 to 74 years in 2015.^{21, 22} The 2009-2017 state-wide rehabilitation service plan reports that South Australia currently provides 237 publicly funded inpatient rehabilitation places (15 places per 100,000 population) and 141 privately funded places (24 places per 100,000 population).²³ Fifty eight outpatient rehabilitation places are also funded, equating to 4 places per 100,000 population.²³

Table 1.1 summarizes the episodes of subacute rehabilitation provided in Australia in 2015 by impairment along with the mean ages of the recipients.

In 2015, 115,173 episodes of inpatient rehabilitation were provided in Australia, with the most common reasons being reconditioning (25%), orthopaedic replacements (25%) and orthopaedic fractures (16%).²¹ The provision of rehabilitation episodes were generally evenly split between the public and private health sectors. In contrast, 8,495 episodes of outpatient rehabilitation were provided in the same time period. The most common impairments were orthopaedic replacements (46%), reconditioning (10%) and stroke (9%).²⁰ Of the ambulatory rehabilitation episodes, 21% were referred from a subacute inpatient service at the same hospital, suggesting a continuation of inpatient rehabilitation. Unlike the inpatient episodes, the majority of ambulatory episodes, 80%, were provided in private facilities.²⁰ As can be seen in table 1.1, many of these episodes of rehabilitation were provided to adults aged 65 years and over.

Table 1.1 Episodes of rehabilitation in Australia in 2015 ^{20, 21} (continued over page)

Impairment	Inpatient episodes	Mean age (yrs)	Outpatient episodes	Mean age (yrs)
Stroke	8,895 (8%)	73.2	767 (9%)	67.6
Brain dysfunction	2,657 (2%)	66.4	186 (2%)	56.8
Neurological condition	3,787 (3%)	66.4	475 (6%)	65.8
Spinal cord dysfunction	866 (1.0%)	62.7	<5 (0%)	Not reported
Amputation	1,354 (2%)	65.9	87 (1%)	62.1
Arthritis	563 (1%)	75.3	89 (1%)	73.4
Orthopaedic fracture	18,999 (16.0%)	78.3	551 (7%)	72.4
Orthopaedic replacement	28,533 (25%)	71.4	3,911 (46%)	69.4
Orthopaedic other	-	-	598 (7%)	67.2
Pulmonary episode	2,211 (2%)	79.6	103 (1%)	76.1
Reconditioning	29,058 (25%)	79.7	851 (10%)	74.0
Pain	4,191 (4%)	71.6	344 (4%)	66.8
Cardiac conditions	3,592 (3%)	79.2	196 (2%)	71.4
Multiple trauma	850 (1%)	50.5	31 (0%)	49.6
Burns	67 (0.1%)	57.6	<5	Not reported

Congenital Deformity	24 (0%)	56.8	6 (0%)	49.3
Developmental disability	12 (0%)	58.8	<5 (0%)	Not reported
Other impairments	633 (1%)	73.4	293 (4%)	71.2
Missing	Not reported	Not reported	4 (0%)	Not reported
Total	115,173	74.4	8,495	69.1

1.1.3 How to define quality of care

In addition to an increased demand for health care and support services, the ageing population is also predicted to have a wider range of needs, preferences and expectations in regard to these services.^{1, 10, 24} In order to meet these expectations, it is important that methodologies are developed and applied which facilitate the incorporation of the views and preferences of older adults into the design and delivery of high quality health care.²⁵

From the patient's perspective, a helpful working definition of quality of care has been proposed by Campbell and colleagues as: "whether individuals can access the health structures and processes of care which they need, and whether the care received is effective".^{26 (p.1614)} Effective care is comprised of two inter-related elements, health outcomes and 'user evaluation' which may include assessment of outcomes (including symptom resolution) and/or processes of care (e.g. the communication skills of the health professional).²⁶ Broadly, the examination of quality of health care centres upon the ability of the care to achieve improvements in health and quality of life, the degree

to which these improvements can be achieved within existing resource and cost constraints, and its acceptability to patients and society.²⁶

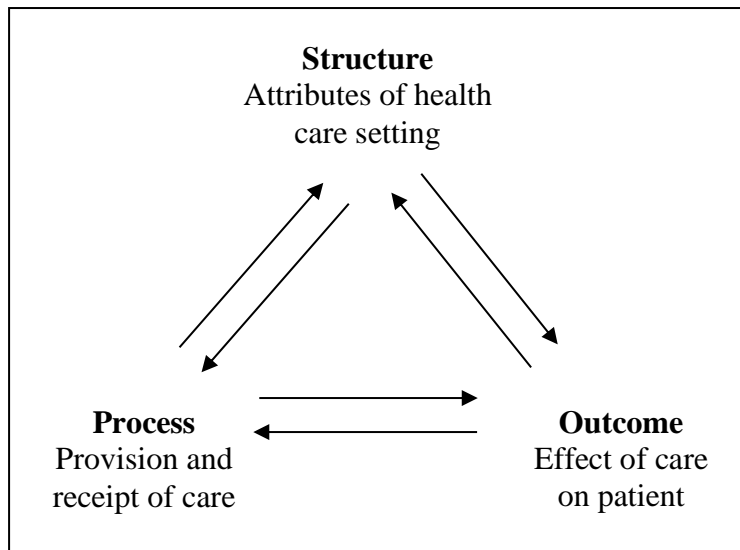
The purposes for which quality of care may be examined in the field of subacute care include program management, the meeting of regulatory requirements, the production of generalizable knowledge and the meeting of the needs of policy makers.²⁷ When conducted from the perspective of patients, examining quality of care can allow the preferences of patients to be ascertained and incorporated into the design and delivery of health care services.

Quality in health care is difficult to define and may be perceived differently by researchers and practitioners in different disciplines with differing perspectives. Whilst quality of health care is increasingly being linked to the health outcomes achieved as the result of the care, traditionally such outcomes have tended to be measured using clinical indicators of patient functioning or well-being as perceived by clinicians and other health care professionals.²⁸ From the perspective of health economics, it has been argued that quality in health care should be based upon the degree to which patients perceive their the needs and preferences have been met.²⁹ Although the landscape is now changing, traditionally older adults have had little involvement in the design of health care services or in determining the outcomes on which quality of care should be based.¹² If the quality of health care provided to older adults is to be determined by the level to which patients' needs, preferences and expectations are met, it therefore follows that the way in which older adults define quality of care needs to be examined.

A widely acknowledged conceptual model for the assessment of quality of care is that developed by Donabedian consisting of a triad of structure, process and outcomes as shown in figure 1.1.³⁰ Structure refers to the attributes of the setting in which care is provided such as material resources, human resources and organisational structure. The process of care refers to the actual provision and receipt of care including the behaviour of both the patient and provider. Outcomes of care refer to the effect of the care on the patients' health status including physical, physiological and psychological aspects of health.³⁰ Increasingly broader aspects of quality of life are also being considered as relevant and important outcomes to capture within this framework.^{31, 32}

Donabedian's pioneering conceptual model is based on the causal relationships between these three categories, with high quality in the structural domain leading to an increase in the likelihood of quality in the process of care which in turn leads to positive outcomes of care.³⁰ For example, in the case of a patient who has suffered a stroke, the number of rehabilitation therapists in the hospital that the patient is being treated at (structure) will influence the amount of therapy that is able to be provided (process) which may in turn affect the level of physical function the patient is able to regain post-stroke (outcome).²⁷ However it is important to note that the relative importance of the structure, process and outcomes of care vary according to the situation under examination and that their relationship may not necessarily be linear.²⁶

Figure 1.1 Donabedian's conceptual model for quality of care assessment



Although little empirical work has been conducted to date to test the Donabedian hypothesis in subacute care, it has been applied to examine the quality of care in rehabilitation, particularly relating to stroke. These studies have established that the structure of care (facility characteristics and personnel professions), predicted the process (care planning and multidisciplinary team meetings) and outcome of care (discharge destination and length of stay).^{27, 33-35}

1.1.4 Process of care in subacute care

Whilst health economists have traditionally focused on outcomes of care being of primary importance in defining quality of care from the patient perspective, the importance of the process of care, first highlighted by Mooney and more recently by Ryan, has gained increasing prominence and recognition.^{36, 37} The process of care refers to the delivery and receipt of health care, incorporating the activities of both patients and health services and the complex interactions that may take place between them.³⁸ The concept includes patient's seeking of care and health professionals' activities in

providing a diagnosis and recommending or implementing treatment.^{26, 30} While acknowledging the clinical management of illness, process also pays attention to other aspects of health care such as rehabilitation, continuity of care, prevention of ill-health and interactions between patients and health professionals.³⁹ The quality of the process of care is commonly measured by assessing the degree to which recognized, national standards of care or treatment guidelines have been adhered to via examination of case notes.^{39, 40} Examples of process of care attributes include waiting times for treatment, the type of treatment provided, the frequency or duration of therapy and the continuity and coordination of care.²⁷ Within the rehabilitation service context, process of care attributes may relate to, for example, discharge planning, how soon therapy is initiated, the frequency of treatment visits, the type of treatment provided, the setting in which treatment is provided and the type of health care professionals providing the service.^{27,}

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In regard to Transition Care, process of care has been examined in regard to the key aspects of quality Transition Care defined by the Australian National Transition Care Program guidelines. This was performed via a content analysis of quality reports from Transition Care providers and the development of a questionnaire designed to measure the experiences of Transition Care recipients.^{42, 43} Process of care attributes included the provision of care in a way that promotes adaption and independence, case management, planning of care, medication management review, multidisciplinary involvement, opportunities for client social interactions, the transfer of information and care between acute and subacute settings, the preparation of clients to enter Transition Care and the provision of services and equipment at discharge.^{42, 43} Clients who were dissatisfied with the care they had received also had lower scores on the subscales measuring social

interactions and the provision of care so as to promote independence and adaption. The finding that the measurement of client experiences is suitable in informing quality improvement in Transition Care supports the notion that process of care has the potential to influence the overall quality of subacute care.⁴³

Process of care attributes have been shown to be influential in patients' satisfaction with health care, which is often used as a proxy measurement for patient-assessed service quality.⁴⁴ However Donabedian suggests that patient satisfaction be used cautiously as an indicator of quality of care. This caveat is based on the notion that patients may be reluctant to voice dissatisfaction in fear of alienating their health care providers.³⁰

An alternative method of examining the process of health care from the patient perspective is to employ discrete choice experiment (DCE) methodology. DCEs have their basis in Lancaster's theory of value, which places importance on the characteristics of health care, stating that individuals derive benefits from the characteristics of goods or services.^{45, 46} Lancaster hypothesized that rather than deriving utility directly from goods and services themselves, consumers derive utility from the characteristics or attributes of the good or service.^{45, 46} Application of Lancaster's theory to health care highlights the potential importance of the characteristics of health care 'process' in addition to health outcomes in determining the overall utility or value to patients of health care. Despite an exponential increase in the number of DCEs conducted in health care in recent years,⁴⁶ the development and application of DCEs specifically targeted in populations of older adults remains rare in comparison with those conducted in adults more generally. DCEs will be discussed in detail in chapter 3.

1.1.5 Outcomes of care in subacute care

Given that subacute care is a growing area of medicine, it is important that instruments exist that allow for the appropriate measurement of outcomes to assess the effectiveness and quality of these services. Geriatric rehabilitation programs have been associated with a reduction in admission to residential care facilities and improvements in functional status.⁴⁷ These outcomes have the potential to not only maintain the quality of life of older adults who have experienced an episode of ill-health, but also to reduce the cost impact upon health services.⁴⁷ Despite this, traditionally, quality in health care such as rehabilitation has largely been assessed in terms of the outcomes or consequences of receiving care using clinical indicators of recovery, mortality and the restoration of function.⁴⁸ Other outcomes which have been captured and reported on in the literature include changes in health-related knowledge, attitudes and behaviours.^{27, 31, 49} Outcomes of care relevant to subacute care such as rehabilitation and Transition Care which are routinely captured in Australian monitoring systems, include hospital readmission rates, rates of discharge to the community and measures of physical and cognitive function.²⁷

Another outcome that is being increasingly measured in populations of older adults receiving health care is the quality of transition between health care settings.⁵⁰ As older people are likely to receive care from a multitude of health professionals and services, it is vital that the transition between staff and sites is as seamless as possible.⁵¹ The provision of fragmented care has been associated with a range of negative outcomes including medication errors, poor clinical outcomes, the provision of unnecessary treatments or services and the transfer of inaccurate or incomplete information about the patient.⁵²⁻⁵⁵ Poor care transitions also have negative impacts from a health economics

perspective, with the provision of duplicate or inappropriate tests or treatments increasing the cost of care per patient.⁵² Additionally, emergency department utilisation and rehospitalisation may also occur which could potentially be avoided with a smooth transition between care settings.⁵² The Care Transition Measure (CTM-3) is an instrument that has been developed specifically to measure the quality of transitions between care settings from the patient perspective.⁵⁶ This instrument focuses on whether the patient understood the purpose of their prescribed medications, whether the patient, and their families' preferences were taken into consideration and if they understood what they were responsible for in terms of managing their health.⁵⁰ The importance of high quality care transitions and the CTM-3 will be discussed in further detail in chapter 6.

Health-related quality of life (HRQoL) is another primary measure of outcome and one that is increasingly being measured to ascertain the effectiveness of health and social care interventions. HRQoL within an economic evaluation framework examines quality of life based on the premise that health has a direct impact on quality of life, and can therefore be influenced by the provision of health care. Instruments that have been utilised for the purpose of measuring and valuing HRQoL within an economic evaluation framework include the SF-6D,⁵⁷ SF-36,⁵⁸ 15-D,⁵⁹ Assessment of Quality of Life (AQoL),⁶⁰ Quality of Well-Being Scale (QWB),⁶¹ the Health Utility Index (HUI)⁶² and the EuroQol 5 Dimension 3 Level (EQ-5D-3L, previously referred to as the EQ-5D prior to the recent development of a new five level version of the instrument, the EQ-5D-5L).⁶³ Examples of the domains encompassed within these instruments include mobility, self-care, physical functioning, sensation, cognition, performing usual activities, pain, anxiety/depression and vitality.

In the context of an economic evaluation HRQoL is measured in terms of utility, a value representing an individual or society's preference for a health outcome such as a particular health state.⁶⁴ It is therefore important to note that whilst the instruments mentioned above are considered to be measures of HRQoL, they are in fact measuring utility. Utility values in economic terms reflect the satisfaction gained from the consumption of goods and services. Generally higher utilities are attached to better health and/or quality of life states than poorer ones. Utilities are cardinal values that range from zero to one, with one representing a health outcome that is equal to full health and zero representing an outcome that is considered to be equivalent to death. However values less than zero can also be obtained, representing health outcomes that are perceived as being worse than death. The measurement of utility not only enables the HRQoL associated with a health outcome to be measured and valued, but also provides for HRQoL to be combined with the duration of time spent in that state. This outcome measurement based on HRQoL can then be incorporated into an economic analysis of health care treatments and services.⁶⁴

However some commonly used HRQoL instruments such as the SF-36 and SF-12 are not preference-based (the health state values do not reflect the preferences of a sample such as the general population) and therefore not able to be used to measure utility outright for use in economic evaluation of health and social care interventions. To enable their inclusion in such analyses, the scores derived from these instruments need to be mapped onto a preference-based instrument to enable utility to be measured. The concept of mapping enables a preference-based score to be estimated from an instrument that is not preference-based.⁶⁵ This process has become commonplace, with

the SF-36 and SF-12 being mapped to instruments such as the SF-6D, EQ-5D, HUI and QWB.⁶⁵⁻⁷¹ This process is particularly useful as it does not require patient level data, allowing for mean non-preference-based scores in published studies to be converted into those of preference-based instruments.

HRQoL is becoming a widely measured outcome of health care. If quality of care is considered to be influenced by the interaction of the process and outcomes of care, as stated by Donabedian, HRQoL could be considered as a contributor to the quality of health care. The measurement and valuation of HRQoL will be further discussed in chapters 3 and 5.

1.1.6 Application of health economic methods for assessing quality of care

Translation of the Donabedian framework to the discipline of health economics highlights the importance of outcome to any assessment of quality of care. One way this has been performed is via the application of DCE methodology, which will be discussed in depth in chapters 2 and 4. In health, DCEs focus on an individual's preferences for particular treatments or services, with their preference reflecting the trade-offs they are willing to make in order to receive what they perceive to be the most ideal outcome. An example of this is the work of Ratcliffe and Buxton which investigated patient preferences relating to liver transplantation services. The findings demonstrated that patient preferences were not exclusively based upon health outcomes, but were also influenced by elements relating to the process of care.⁷² This reinforces the importance of not only measuring the outcomes of health care, but also the process of providing care and the interaction between these concepts in the assessment of the quality of care. To enable the inclusion of patient preferences into economic evaluation frameworks,

methods have recently been developed by which DCE data can be combined with the cost data of health care programs.^{73, 74} This allows the cost-effectiveness of a health or social care intervention to be calculated based upon the process of care, in addition to, or instead of outcomes of care. The findings of this evaluation can then be compared with that of other interventions to ascertain their relative cost-effectiveness.

Health-related quality of life outcomes are increasingly being used to assess the quality of health and aged care interventions within the framework of economic evaluations.¹² For example, in 2009 the United Kingdom National Health Service introduced the routine utilisation of the EQ-5D-3L, a generic preference-based instrument, meaning the health state values reflect the preferences of a general population sample. In this instance, the EQ-5D-3L is being utilised to assess the HRQoL outcomes for patients undergoing elective surgical procedures for hip or knee replacements or the repair of hernias or varicose veins, with future plans to include additional diagnoses.²⁹

The need to apply economic theory to facilitate health care decision-making lies in the inconsistency between society's infinite health-related wants and needs, and the finite number of resources which are available to be utilised to meet them. Such is the scarcity of these resources, including staff and equipment, that allocating resources to one area of health typically requires redirecting resources from another area.⁷⁵ The removal of resources from the second area however means that the benefits that would result from providing that service will be sacrificed.^{75, 76} These lost benefits are referred to as opportunity costs. Therefore, given the scarcity of resources, it is optimal for resources to be allocated in a way that provides for both equity and efficiency.⁷⁷ Equity may be defined in several ways. A common definition often applied in the health care context

refers to the equal distribution of access to health care, while efficiency is the allocation of resources in a way that results in the maximum possible output.^{37, 78} However in practice, trade-offs may sometimes need to be made between efficiency and equity.

The framework of economic evaluation offers a systematic and transparent approach for assessing and comparing the relative costs and benefits of health care services, programs and interventions.⁶⁴ By measuring and valuing the process and outcomes of health care, economic evaluation primarily serves to answer two main questions. Firstly, is the health program, service or procedure worth performing when compared with alternative potential uses of the same resources, and secondly, should these resources be utilised in this way rather than put to an alternative use?⁶⁴

One widely applied technique of economic evaluation is cost-effectiveness analysis (CEA) which examines the most cost-effective way of providing a particular intervention. This technique compares the costs of alternative methods of achieving a particular outcome, measured in terms of cost per unit of treatment effect, for example, cost-per day of being symptom-free.^{64, 75, 79} Cost-utility analysis (CUA) is another widely applied technique of economic evaluation and may be considered as particularly appropriate for subacute care and other areas of health care where quality of life is an important outcome of the interventions in question.⁶⁴ CUAs are the technique of economic evaluation recommended internationally by regulatory bodies including Australia's Pharmaceutical Benefits Advisory Committee (PBAC) and the United Kingdom's National Institute for Health and Care Excellence (NICE) to appraise the cost-effectiveness of medications and health care interventions respectively.⁸⁰⁻⁸² This approach compares the cost of health care interventions with their outcomes, which are

measured in terms of quality adjusted life years (QALYs).⁷⁵ While the economic evaluation of health services and interventions often focus on clinical outcomes, QALYs enable the perspective of the patient to be incorporated into the evaluation.

The QALY construct combines the HRQoL associated with a particular health state and the length of time spent in that state. One QALY is equivalent to 1 year in full health. The QALY is calculated by multiplying the length of time spent in a particular health state by its value. A health state value is a numeric value assigned to a health state that reflects, most commonly, the general population's preferences for living in that state. As highlighted previously, these values range from zero to one, where one refers to a state that is considered to be full health and zero represents a state perceived as equivalent to death. However some states may be considered to be worse than death, in which case values less than zero may be generated and applied.⁷⁵ Health state values therefore signify the "quality" aspect of QALYs, enabling both HRQoL and time to be combined into a single outcome measure suitable for use in economic evaluation.⁷⁵

Several techniques exist for the estimation of health state values (also known as preference elicitation techniques), producing values which are either ordinal or cardinal. The most commonly used cardinal techniques are the Standard Gamble (SG), Time Trade-Off (TTO), and the Visual Analogue Scale (VAS).⁷⁵ A SG task involves respondents being presented with, and being asked to imagine living in a particular health state (i). They are then presented with two hypothetical options. Option A is to receive a medical intervention which has a chance of either immediate death or returning them to full health for an additional t years. Option B involves remaining in state i for a specific period of time (t). The probability of returning to full health and

immediate death is varied until the respondent reaches a point in which cannot chose whether they would prefer Options A or B. The health state value is given as $h_i = p$.⁶⁴

In a TTO task, the respondents are asked to imagine that they are living in a particular health state for a specified period of time (t) which would then be followed by immediate death. They are then asked to compare that with living in a variety of shorter time periods (x) in full health until they reach a point where they are unable choose which state they would prefer. The health state value is given as $h_i = x/t$. TTO can also be used to value temporary health states, in which respondents choose between living in temporary health state i for a specific period of time (t) followed by returning to full health, or living in temporary state (j) for a shorter period than t , followed by a return to full health. Again, x is varied until the respondent becomes indifferent between the options. Here the health state value is given as $h_i = 1 - (1 - h_j)x/t$.⁶⁴

The VAS is a 10 centimetre line in which one end represents zero (the equivalent of death) and the other represents one (full health). Respondents are presented with health states, including death and asked to place them on what the scale, reflecting their perception of where each state falls in the range of full health and death. However the possibility that respondents may consider some states to be worse than death must also be taken into account. The health state is therefore given as $A_i = R_i - \frac{R(dead)}{R(best)}$ $R(dead)$. Where A_i represents the adjusted VAS rating for that particular health state (h_i), R_i represents the raw rating given to h_i , $R(dead)$ represents the raw rating given to death and $R(best)$ representing the raw rating given to the health state the respondent considered to be the best.⁷⁵

Other techniques also exist for the valuation of health states, although providing ordinal values. One such approach is that of ranking a series of health states in order from best to worst, or vice versa, as perceived by the respondent. Alternatively, respondents can be asked to rate health states individually using ordered categories. These categories relate to how good or bad the level of health they associate with it to be, such as excellent, very good, good, fair or poor. Finally, another preference elicitation technique for the valuation of health states is the DCE in which respondents are presented with two or more alternative health states and asked to select their preferred state. Respondents may be asked to make choices such as which state they believe represents the best level of health or which state they would prefer to live in for a particular period of time.⁷⁵ An advantage of the use of techniques that provide ordinal information is that they are considered to be less complex than techniques such as SG and TTO⁷⁵, which is important to take into consideration when valuing health states in populations who may experience cognitive impairment such as older adults.

Once the QALY gains attributable to a particular health or aged care intervention have been estimated, these can then be utilised within the framework of economic evaluation by estimation of the incremental cost-per-QALY gained. QALYs provide a common standard of measurement which enables the quantification of the outcomes of health services or treatments in terms of their impact upon quality of life and survival.¹² In principle, it is therefore possible to compare all health care interventions, including across sectors, according to their associated costs and QALYs gained, thereby providing an indicator of their relative cost effectiveness.

Health-related quality of life is most often incorporated within CUA via the use of patient reported, multi-attribute utility instruments (MAUIs) such as the EQ-5D-3L or the AQoL.^{2, 83} MAUIs are commonly used in economic evaluations conducted alongside clinical trials to measure and value health. These instruments are typically generic (meaning they are suitable to be applied across all health care conditions) and are preference-based, in that their health state values reflect the preferences of a sample, for example, the general population. Each instrument consists of a descriptive system of domains with various response levels for completion by patients or members of a general population, the completion of which provides for the measurement of HRQoL. The valuation of HRQoL via the calculation of QALYs is performed using an off-the-shelf scoring algorithm which enables values or utilities to be attached to all possible health and/or quality of life states defined by the instruments by a sample of the general population.⁷⁵ Application of the scoring algorithm generates a health state value for each respondent at each point in time for use in QALY estimation. Other popular quality of life measures such as the Nottingham Health Profile,⁸⁴ the Sickness Impact Profile⁸⁵ and the SF-36 are not suitable for use in QALY estimation as they use simple summative scoring algorithms which are not preference-based.² However, as previously stated, the SF-36 can be utilised following the conversion of its scores to those of a preference-based instrument such as the SF-6D or the EQ-5D-3L when individual patient level data is unavailable but SF-36 domain scores have been published.^{57, 66, 67}

The potential limitations of the traditional approach for the calculation of QALYs in older adults have been highlighted recently by a number of researchers both within Australia and internationally. This includes the observation that older adults often place high importance on broader aspects of quality of life in addition to health status such as

companionship or feeling safe, attributes which are not routinely captured by established MAUIs.^{12, 32, 75, 86} Many health interventions may result in positive outcomes that are not strictly health related. For example, the provision of an electronic medical alert bracelet or necklace enables an older person to call for help in the case of illness or accident. While the device itself may not necessarily improve the individual's health per se, its presence has the potential to assist the older person to continue to live independently and provide reassurance and a sense of safety, factors that may influence an individual's quality of life. It has therefore been argued that it is beneficial to be able to also measure quality of life in a way that is suitable for inclusion in an economic framework, but also incorporates non-health related factors of quality of life.^{87, 88}

1.2 Rationale for thesis

The health care system is faced with not only an ageing population, but one with greater care needs and expectations of health care services than previous generations of older adults. Careful allocation of scarce resources is required if high quality subacute care is to be provided to older patients, as with a fixed budget for health care expenditure, increased spending in one area of health care will subsequently result in a deficit in other areas. Health economic methods may be applied to examine older adults' preferences in relation to the process of subacute care through the development and application of DCEs, and the outcomes of subacute care through the measurement and valuation of HRQoL outcomes. However the measurement and valuation of non-health related outcomes using methods suitable for inclusion in economic analysis is also important. Doing so can not only inform resource allocation and ensure the maximum benefit to older adults is achieved via the provision of cost-effective health care, but

also enable the incorporation of patients' preferences into the design and delivery of subacute care services.

To date, little work has been conducted to specifically measure and value the quality of subacute care provided to older patients. Given the expected increase life expectancy and need for subacute care services such as rehabilitation, a need therefore exists to firstly establish how older adults define quality of care, and secondly to measure and value the outcomes of subacute care using methods suitable for inclusion in the economic evaluation of health services.

1.3 Research objectives

The objective of this thesis is to develop and apply health economic approaches for assessing quality in subacute care. In particular the thesis will focus on the development and application of DCEs to measure and value the process of subacute geriatric rehabilitation and Transition Care services from the older patient's perspective. The application of existing health status and new broader quality of life focused instruments for the measurement and valuation of the outcomes of sub-care will also be examined.

The specific objectives of the research are:

1. To examine the process of subacute care from the patient perspective using a discrete choice experiment to determine features of care that are important to older adults.
2. To investigate the extent to which the HRQoL outcomes of subacute rehabilitation interventions for older adults have been captured in published randomised controlled trials to date, and the methods used to do so.
3. To examine the outcomes of subacute care for older adults by measuring and valuing both HRQoL and non-health related quality of life.
4. To measure and value the quality of life of a general population sample of older adults to enable comparisons with that of a subacute care population and obtain normative data for use in future research studies.
5. To examine the relationship between the process and outcomes of subacute care for older adults by examining the association between quality of life and the quality of transition between care settings.

Chapter 2

**Literature review: the use of discrete choice
experiments to measure quality in health care
from the patient perspective**

Chapter 1 outlined the importance of process and outcomes in determining quality in health care, and the importance of incorporating patient views and experiences when doing so. This chapter will focus more specifically on the process of health care by reviewing the current literature reporting on the use of DCE methodology, an approach for examining the relative importance of key aspects of the process of care from the patient perspective. This chapter begins to address the first research objective, “to examine the process of subacute care from the patient perspective using a discrete choice experiment to determine features of care that are important to older adults”.

2.1 Patient participation

Patients in general, and older patients in particular, have traditionally had little participation in health care decision making at either the micro, individual patient or macro levels, for example in contributing towards health services planning and policy.¹²

⁸⁹ This is despite evidence to indicate that patient involvement facilitates the development of health services which are more both more acceptable and accessible to patients and may ultimately lead to improvements in the quality of life and health of patients.⁹⁰⁻⁹² Therefore an increase in patient involvement at both the micro and macro levels has recently been encouraged by both policy makers and health care practitioners.⁹¹ Despite the potential benefits of patient participation, it is also important to note that not all patients wish to be involved in clinical decision making. As a population, older adults have been shown to often prefer to take a passive role in the decision making process regarding their health care.⁹³⁻⁹⁵ This has been attributed to a variety of reasons including ill-health, fatigue, pain, feelings of powerlessness, and a preference for a more paternalistic model of care.^{94, 96} However not all older adults are

adverse to involvement in health care decision making, with individuals preferring differing levels of participation. While some older patients are satisfied with the level of involvement they have in decision making and the information they are provided with, others have expressed a desire for more active involvement.⁹⁷ These different preferences for autonomy highlight the importance for health professionals to avoid making assumptions about a patient's preferred level of involvement in decision making and to provide care in a manner that accommodates this. It is also important that the participation of older patients in the process of care is enabled by considering factors that may inhibit involvement such as communication difficulties, cultural differences, feeling intimidated, cognitive impairment and low health literacy.^{96, 98-100}

As process of care attributes have been shown to be influential in patients' satisfaction with health care, patient satisfaction has often been used as a proxy measurement for patient-assessed service quality.⁴⁴ However the suitability of this approach for use with older adults has been questioned. Research has shown older adults, when compared to younger adults, to be more likely to express gratitude and report high levels of satisfaction, less likely to complain and more likely to provide socially-desirable responses.^{44, 101, 102} The accuracy of older adults' responses has also been questioned given the finding that older adults are more likely to agree to questions which have been worded in a positive way.⁴⁴

2.2 Discrete choice experiments (DCEs)

An alternative approach to assessing those characteristics of the process of care which are most highly valued from the patient's perspective is the DCE. Originating in the

area of market research, the development and application of DCEs within the health economics discipline commenced in the early 1990s with the seminal work by Proper to value patient experiences on the United Kingdom's National Health Service (NHS) waiting lists.^{103, 104} Although introduced to the area of health economics to value patient experiences of the process of health care, which remains a common use for DCEs, the methodology has also been used to value the trade-offs between process and health outcomes, to estimate utility weights within a QALY framework and to inform both priority setting frameworks and clinical and organisational decision making.^{46, 104}

The methodology is based on Lancaster's economic theory of value, comprising of 3 key principles: 1) That consumers derive utility from the *characteristics* of a good or service rather than from the good *itself*. For example, patients may not only value or obtain utility from the end result or *outcome/s* of receiving health care such as the level of recovery experienced, but also from aspects of the *process* of receiving that care such as waiting time, treatment location or staff attitudes; 2) A good or service possesses multiple characteristics and these characteristics may be shared by more than one good; 3) When combined, goods or services may possess different characteristics than when separate.⁴⁵

DCE respondents are presented with a series of existing or hypothetical scenarios (goods or services) comprised within choice sets from which they are asked to indicate which scenario they would prefer, or sometimes least prefer (e.g. "treatment A" or "treatment B"). A "neither" option may also be included if this is considered to be a realistic option. For example in a 2005 study by Ryan and colleagues to estimate the monetary value of reducing the waiting time in a rheumatology clinic, respondents were

asked to choose between three options: attending “clinic A”, attending “clinic B” or attending neither clinic.¹⁰⁵

In a DCE, each scenario is described in terms of its attributes (characteristics) consisting of varying levels which alternate between the scenarios. For example, an attribute of “chance of complete recovery” may have levels of 50%, 75% and 100%. Figure 2.1 shows an example of a DCE hypothetical choice set regarding a choices in shopping venues. Respondents are expected to “trade-off” between the attributes in order to choose their preferred scenario. However rather than trading-off, respondents may appear to make their choices between scenarios based upon a single attribute rather than trading between all the of attribute levels presented.¹⁰⁵ As these dominant responses are not necessarily invalid, they are often included in DCE analysis as excluding them may result in sample selection bias and statistical inefficiency.⁴⁶

Figure 2.1 Example of a hypothetical DCE choice set

Attributes	Store A	Store B
Variety of products	A lot of products	Few products
Location	Far away from home	Close to home
Parking	A lot of car parks	Few car parks
Price of products	Cheaper	More expensive
Quality of service	Poor service	Good service

↓	↓	↓
Attribute (characteristic)	Scenario (good/service)	Attribute level

To aid the effectiveness of a DCE task, the attributes must appear relevant and realistic to the respondents, with levels that are able to be traded. To achieve this, it is recommended that attribute development be based upon qualitative work such as interviews and focus groups to ascertain the opinions of sample groups of participants and experts.^{46, 106} In the case of DCEs designed to examine patient preferences, these qualitative explorations are frequently undertaken with patients and/or health professionals. This has often been performed in conjunction with an examination of literature on the topic under investigation.¹⁰⁷⁻¹¹¹ Other approaches to attribute development have included patient surveys,¹¹² health outcome measures¹⁰⁶ and the results of randomised control trials.^{105, 106}

The number of levels and attributes to be included in a DCE task must also be considered. The inclusion of a wide range of levels per attribute may risk respondents ignoring changes in levels due to little difference existing between them. Additionally, the inclusion of a large number of attributes may make the task too complex for the participant to complete and encourage the utilisation of decision heuristics (e.g. an attribute non-attendance whereby one or more attributes are ignored) as mechanisms for the participant to manage the complexity of the task.⁴⁶ This is a particularly important consideration for DCEs to be conducted in populations of older people who may present with significant physical and/or cognitive limitations.¹¹³ Therefore rigorous pilot testing is recommended following attribute development to ensure that the complexity and plausibility of the task is appropriate for the population to be surveyed.^{46, 113, 114}

The analysis of responses to DCEs provide information regarding the relative importance or acceptability of each attribute to the respondent and whether they are

willing to make trade-offs between the attribute levels presented.¹¹⁴ DCE methodology has its theoretical foundations in random utility theory which states that the utility derived from attributes of a good or service consists of two components, systematic (explainable) and random (unexplainable). Systematic utility is derived from the attributes of the good or service, whilst random utility reflects the influential factors that cannot be directly observed by researchers based on an individual's preferences and opinions.¹¹⁵ Random utility theory is expressed by the following equation:

$$U_{in} = V_{in} + \varepsilon_{in}$$

Where U_{in} is the utility associated by the individual (n) with choice option (i), V_{in} is the systematic component of utility, and ε_{in} is the random component of utility.¹¹⁶

The utility estimates relating to each attribute included within the DCE can be aggregated to obtain the total utility. For example, within the context of the evaluation of characteristics relating to the provision of a health care service, the individual utility estimates relating to each attribute level may be combined to ascertain the total utility pertaining to alternative service configurations. Recent work by Benning and colleagues has demonstrated how these total utility estimates may be combined with the costs of providing the associated program or service configuration to ascertain its relative cost-effectiveness.⁷³ This approach facilitates the incorporation of patient preferences within a decision making framework for the development and provision of patient-centred health and social care services and the allocation of finite resources. Where cost is included as an attribute, DCEs also enable the willingness to pay (WTP) for changes in attribute levels to be calculated.^{104, 117} This WTP value represents the monetary value a

respondent is willing to pay to receive a particular level of an attribute such as a reduction in treatment waiting time (a process characteristic) or a reduction in the risk of death or illness (an outcome characteristic).^{64, 75} The higher the WTP value, the more importance an individual places on that particular attribute. The estimation of WTP values is advantageous in that it can provide policy makers with information regarding patient preferences for particular health services or treatments in a common metric which is easily understandable and interpretable. However the estimation of WTP values within a DCE framework does have associated limitations. For example, WTP values have been found to differ according to the method used to elicit them, with a study by Grutters demonstrating that the WTP associated with three health care programs varied within the one study depending on the order in which the programs were presented to respondents.¹¹⁸ A disadvantage particularly relevant to older adults, who are likely to not be engaged in paid employment, is that the determination of WTP may favour individuals who are more affluent and therefore more easily able to pay to receive health care that they deem to be preferable.⁶⁴

Willingness to accept (WTA) values can also be calculated when a monetary payment or discount to the respondent is included as an attribute in a DCE. WTA represents the monetary value that a respondent would need to be compensated in order to accept a particular (undesired) level of an attribute. It therefore represents the converse of the WTA concept. However, a disadvantage of determining WTA, and WTP, values lies in the possibility that respondents' choices may be influenced by what they believe a commodity such as a treatment or intervention costs rather than the monetary amount they would be willing to pay or be compensated to receive it.^{118, 119}

More recently, DCEs have also been used to elicit values for health state profiles and for deriving preference-based quality weights for use in the calculation of QALYs.¹⁰⁴ An additional advantage of DCEs is that they enable the relative importance of multiple aspects of health care (including process and/or outcome focused attributes) to be assessed simultaneously.^{72, 117}

2.3 Prevalence of older adults in DCE study samples

Within health care there has been an exponential increase in the number of DCE studies undertaken to assess patient preferences within a wide variety of health care programs and services within the last decade. However, DCE studies specifically designed for and conducted with older adults (aged 65 years and over) remain relatively rare in comparison with those conducted with general adult samples.² To ascertain the prevalence of DCE studies that include older adults and relate to the provision of health care services, a literature search was conducted of the Medline and Embase databases. The databases were searched between 1990 and June 2016 using “discrete choice experiment” as the key word, with results limited to articles that were written in English and including participants aged 65 or over. The search focused on studies in which DCEs were applied to ascertain respondents’ preferences regarding health care provision rather than those using DCEs to value or compare health states as defined by preference-based instruments such as the EQ-5D. As the focus was on DCEs, studies using other preference-based approaches such as Best Worst Scaling were excluded as they have been identified as being more complex and outside the scope of this literature review. The search retrieved 365 results, of which full-text articles were obtained for 189, reporting on 177 individual studies.

Of those studies, 66 (37%) stated the percentage of respondents aged 65 years and over included in the sample. Due to the relatively small sample sizes used in the studies, those in which a minority (less than 50%) of the sample were aged 65 years and over were excluded as this was deemed to be too few respondents on which to base a meaningful conclusion regarding the application of DCE methods to elicit the preferences of older adults specifically. This study inclusion criterion resulted in a total of 11 articles reporting on nine studies with the samples of older adults ranging from 53% to 100%. Of these studies, all except one were based upon patient samples. The ages of the participants ranged from under 25 (exact age not specified) to 100 years. Three of these studies included only adults aged 65 years and over, while the remaining six included, but were not limited to older adults.

Of the studies including, but not limited to older adults, three (50%) compared the findings relating to older and younger respondents. From these statistics, it can be inferred that while numerous DCE studies have been conducted in the area of health care, very few study samples include a sizeable number of older adults. Of those that do, fewer still focus solely on ascertaining the preferences held by older adults indicating a gap in this field of study.

2.4 Application of DCE methodology in samples including, but not limited to older adults

DCE methodology has been applied in a range of samples including, but not limited to older adults to ascertain preferences for the treatment, management and screening

options for a variety of health conditions. The characteristics of these studies are summarised in table 2.1.

Table 2.1 DCE studies with samples including, but not limited to older adults (continued over page)

Author	Participants	Topic	Attributes	Findings relating to older adults
de Bekker-Grob 2008 & 2009 ^{120, 121}	General practice patients at risk of osteoporotic fractures N = 120 Age: Mean 72 yrs; Min 60 yrs; 62% 70+ yrs Country: The Netherlands Method: Interviewer administered questionnaire via telephone. Respondents mailed questionnaire prior.	Patients' preferences for osteoporosis drug treatment	Treatment effectiveness Side effects Total treatment duration Route of drug administration Out-of-pocket costs	Respondents' preferences were not analysed by age Patients preferred to receive the drug treatment rather than no drug treatment, with a monthly tablet being the preferred administration route. The preferred drug treatments were those that were cheaper, shorter in duration, having fewer side effects and providing the highest fracture risk reduction.
Kaambwa ¹²²	Consumers of aged care service providers and informal carers N = 117 Age: Mean 79 yrs (80 yrs consumers, 74 yrs carers); Min age for consumers 65 yrs; Min 74% aged ≥65 yrs Country: Australia	Consumer and carer preferences for consumer directed care	Choice of service provider Budget management Saving unused funds Choice of support worker Support worker flexibility Contact with service provider	Respondents' preferences were not analysed by age, however they were dichotomised according to consumer (all aged ≥65) and informal carer status. Preferences were shown by both groups for being able to save all of the unspent funds from the care package for future use, the option to choose some of the support workers themselves and having flexible support workers who were able to change activities within the care package.

Author	Participants	Topic	Attributes	Findings relating to older adults
	Method: Face-to-face interviewer administered questionnaire			Consumers also demonstrated a preference to be able to save half of the unspent funds for future use while the carers did not. Additionally, the carers valued care being provided by multiple service providers, an attribute that was not significant to the consumer group.
King 2012 ¹²³	<p>Random sub-sample of participants in a prostate cancer care and outcomes study, and aged matched controls without prostate cancer</p> <p>N = 422</p> <p>Age: Mean 66 yrs; 66% aged ≥65 yrs</p> <p>Country: Australia</p> <p>Method: Interviewer administered questionnaire via telephone survey using a questionnaire mailed to respondents prior</p>	Preferences for localised prostate cancer treatment	<p>Erectile dysfunction</p> <p>Libido loss</p> <p>Urinary leakage</p> <p>Urinary blockage</p> <p>Bowel symptoms</p> <p>Fatigue</p> <p>Hormonal effects</p> <p>Life expectancy</p> <p>Life expectancy certainty</p>	<p>Age was found to have no effect on respondents' preferences.</p> <p>The least preferred side effects were severe urinary leakage, bowel symptoms and urinary blockage. Higher survival gains were required compensate for the impact of experiencing these effects.</p>

Author	Participants	Topic	Attributes	Findings relating to older adults
Laver 2011 ¹²⁴	Stroke rehabilitation patients N = 50 Age: Mean 72 yrs; Range 27-71+; 64% ≥71 yrs Country: Australia Method: Face-to-face, interviewer administered questionnaire	Patient preferences for rehabilitation management	Mode of therapy Dose of therapy Team providing therapy Cost to patient Amount of recovery	Respondents valued one-to-one therapy however did not favour very high intensity programs. The most undesirable attribute was computer-based therapy followed by a cost of A\$100 per week and 6 hours of therapy per day. The most highly valued attribute was achieving 90% recovery followed by individual therapy. Respondents aged over 70 years demonstrated a stronger aversion to computer-based therapy than younger participants
Milte 2013 ^{113, 125}	Hip fracture patients N = 87 Age: Range 60-80 yrs; 70% aged ≥71 Country: Australia Method: Face-to-face, interviewer-administered questionnaire	Preferences of hip fracture patients for multidisciplinary rehabilitation programs	Risk of falling and breaking another bone Level of pain during rehabilitation Level of effort needed during rehabilitation Ability to recover walking	Respondents exhibited strong preferences toward interventions which resulted in increased mobility and lower levels of fracture risk. However participants were averse to interventions which involved high levels of effort or pain.

Author	Participants	Topic	Attributes	Findings relating to older adults
Yeo 2012 ¹²⁶	<p>Diabetes outpatients</p> <p>N = 160</p> <p>Age: Range <25 - ≥75 yrs; 53% aged ≥65 yrs</p> <p>Country: UK</p> <p>Method: Self-completed questionnaire with researcher present to assist face-to-face if required</p>	<p>Patient preferences for diabetic retinopathy screening</p>	<p>Frequency of screening</p> <p>Travel time to screening venue</p> <p>Ability of screening to detect other changes in eyes</p> <p>Method of explaining screening results</p>	<p>Both younger patients and those aged ≥65 years placed importance on the frequency of screening and the ability of the screening to detect other changes. Additionally, younger respondents also valued travel time, while older respondents found the method of explaining screening results important.</p>

The health care interventions under examination included physical rehabilitation, screening for diabetic retinopathy and treatments for osteoporosis, chronic obstructive pulmonary disease and prostate cancer. Given the multitude of health challenges associated with ageing, it is beneficial that health care preferences for a range of conditions have been investigated using DCE methods. However significant heterogeneity in the methods and applications of the DCE studies conducted to date limits the extent to which meaningful conclusions can be drawn about best practice methods for the development and application of DCEs incorporating populations of older adults.

Varying research methods have been employed in DCE studies with samples including, but not limited to older adults. All of the articles identified through the literature search reported on studies that utilised patient samples, with most respondents being recruited via health services including general practice and diabetes clinics, and rehabilitation services. Other respondents were recruited via internet survey panels and participation in other, clinical, studies. In terms of data collection, the most common approach was the use of an interviewer mode of administration. Two of these were conducted face-to-face; with a further two studies conducting telephone interviews with the aid of hard copy questionnaires mailed to respondents. The remaining studies administered self-completed questionnaires, the first being internet-based and the second using a hard copy questionnaire with research staff available to assist respondents if necessary. Whilst it offers a more resource intensive data collection process than self-completion surveys, an interviewer mode of administration has been found to be increasingly common, facilitating participant understanding and engagement with the task thereby

improving the quality of the data collected and improving task completion rates.^{104, 127,}

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2.4.1 Preferences for the process of health care provision

Several aspects of the process of care have been identified as influential in older patients' preferences for receiving health care. The hypothetical scenarios presented to respondents in the DCE studies elicited preferences regarding the frequency and intensity with which the health care treatment or intervention is provided, the way in which it is provided, the associated effort and pain, the out-of-pocket costs to the recipient and the level of consumer control in the receipt of health care.

The *intensity* and *duration* of treatments or interventions has been shown to be influential in older adults' choices regarding health care, particularly in regard to rehabilitation interventions. A recent study by Milte and colleagues examined the preferences of older adults who had sustained a recent hip fracture.^{113, 125} The findings revealed aversions toward interventions which involved high levels of effort or pain. Similarly, Laver et al found that respondents were adverse to high intensity programs post-stroke, preferring 30 minutes of therapy per day rather than three or six hours.¹²⁴ de Bekker-Grob and colleagues also presented respondents with an attribute relating to intervention duration.^{120, 121} These respondents demonstrated a preference for osteoporosis treatments that were shorter in duration.

The *frequency* and *administration mode* of health care interventions has also been shown to influence the preferences of older adults. This was demonstrated in the work of de Bekker-Grob and colleagues in which patient respondents aged 64 years and over

displayed preferences to receive osteoporosis treatment rather than forgo treatment.¹²⁰

¹²¹ More specifically, a monthly tablet was preferred instead of a weekly tablet or injections either monthly or every four months. These findings may be attributed to the respondents endeavouring to avoid the perceived discomfort of an injection, preferring a less invasive treatment. Yeo and colleagues also examined the influence of treatment frequency, discovering that respondents aged 65 years and over placed importance on the frequency of screening for diabetic retinopathy.¹²⁶ However unlike the sample in the work of de Bekker-Grob et al, these respondents preferred to receive the intervention more frequently. From this, it could be deduced that while older adults place importance on screening for health conditions at shorter intervals, they value being able to extend the frequency for which treatment for existing conditions is received. This may differ depending on the perceived severity of the health condition in question, with respondents potentially wanting to diagnose and treat conditions they deem as serious earlier and a belief that early diagnosis will mean the condition can be treated more successfully. The nature of the intervention may also influence preferences regarding frequency, with respondents perhaps wanting to undergo painful interventions with less frequency than they would with less invasive interventions. Respondents may also want to simply reduce the time commitment that is required in order to receive treatment for an existing condition.

The influence of the *administration mode* of the health care treatment or intervention has also been examined. For example a recent study by Laver and colleagues compared preferences for computer-based versus traditional individual physical rehabilitation post-stroke.¹²⁴ The study revealed that older adults displayed an aversion toward computer-based therapy which was the most undesirable attribute to respondents,

instead favouring the traditional therapy. The hesitation regarding computer-based therapy was found to be stronger in patients aged 70 years and over. Yeo and colleagues also investigated the administration mode, focusing on the way in which results of diabetic neuropathy were delivered. Respondents indicated a preference for have their results explained to them by a health professional rather than receiving the information in a letter.¹²⁶ The preferences expressed in these articles could be attributed to a potential lack of knowledge and experience regarding computers and technology among the older respondents, or a preference for the status quo, “traditional” therapies with which they are more familiar. This status quo bias arises when respondents value one option, in this case traditional therapy, more highly once they have experienced it and demand more to give it up than they would be willing to accept in order to receive it.^{112,}¹²⁹ Respondents may have also been displaying a hypothetical bias, in which respondents may not consider an alternative within a DCE, for example computer therapy, to be a realistic option.¹²⁹ Furthermore, respondents may have valued the higher level of human interaction and support provided by health professionals which may be lower when receiving computer-based therapy and screening results via a letter.

Another attribute of health care that has been examined in a variety of previous DCE studies is the financial out-of-pocket *cost* to the recipient. De Bekker-Grob and colleagues explored the impact of this factor on respondents’ choices for osteoporosis treatment. The results indicated a preference for treatments with lower out-of-pocket-costs for the patient compared to those with higher costs.^{120, 121} The study by Laver and colleagues previously reported comparable results. Participants were strongly averse to paying A\$100 for their post-stroke rehabilitation therapy, instead preferring therapy with no out-of-pocket cost.¹²⁴ This aversion may have been influenced by the fact that

the respondents were currently receiving rehabilitation at no cost, suggesting a status quo bias. The value placed on lower-cost treatments could be expected given that the mean age of the respondents in both studies was 72 years, suggesting that a large percentage of the respondents may be retired and potentially dependent on savings, superannuation and/or government-issued pensions. This may therefore mean they may have limited financial resources to spend on health care. Furthermore, the level of experience respondents have with experiencing ill-health or health care may also impact on their WTP, with those with greater experience potentially being willing to pay higher out-of-pocket costs.

Another impact was that of the *travel time* required in order to receive a health care treatment or intervention. Yeo and colleagues examined this attribute in relation to screening for diabetic retinopathy.¹²⁶ The findings indicated that while travel time was important to younger respondents, those aged 65 years and over did not deem this to be of value.¹²⁶ This may be because the older respondents are less likely to be engaged in employment than younger respondents, meaning they have fewer time constraints.

Overall, the findings of these studies suggest that some forms of burden are more influential in health care decision making for older adults than others. While the older adults in these studies were willing to accept the burden of a longer travel time in order to receive a service that is otherwise desirable, they were less prepared to accept burdens relating to pain or therapy intensity. The aversion to interventions that required higher levels of duration, intensity or pain may be representative of a status quo bias if the respondents were currently or had previously participated in interventions that are associated with lower levels of duration, intensity and pain. Regret theory may also be a

contributing factor, with respondents preferring interventions similar to those that they may be familiar with in order to minimise the chance of experiencing disappointment if they select an unknown option but later feel that it was the wrong decision.^{129, 130}

Further to this, respondents may also have selected the options that were less burdensome in order to minimise the potential of feeling regret for choosing an intervention that was more likely to cause pain or discomfort.

Another aspect of the process of health care that has been examined via DCE is the level of *control* afforded to consumers whilst receiving care. Kaambwa and colleagues examined the concept of control in the context of consumer-directed care by ascertaining the preferences of older adults and informal carers of older adults receiving community aged care services.¹²² Respondents demonstrated preferences for the option to save unspent funds from care packages for future use, however the amount they wished to save differed, with older adults displaying a preference for saving all of the unspent funds and the informal carer group preferring to save half of the unspent funds. Preferences were also shown for consumers to be able to choose for themselves, some of the support workers who would be providing their care. Also valued was the flexibility of support workers in terms of changing the activities they provide assistance with within the care package. Additionally, the informal carers displayed preferences for care being provided by multiple services, an attribute that was not significant in the choices made by the consumer group.¹²² These findings suggest that older adults and the informal carers of older adults accessing community aged care services clearly valued being able to have input in decision making regarding the care that is provided and by whom. Several factors may have been influential in the preferences demonstrated by these respondents. The concept of empowerment may also have affected the

respondents' choices. Those that felt more capable of making decisions about their health and aged care may have been more likely to want to take a proactive approach and participate in decision making. Conversely, respondents who felt less empowered may have opted for a more passive approach, preferring to defer the decision making to service providers. Higher levels of empowerment may be associated with having been receiving or involved with community care for a greater time period, resulting in familiarity and experience with the services provided and a sense of what attributes were important to them. Respondents' choices may also have been influenced by whether their experiences with community care provision had been positive or negative to date. Those who had positive experiences may have been more susceptible to status quo bias, whereas those who were more dissatisfied with their care may have been more likely to select a hypothetical care package that was different to what they were currently receiving.

The journal articles reporting on the health care preferences of samples including but not limited to older adults demonstrated clear trends regarding the process of care. The respondents in these studies indicated preferences for health care interventions that were generally more flexible, less intense and invasive and provided in person on a one-to-one basis. Preferences for services that were associated with little or no out-of-pocket cost were also demonstrated. Respondents also displayed preferences for choice in terms of the health professionals providing their care and for continuity of care providers. Travel time was not found to be a strongly influential factor overall in influencing preferences for the older age group despite being highly influential overall for younger respondents. These findings can be attributed to several factors.

Respondents may have been influenced by a status quo bias; selecting health care

options that were similar to those that they were currently, or had previously received or were familiar with. Regret theory may also be driving respondents' choices in an endeavour to minimise potential remorse regarding their decision making. Hypothetical bias may also have been influential, with participants not viewing a scenario or attribute presented to them as realistic or feasible. Sociodemographic factors such as income may have also influenced respondents' preferences. It is reasonable to expect that the majority of older adults are no longer engaged in paid employment and therefore they may have limited financial resources to allocate to their health care.

2.4.2 Preferences for the outcomes of health care provision

In addition to the process of care, the outcomes of health care also proved to be an influential factor in health care decision making among samples including, but not limited to older adults. The DCE attributes used in these studies pertaining to health care outcomes can be divided into two categories: the *adverse events* associated with receiving the intervention in question, and the *benefits* associated with receiving the intervention.

The severity and likelihood of the *adverse events* associated with receiving health care treatments and services was examined by several studies. As could be expected, respondents consistently demonstrated preferences for health care interventions that were associated with lower levels of adverse event risk or severity regardless of the health condition in question. For example prostate cancer patients surveyed by King and colleagues favoured treatments that resulted in mild rather than severe adverse effects pertaining to bladder, bowel and sexual function, while the respondents in the work by Milte et al indicated preferences for scenarios in which they were presented with lower

levels of fall and fracture risk following rehabilitation.^{113, 123, 125} Comparatively, the respondents in the study of osteoporosis treatments by de Bekker-Grob et al preferred options in which they would not experience subsequent nausea as opposed to those in which they would experience this side-effect.^{120, 121} This may be attributed to loss aversion in which respondents are hesitant to accept an option, in this case treatment options with high levels of adverse events, as they believe that the utility they would be sacrificing would outweigh any potential gain in utility that the alternative treatment option would offer.¹²⁹

Similar preferences were also shown in regard to the *benefits* acquired as the result of receiving health care. The benefits generally pertained to the effectiveness of the intervention or service being provided. As could be expected, respondents' preferences consistently demonstrated that value was placed upon interventions associated with high levels of effectiveness. For example, Yeo and colleagues discovered that respondents valued screening techniques for diabetic neuropathy that were also able to detect other changes in the eye.¹²⁶ Additionally, the work of de Bekker-Grob and colleagues demonstrated that a reduction in the risk of future hip fracture was an influential factor in the preferred treatment of osteoporosis, with respondents preferring interventions which would provide the highest risk reduction.^{120, 121} Similar findings were evident in the area of rehabilitation, with both Laver et al and Milte and colleagues reporting that respondents demonstrated preferences for interventions that would result in the highest possible level of recovery and increased mobility respectively.^{113, 124, 125} The finding that recovery level was the most highly valued attribute in the DCE conducted by Laver and colleagues further suggests the importance of treatment effectiveness to patient populations with large proportions of older adults.¹²⁴ The findings relating to the

benefits of health care further support the loss aversion demonstrated in regard to the adverse effects associated with health care. Respondents consistently displayed preferences toward the treatment scenarios they believed would maximise their utility. Further to this, regret theory may also be a contributing factor to the respondents' choices, with respondents attempting to avoid feelings of disappointment for accepting treatment options they perceived as offering a lower level of benefit.

Although the findings of these studies demonstrated a general aversion to interventions that posed some form of risk or burden, the findings also demonstrated that respondents were prepared to tolerate some level of inconvenience in order to obtain benefit from the interventions. This was demonstrated in the work of Milte and colleagues, in which respondents, while averse to high chances of experiencing a future fall and fracture, were willing to accept a slight increase in this attribute in order to avoid experiencing severe pain.^{113, 125} These respondents were also willing to accept an increase in rehabilitation duration in order to reach the highest level of mobility despite being generally averse to interventions that were higher in duration. Similar results were reported by Laver and colleagues in which respondents, despite being generally averse to out-of-pocket costs, favoured interventions that would result in 90% recovery, for which they were willing to pay A\$60, indicating that they were willing to accept some level of financial burden in order to receive a high level of benefit.¹²⁴

The respondents in the study conducted by de Bekker-Grob and colleagues also demonstrated that, while preferring treatments that were lower in cost and duration, they were willing to pay and undergo longer treatment periods in order to avoid high levels of attributes they viewed as unfavourable.^{120, 121} Respondents were prepared to pay in

order to receive treatment rather than receive no treatment at all. The importance of reducing the risk of fracture was shown to be strong, with respondents not only willing to pay to receive the lowest level of this attribute, but also willing to undergo a longer treatment duration to do so, despite being generally averse to longer durations. This aversion is further supported by the respondents' WTP to receive a treatment that was shorter in duration. Respondents were also prepared to accept a longer treatment duration in order to receive medication orally rather than via injection. However despite a willingness to accept other unfavourable treatment attributes in order to reduce fracture risk, the respondents were willing to accept an increase in fracture risk in exchange for not experiencing nausea as a treatment side-effect.^{120, 121} Therefore, respondents were willing to accept financial burdens in exchange for increases in treatment effectiveness and reductions in treatment duration, but prepared to forego this reduction in duration in order to receive increases in effectiveness and a less invasive treatment method. Further to this, they were willing to accept lower levels of effectiveness in order to avoid adverse events.

King and colleagues also explored preferences pertaining to treatment-related adverse events.¹²³ Using compensating variation, the authors estimated the survival gain required to compensate respondents for experiencing different health states as described by the levels of the DCE attributes. The survival gains ranged from three to 28 months. Higher survival gains were required to compensate for the adverse effects that were deemed most unfavourable by the respondents such as severe levels of bowel and urinary impairment, while effects such as minor hormonal impairments required smaller gains. However it must be noted that some of the respondents in this study had not experienced prostate cancer or its treatment. This factor is important to consider as the

experience of cancer potentially may impact on the respondents' preferences. It has been suggested that a period of ill-health may result in a response shift in which an individual's values and/or internal standards of measurement change.¹³¹ This may then consequently influence the treatment choices made. For example, it has been shown that cancer patients were more likely to accept potentially dangerous treatments than individuals who were either healthy or experiencing a benign illness suggesting a shift in their values and the risks they were willing to accept.¹³¹

The findings of the studies discussed here highlight that in addition to the process of health care, populations including, but not limited to older adults have demonstrated clear preferences regarding the outcomes of health care. The respondents' acceptance of unfavourable process of care attributes in order to receive a beneficial outcome of care indicates a willingness to make trade-offs and prioritize. Respondents' choices leaned towards interventions that presented lower chances of experiencing adverse events, or those in which the adverse events were less severe. Along with this, respondents favoured interventions that were associated with higher levels of effectiveness. The importance of health care effectiveness to this population was further supported by their willingness to accept attributes pertaining to both the process and outcomes of health care that were otherwise considered unfavourable in order to receive maximum effectiveness. Respondents were prepared to accept increases in cost, adverse events and treatment duration in order to maximise levels of recovery despite a general aversion to these attributes in isolation. The preferences displayed by the respondents in these studies can be attributed to several potential phenomena including status quo bias, hypothetical bias, regret theory, response shift and loss aversion.

2.5 Application of DCE methodology in samples specifically of older adults

Of the 9 studies utilising DCE methodology to ascertain the preferences for the provision of health care of older adults, only 3 studies (33%) focused exclusively on older adults. These studies focused on varying aspects of health for older adults and are summarized in table 2.2.¹³²⁻¹³⁴

Table 2.2 DCE studies including only older adults (continued over page)

Author	Participants	Topic	Attributes	Findings
Hong ¹³²	Members of senior citizen centres N = 343 Age: Mean 75 yrs; Min 65 yrs Country: USA Method: Self-completed questionnaire with research staff available to assist face-to-face	Preferences and WTP for medication therapy management	Service setting Provider geriatric experience Provider years of practice Provider training Number of drug therapy problems Service duration Cost	The attribute for which respondents demonstrated the highest preference was the cost of the service, followed by the service setting. This was followed by the provider's overall experience, and more specifically in geriatrics. Respondents also demonstrated WTP to receive clinic based services rather than telephone or pharmacy based services.
	Patients of a primary care centre N = 116 Age: Range 70-90 yrs Method: Face-to-face interviewer assisted computer questionnaire		Test preparation (duration, location, discomfort level and recovery time) Decrease in chance of dying from cancer Test frequency Risk of complications	

Author	Participants	Topic	Attributes	Findings
				The negative utility score associated with the “opt-out” option indicates that the respondents preferred to partake in screening than to not do so.
Laver 2011 ¹³⁴	<p>Geriatric rehabilitation unit patients</p> <p>N = 21</p> <p>Age: Mean 85 yrs; Min 65yrs</p> <p>Country: Australia</p> <p>Method: Face-to-face interviewer-administered questionnaire</p>	<p>Acceptability of the Nintendo Wii Fit as a therapy tool for hospitalised older adults</p>	<p>Mode of therapy</p> <p>Difficulty of therapy</p> <p>Cost to patient</p> <p>Amount of recovery</p>	<p>At baseline, respondents displayed an aversion to longer and more demanding therapy sessions; however program choice was not significantly influenced by therapy mode. Preference was shown towards programs that would provide the maximum amount of recovery.</p> <p>At follow-up, therapy mode was more influential. Respondents were hesitant to pay A\$50 per week for a therapy program and remained averse to challenging therapy programs. Favour was shown however to programs that would result in maximum recovery.</p>

2.5.1 Preferences of older adults for the process of health care provision

The samples of older adults surveyed in these studies identified preferences for several aspects of the provision of health care. Some of these related to the health intervention itself, such as the intensity, frequency, setting and cost. Others however related to the staff providing the health care, namely their profession, and experience.

The *intensity* of the intervention in question proved to be an influential factor in the preferences of older adult samples. Laver and colleagues incorporated a DCE within a randomised controlled trial designed to compare the effectiveness and safety of the Wii Fit in physiotherapy sessions with conventional physiotherapy.¹³⁴ These respondents, who were patients of a geriatric rehabilitation unit with a mean age of 85 years, completed the DCE on two occasions, firstly within 24 hours of admission and again one month after discharge. The respondents displayed an aversion to therapy sessions that were longer in duration and higher in intensity, preferring to participate in 30 minutes of light activity rather than one hour of moderate activity.¹³⁴ The fact that this was evident in both the baseline and follow-up DCEs highlights the importance of this to respondents.

The work of Kistler and colleagues also explored the impact of intensity in relation to colorectal cancer screening.¹³³ The respondents ranged in age from 70 to 90 years and were either patients of a primary care centre or members of a research register. The respondents displayed preferences for scenarios in which the test preparation could be completed at home with mild discomfort and no recovery time required. This was in comparison to preparations which took half to a full day at a medical facility, were accompanied by moderate discomfort and a recovery time of either one hour or 24

hours. It must be noted however that as there were several factors (location, discomfort and recovery time) combined into one attribute, it cannot be ascertained whether all three aspects were influential on the respondents' choices, or if they were basing their selection on one or two only. The findings arising from these studies imply that older respondents perceive health care that is higher in intensity, discomfort and recovery time as unfavourable and therefore resulting in lower utility than the presented alternatives. These preferences may be attributed to status quo bias in which the utility loss from giving up something is greater than the utility it would provide if received.¹³⁵ For example, in the work by Laver et al,¹³⁴ respondents may have felt that the utility they would lose from giving up of 30 minutes of mild exercise (similar to their current rehabilitation program) in exchange for one hour of moderate exercise would be greater than the utility they would receive for selecting the 30 minutes of mild exercise.

Along with Kistler and colleagues, Hong et al also examined the importance of health care *settings* among older adults.^{132, 133} Focusing on members of senior citizen centres, Hong and colleagues ascertained preferences for medication therapy management.¹³² The respondents, with a mean age of 75 years, displayed a preference to receive a consultation at a pharmacy rather than over the telephone or at a health clinic. This may be due to an element of a labelling effect, where respondents interpret scenarios presented in a DCE in a way that is different than that which is intended.¹²⁹ For example a respondent may have been more likely to select the pharmacy than the health clinic if they perceive that they would receive a higher standard of care, or more specialised service at the former. The *profession* of the staff providing the service was also an important aspect of health care. While this attribute in isolation was not a significant influence on the preferences of the respondents, further analysis revealed that a

significant increase in utility was associated in receiving care from a pharmacist rather than a nurse.¹³² The *experience* of the health professional providing care was also an influential factor as shown by Hong et al. Respondents demonstrated preferences for staff who had more than five years' experience, and also for those with more than five years' experience in the area of geriatrics specifically.¹³² This suggests that older adults value health professionals who are practiced and skilled in not only their profession, but in areas that are specific to their health care needs.

Frequency was another attribute of the process of care that was examined among the older adult samples. The respondents in the work of Kistler and colleagues demonstrated a preference for colorectal cancer screening programs that were performed every five years rather than annually or every 10 years. This preference could be attributed to respondents potentially feeling that annual screening was too frequent, while 10 yearly screening may not allow for early detection and diagnosis. Also influential to respondents' choices was the *mode* of therapy. Laver and colleagues presented older adults receiving rehabilitation with the hypothetical option of receiving either traditional gym-based rehabilitation therapy or rehabilitation therapy using a Wii Fit consisting of balance, strength and aerobic tasks (their current mode of therapy). Although the mode of therapy was not influential at baseline, in the post-discharge follow-up, respondents demonstrated a strong preference for the traditional mode of therapy despite having not received this during their admission. Several factors may have contributed to this response. As noted by the authors, some participants commented that they felt the traditional rehabilitation therapy would be more effective than the computer-based mode. This may have been accompanied by a hypothetical bias, with participants not viewing the computer-based therapy as a realistic

rehabilitation option, perhaps seeing it as more of an entertainment activity rather than a therapeutic task. Additionally, respondents may have been adverse to technology, instead preferring the mode with which rehabilitation has typically been provided in the past. Interestingly, these findings contradict the commonly found status quo bias, with respondents demonstrating preferences for a therapy that they did not receive.¹³⁶ However their choices may have been influenced by their pre-existing understanding of traditional rehabilitation therapy either having experienced it themselves or via that of others receiving it.

The final process of care attribute that was examined in the studies was that of *cost*. Laver and colleagues elicited the therapy preferences of patients in a geriatric rehabilitation unit at baseline and one month post-discharge. Despite it not being an influential factor at baseline, at the post-discharge time point, respondents displayed a strong aversion to paying A\$50 for therapy.¹³⁴ This may indicate that their choices in the follow-up DCE were being influenced by their experiences during their admission to the rehabilitation unit. This further illustrates the tendency of DCE respondents to draw upon additional knowledge and experiences rather than basing decisions purely on the information provided in the DCE task. Hong and colleagues also included a cost attribute in their DCE. As in the work by Laver et al, respondents were averse to the higher levels of out-of-pocket cost. WTP calculations did however indicate that the respondents were willing to pay varying amounts to receive the aspects of care that were important to them. The highest WTP amount was US\$36.30 to receive medication management from a professional with five or more years' experience.¹³² This suggests that while recipients may be hesitant to pay out-of-pocket costs to receive care in the

first instance, they are willing to pay in order to receive the specific aspects of care that they deem to be important in the overall quality of health care.

The findings of these studies have demonstrated that older adults hold discernible preferences about the provision of health care. Respondents demonstrated preferences for interventions that were lower in intensity, discomfort and recovery time. Preferences were also held for receiving health care in a clinical setting and for screening preparations that could be performed at home. In terms of the professionals providing health care, higher levels of experience was also valued, along with expertise in the areas of pharmacy and geriatrics. The timing of health screening was also important, with respondents preferring to receive monitoring at five yearly intervals rather than more or less frequently. Aversions were also evident in the findings, with respondents viewing computer-based rehabilitation therapy unfavourably along with paying higher out-of-pocket costs for the receipt of health care.

The preferences reported in DCE studies with samples of older adults generally complement those evident in the studies including, but not limited to older adults discussed earlier. The respondents in both groups displayed preferences for health care, in particular rehabilitation, that was less intense in terms of the duration and effort required on the recipient's behalf.^{113, 124, 125, 134} Similarities also existed in regard to therapy mode and out-of-pocket cost to the recipient, with respondents preferring interventions that were provided at little to no cost and were more traditional in nature rather than utilising new technology such as computer-based therapy.^{124, 132, 134} However discrepancies also existed between the older adult samples and the samples including but not limited to older adults. This was evident in relation to the ideal staff and

frequency of health screening. Respondents demonstrated preferences to receive screening for diabetic neuropathy more frequently, however when monitoring for colorectal cancer, respondents preferred less screening .^{126, 133} This may be attributable to the invasiveness of the screening process. In regard to the staff providing health care, Hong and colleagues discovered a preference for pharmacists to provide medication therapy management rather than nurses.¹³² In contrast, the work of Laver and colleagues found the health care providers to be an insignificant attribute in post-stroke rehabilitation.¹²⁴ This may be due to the attribute levels in the DCEs administered by Hong et al and Laver and colleagues. In the task presented by Hong et al, respondents were presented with levels of different health care professionals, pharmacist, nurse and nurse practitioner.¹³² In contrast, each level presented by Laver et al comprised of staff of similar professions, but differed in terms of continuity of care.¹²⁴ Therefore, it may be possible that while the area of expertise of staff is important to older adults, receiving care from the same professionals throughout the recovery period is less so.

2.5.2 Preferences of older adults for the outcomes of health care provision

Only two studies explored the preferences for outcomes of health care provision using samples consisting of only older adults. Preferences were shown for both the adverse events that may arise from receiving health care along with the benefits that may be gained.

In terms of *adverse events*, respondents displayed preferences regarding the risk of experiencing complications resulting from a health care intervention. In the work by Kistler and colleagues, respondents demonstrated preferences for colorectal cancer screening options which were associated with lower levels of complication risk,

preferring a one in 1,000 risk over a 10 in 1,000 risk.¹³³ However it must be noted that the nature of the risk itself was not specified.

Conversely, the *benefits* of receiving health care were also explored, in terms of the level of mortality reduction and the level of recovery gained by recipients. When presented with the reduction in cancer-related mortality as an attribute, older adults indicated an aversion to lower reductions in mortality, preferring a survival rate of ten in 1,000 or 20 in 1,000 as opposed to a five in 1,000 chance.¹³³ Additionally, Laver and colleagues ascertained the level of recovery preferred by older adults receiving rehabilitation therapy utilising a computer-based approach. Preference was shown towards programs that would provide the maximum amount of recovery.¹³⁴ This finding was evident at both the baseline and post-discharge time-points, indicating the importance placed on it by the respondents.

These findings indicate the attributes of health care that were significant to older adults in terms of the outcome of care. As discussed, these attributes were comprised of the adverse events along with the benefits that may arise from receiving health care. An aversion to complications or side-effects was evident in both of the studies that focused solely on older adults and also those that included, but were not limited to older adults. Respondents consistently demonstrated preferences for options that were associated with lower levels of side-effects deemed to be unfavourable including nausea, incontinence, sexual dysfunction, fall and fracture risk, and unspecified complications.^{113, 120, 121, 123, 125, 133} In terms of preferences relating to the benefits of health interventions, similarities also existed between the studies that focused on older adults and those that included but were not limited to older adults. Both groups of studies revealed findings in which the level of recovery achieved was an influential

attribute in respondents' choices. Preferences were demonstrated for interventions that would result in increased levels of recovery including mobility.^{113, 124, 125, 134} The main discrepancy between the study groups existed in regard to the range of outcome attributes utilised, with few attributes used across multiple studies. However this may be attributed to the range of health conditions and health interventions under exploration.

Overall, the studies comprised of samples either including or limited to older adults have demonstrated that this population possesses distinct preferences regarding the process and outcomes of health care. Preferences for the process of care related to the intensity, frequency, mode and cost of treatment, the setting in which it was provided in and also the experience and profession of the staff providing the care. Preferences for the outcomes of care pertained to both adverse events, specifically particular side effects and the chance of experiencing them, and also the benefits of the intervention, namely recovery level. In addition to this, older adult respondents demonstrated that they were willing to make trade-offs in order to receive what they deemed to be an optimal scenario.

2.6 Feasibility of using DCE methodology with older adults

The findings from these previously published DCE studies indicate that older adults were not only willing to complete DCEs, but also possessed the ability to do so.

Although two studies did not report their response or consent rates, the remainder reported rates ranging from 28% to 98%.^{113, 120-122, 124-126, 133, 134} However it must be noted that those studies with lower response rates, went on to report high completion rates.^{122, 134} A trend of moderate to high completion rates was evident throughout the

studies reviewed, with the number of respondents providing complete responses ranging from 55% to 100%.^{113, 120-122, 124-126, 133, 134} These findings suggest that the majority of respondents (including older adults) were able to understand and complete the DCE task.

The reliability, response and completion rates of data can be impacted upon by the method of questionnaire administration.¹²⁸ From the studies reviewed here, it may be concluded that interviewer-administered questionnaires are preferable for DCE tasks being presented to older adult samples. Each of these studies utilised an interviewer-administered approach to data collection in a variety of ways. Some studies conducted a typical face-to-face interview with respondents to complete the DCE,^{113, 122, 124, 125, 134} others mailed the questionnaire to respondents and followed-up with a phone call to complete the task over the telephone,^{120, 121, 123} while another conducted a face-to-face interview using a computer-based questionnaire, with the computer being operated by the interviewer.¹³³ Although the final two studies required respondents to self-complete the DCE, research staff were present to provide assistance if needed.^{126, 132} Interestingly, the studies that used purely a face-to-face interviewer-administered questionnaire generally reported lower response rates than those using either a telephone questionnaire or the addition of a computer.^{113, 120-122, 124-126, 133, 134} This may be attributable to the possibility that the flexibility of a telephone interview may have been more convenient for respondents than a face-to-face interview or arranging for an interviewer to visit the respondent. As only one of the included studies that used a self-completion approach reported the response and/or completion rates, it is difficult to draw definitive conclusions regarding the impact of utilising this method on response and/or completion rates in comparison to an interviewer-administered questionnaire.

The administration modes used in these studies present several advantages and disadvantages. Given that DCEs can be cognitively complex, the presence of a research staff member to provide assistance allows respondents to seek clarification about the task they are being asked to complete, and for the staff member to provide guidance if the respondent is not completing the task correctly. This has the potential to contribute to both the collection of reliable data and reassurance for the respondent. However the presence of an interviewer may also result in respondents feeling pressured to complete the task in a timely manner rather than taking as much time as they would like, or may cause them to feel judged regarding their choices. These possibilities can be avoided by careful explanation of the task to respondents. While DCEs that are designed for a computer-based mode of administration present some practical advantages, for example that the data is not required to be entered from a paper format questionnaire, minimising the chance of data recording errors, it also poses a dilemma in that respondents are required to have access to, and be proficient in the use of computers. This may be particularly challenging for at least a proportion of older adults who may be unfamiliar and apprehensive about using this technology. Kistler and colleagues avoided this problem by using an approach in which a research staff member operated the computer, in a central location, on behalf of the respondent.¹³³

The cognitive challenges potentially faced by older adults must also be considered when designing a DCE for completion by older adults. Considerations may include the wording of the instructions and information provided within the task along with the number of attributes and scenarios presented to respondents. This was addressed in the majority of the studies reviewed, with the number of attributes and choice sets being

limited in order to minimise the burden on participants in terms of cognitive demand, boredom and fatigue.^{113, 124-126, 132, 134, 137} Another technique utilised was the pilot testing of DCE tasks with older adults to ensure the appropriateness of the attributes and choice sets for the target population.^{113, 122-126, 132, 134} Also conducted were qualitative interviews with older adults to ensure that the attributes and levels of the DCE tasks were relevant to the topic under examination.^{120-124, 133} In addition to this, literature, care guidelines and health care professionals were also consulted in the process of attribute development.^{113, 124-126, 134} Other approaches were also taken to maximise the reliability of responses and minimise respondent burden. Three studies measured the cognitive impairment of potential respondents prior to administering the DCE, using standardised instruments. Those respondents deemed to be experiencing a significant cognitive impairment were either excluded or proxy respondents were utilised instead.^{113, 122, 124, 125, 134} Alternatively, Kistler and colleagues along with de Bekker-Grob et al included a consistency check within the design of their DCEs whereby one of the choices contained a clearly dominant scenario (containing superior levels for all attributes relative to a comparator scenario) which should therefore be the logically chosen alternative.^{120, 121, 133} Respondents who selected the inferior scenario were considered to be unreliable and were therefore excluded from the DCE data analysis.

Another aspect of DCE administration that requires consideration with older samples is the impact of respondent characteristics on response reliability. Milte and colleagues explored whether cognitive status had any impact on DCE response consistency. It was found that cognitive status did not have any impact on the consistency of responses provided, with respondents with mild cognitive impairment exhibiting similar reliability to those with good cognition levels.¹¹³ de Bekker Grob and colleagues also examined

the impact of respondent characteristics differentiated according to their 10 year risk of incurring a hip fracture.^{120, 121} This work reported higher DCE study consent rates among respondents with a low risk of hip fracture as opposed to those at higher risk. Those respondents at lower risk were also younger on average than the respondents with a higher risk. This may indicate that younger individuals who are generally in better physical health are more likely to agree to undertake a DCE task than older individuals who are experiencing poorer health. Overall, these studies indicate that sample characteristics, for example in relation to physical health, may have some impact on the feasibility of DCE administration among older adults. Although not sufficiently studied to date it is also likely that the level of cognition, for example those with more severe cognitive impairment than the levels included in the study by Milte and colleagues,¹¹³ will impact upon the reliability of DCE responses. However due to the very small number of studies upon which this conclusion is based, it must be considered with some caution.

In relation to the inclusion of a cost attribute to facilitate the calculation of WTP, several studies found that respondents were averse to scenarios that were associated with higher out-of-pocket costs. This may be attributed to respondents possibly not being engaged in paid employment, with 83% of the respondents in the work by Hong and colleagues reporting that they were retired.¹³² Along with this is the impact of receiving a lower income than individuals who are employed. For example, two of the reviewed studies found that nearly half of their respondents had annual household incomes of A\$20,000 and US\$20,000 or less.^{124, 132} The influence of financial status can be taken into account by the inclusion of income as an attribute or conducting sub-group analysis according to income level.⁶⁴

The majority of the DCE studies included in this literature review utilised a conditional logit model for conducting the data analysis.^{120, 121, 124, 132, 134} Some of these studies also conducted further additional analyses, namely heteroskedastic conditional logit, mixed logit and general multinomial logit models.^{113, 122, 125} A minority of studies used more sophisticated econometric approaches for DCE data analysis including a random parameter logit (mixed logit) model random effects logit model or hierarchical bayes model.^{123, 126, 133}

Overall, the feasibility of DCE administration with samples of older adults has been demonstrated. However there are several factors that require consideration when employing this method of preference elicitation in order to maximise its effectiveness. This includes issues relating to both the design and administration of DCEs for older adult samples. Firstly the cognitive complexity of the task must be considered, and efforts made to minimise the burden placed upon respondents by limiting the number of attributes and choice sets presented to respondents. When selecting the attributes to be included, it may also be advantageous to reflect on the inclusion of cost, as this may not be a reliable attribute. Secondly, it is beneficial to be aware of potential respondent characteristics that may impact on the ability and willingness to complete a DCE such as age and health status, or sociodemographic attributes such as income which may impact on WTP. In terms of the actual administration of DCE tasks with older adults, it is vital that the DCE task is clearly explained to respondents to ensure that they are completing it correctly in order to minimise the display of dominant preferences or unreliable data. Finally it would appear that the presence of a research staff member to assist or provide clarification to respondents while completing the DCE is optimal.

2.7 Conclusion

This review has demonstrated that despite the proliferation of DCE studies within health care within the last decade, to date very few studies have been conducted in samples consisting entirely of older adults. The methodology has been used more widely in adult populations that have included older adults. DCEs have been used to obtain the preferences of older adults on a range of health issues predominantly related to the process of delivery including treatment, screening and management options for specific conditions and the configuration of health services. Significant preferences were identified in relation to the duration, cost, outcomes and mode of health interventions. The finding that older adults took the outcome of alternative options into consideration when making a selection supports the relationship between the process and outcomes of care proposed by the Donabedian model.

The high completion rates identified by the majority of studies indicate both the willingness and ability of older adults to partake in DCEs. These findings coupled with the few reports of unreliable or dominant responses provided by the studies included in this review demonstrate the potential for DCE methodology to be both an acceptable and appropriate method for ascertaining the preferences of older adults in the context.

Chapter 3

Literature review: Outcome utility measurement in subacute rehabilitation for older adults

Chapter 2 discussed the utilisation, to date, of DCEs to measure the preferences of older adults regarding the *process* of receiving. Chapter 3 will focus on the extent to which the *outcomes* of health care provided to older adults have been measured from the perspective of older adults themselves. This chapter presents a review of the current literature in which the health-related quality of life of older adults receiving subacute rehabilitation was measured using preference-based instruments. This enabled the outcomes of subacute rehabilitation for older adults to be calculated in terms of utility values and incremental QALY gains. Chapter 3 will address the second research objective of the thesis, “to investigate the extent to which the HRQoL outcomes of subacute rehabilitation interventions for older adults have been captured in published randomised controlled trials to date, and the methods used to do so”.

3.1 Background

The purpose of subacute care such as rehabilitation is to maximise function and prevent the deterioration of function arising from impairment.⁴ However as in many other areas of medicine, the resources available for expenditure on rehabilitation services are inevitably constrained. Difficult decisions must therefore be made about how to allocate limited resources in order to maximise the health benefits gained for individuals from participation in, and engagement with rehabilitation services. Hence it is necessary to compare alternative configurations of rehabilitation services (e.g. in terms of the target population group, the type and grade of health care personnel administering the service, the intensity and duration of rehabilitation provided and/or the location of the service) according to the benefits and the costs incurred by their provision.⁷⁵ Traditionally these benefits have been determined by health professionals rather than the patients themselves.²⁹

The outcomes of rehabilitation have typically been measured in terms of functional ability such as mobility. The most commonly used instruments used for this purpose are the Functional Independence Measure (FIM) and the Barthel Index.¹³⁸ The Functional Independence Measure was designed to assess disability severity and the type and amount of assistance needed by a person.^{139, 140} The instrument consists of 18 items; 13 of these relate to motor skills (self-care and locomotion), while the remaining five relate to cognitive ability (comprehension, expression, problem solving, social interaction and memory). Each item is assessed using a seven level ordinal scale ranging from one, representing dependence, to seven which represents independence.¹⁴⁰ Total scores range from 18 to 126, with higher scores indicating higher levels of independence. The FIM was developed to fill the need for a universal measurement of function and outcomes and to address the limitations of the Barthel Index, namely the presence of floor and ceiling effects.^{138, 140}

The Barthel Index was developed to assess disability in people receiving inpatient rehabilitation for musculoskeletal and neuromuscular conditions.¹⁴¹ The instrument takes the form of an ordinal, three point scale including 10 domains relating to activities of daily living: feeding, bathing, grooming, dressing, continence, toilet use, transfers, mobility and negotiating stairs.¹³⁸ Each domain has a maximum score of either 10 or 15 and the instrument produces a total score out of 100, with higher scores indicating higher levels of independence. A modified version of the Barthel Index has also been developed. While it includes the same domains as the original, the modified version has a five point scale rather than three to allow for greater sensitivity.¹⁴² As with the original version, a score out of 100 is produced. The Barthel Index is recommended for use in

the routine assessment of older adults, and has been utilised to measure and compare pre-and post-treatment outcomes and predict discharge outcomes. In addition to this, the instrument has also been administered in rehabilitation settings to predict length of stay and the level of nursing care a patient requires.^{138, 141}

While many of the rehabilitation outcomes that are measured tend to relate to clinical factors such as functional ability, there is growing recognition of the importance of measuring additional outcomes in order to gain a more extensive insight into a patient's current situation. When asked to list the outcome measures they believed would be useful in rehabilitation medicine, a survey of clinicians listed community integration, patient confidence, social supports, communication, carer burden, nutrition status, medication management, general health status and quality of life.¹³⁸ However these areas are often not the focus of resource allocation in rehabilitation settings.¹³⁸ This is despite the routine assessment of HRQoL, for example, being associated with improvements in not only HRQoL, but also in patient-physician communication and patient satisfaction. Additionally increases in the identification of problems and patient management activities to improve them have also been noted.¹⁴³

Further to this, instruments such as the Functional Independence Measure and the Barthel Index are typically completed by health professionals and based upon patient observation, rather than being based on the views of patients. However growing importance is now being placed on obtaining the views of patients themselves when measuring the outcomes of health care. In order to facilitate this, many outcome measurement instruments, particularly pertaining to HRQoL and quality of life in a broader sense, have been developed using patient preferences.

DCE methodology was used in large samples of the general population to ascertain preferences regarding states for both the ICEpop CAPability measure for Older People (ICECAP-O) and the Adult Social Care Outcomes Toolkit (ASCOT).^{32, 144} These preferences were used to derive values or weights to be applied to each potential combination of responses to the instruments. Both of these instruments measure quality of life but do not include health status. The ICECAP-O was designed to both measure and value the quality of life of older adults in a broader sense based upon an individual's capabilities. This instrument will be discussed in greater detail in chapter 5. The ASCOT instrument was designed for the measurement and valuation of quality of life in relation to social care and consists of eight domains: personal cleanliness and comfort, accommodation cleanliness and comfort, food and drink, safety, social participation and involvement, occupation, control over daily life and dignity.¹⁴⁴

Both the ICECAP-O and ASCOT instruments were designed to be potentially suitable for incorporation into the framework for economic evaluations of health and social care services. Given the growing importance of resource allocation and by extension, economic evaluation within health services, it is important for outcome measures to be suitable for use in the economic evaluation of health services. This requires outcome measures to be preference-based and consist of a descriptive system and a scoring algorithm which produces health state values on the zero to one QALY scale such as the EQ-5D-3L. Further research is needed to explore the potential applicability of non-HRQoL measures which are preference-based such as the ICECAP-O for use in economic evaluations.

QALY estimation is internationally accepted as the most widely used outcome measure for economic evaluation.⁷⁵ However, it appears that no study has yet set out to systematically document and compare published studies in terms of estimated health state values between different patient groups and/or service configurations for patients currently receiving rehabilitation. Additionally, it would appear that no study to date has conducted a longitudinal assessment of changes in health and/or quality of life and QALYs gained from the rehabilitative therapies used in different studies.

3.2 Objectives

The main objective of this literature review was to generate estimates of the average incremental QALYs gained by patients aged 65 years and over receiving subacute rehabilitation programs. The purpose of this was to indicate the extent to which QALY gains have been reported in published studies focusing on the provision of rehabilitation interventions for older adults. Additionally it would allow for an overview of the MAUI instruments that have been utilised to be captured, and also identify whether QALY gains are being generated when their calculation is possible.

Wherever possible utility and QALY gains were reported directly using the results presented in published studies. However where this was not possible, for example due to the presentation of individual domain summary scores for the SF-36 only, these were calculated by applying algorithms developed by Ara and Brazier, and Sullivan and Ghushchyan to generate health state values.^{65, 67} Where a longitudinal assessment of change over time in utility values could be generated, the area under the curve method

was utilised to calculate the associated QALY gains for intervention and comparison groups.¹⁴⁵

3.3 Methods

3.3.1 Criteria for considering studies for this review

Types of studies

Studies investigating the outcomes of rehabilitation interventions were included in the review. Studies that were not available in the English language were excluded from the review, as were study protocol papers. Studies were required to be either randomised controlled trials or quasi-randomised controlled trials. The search was limited to studies of these designs as they would allow for direct comparisons to be made between older adults who were and were not receiving subacute rehabilitation or an alternative form of subacute rehabilitation.

Types of participants

The study population was adults aged 65 years and over (mean age within 1 standard deviation) who had experienced an acute episode of ill-health requiring hospitalisation.

Types of interventions

Studies reporting on rehabilitation interventions that were provided within three months of an acute health event requiring hospital admission were included in this review. For the purpose of this review which focused on clinical studies, rehabilitation was considered to be a service provided with the intention of helping recipients to attain the highest

possible level of independence following injury or illness as defined by the Australasian Faculty of Medicine.¹⁸

Based on this definition, the rehabilitation interventions were required to be provided by a multidisciplinary team of health professionals. This was defined as health professionals from two or more professions, with at least one being allied health.

Types of outcome measures

The main outcome measure of interest was quality of life measured using instruments which facilitate the calculation of utility values. Hence only studies which measured quality of life over time using a generic, preference-based instrument suitable for QALY estimation were included. Examples of these are the EQ-5D-3L,⁶³ AQoL,⁶⁰ SF-6D,⁵⁷ 15-D,¹⁴⁶ Health Utilities Index (HUI)⁶² and Quality of Well-Being Scale (QWB).¹⁴⁷ Although not of themselves MAUIs, studies utilising the SF-12 and SF-36 were also included as algorithms have been developed from which SF-6D utilities can be estimated from SF-36 data¹⁴⁸ and EQ-5D-3L utilities from the SF-36⁶⁷ and SF-12,⁶⁵ thereby enabling the calculation of QALYs.

3.3.2 Search methods for identification of studies

The following electronic databases were searched on the 8th August 2016. Medline (1946 to August 2016), Embase (1980 to August 2016), CINAHL Plus (1978 to August 2016) and Cochrane Library and Central Register of Controlled Trials (up to August 2016). Keywords were selected that pertained to older adults, quality of life, QALYs, MAUIs and differing forms of health care that may be provided instead of or following an episode of acute care. Medline was searched using the sensitivity and precision

maximizing version of the Cochrane Highly Sensitive Search Strategy developed for use in the Medline database.¹⁴⁹ This search strategy was modified for use in the other databases and is presented in appendix 1.

3.3.3 Data collection and analysis

Selection of studies

The candidate and an additional reviewer identified papers as being potentially eligible for inclusion from the database searches, with any reasons for exclusions documented. A third reviewer was consulted in the case of discrepancies. The authors of the papers were contacted for clarification if the details needed to determine eligibility were not presented in the papers. The process of selecting the included studies is outlined in figure 3.1.

Data extraction and management

Data from the included studies were extracted using a data extraction form covering the study design, study population, interventions, outcome measure, and length of follow-up.

Calculation of utility values and QALY gains

Where presented, utility values were extracted directly from the published studies. Where utility values were unavailable but SF-12 or SF-36 summary scores were presented for individual health domains, it was possible to generate utility values by applying the conversion algorithms developed by Ara and Brazier for the SF-36, and Sullivan and Ghushchyan for the SF-12.^{65, 67} The algorithm developed by Ara and Brazier was applied to transform SF-36 scores into EQ-5D-3L index scores by inserting

the mean scores for each of the SF-36 dimensions into the algorithm in which they were then multiplied by coefficients derived from an individual regression analysis of the SF-36 dimensions and their squares.⁶⁷ An example of this is shown in appendix 2. SF-12 and SF-36 summary scores were transformed into EQ-5D-3L index scores rather than SF-6D scores as none of the included studies utilised the SF-6D, whereas two studies used the EQ-5D-3L. Therefore estimating EQ-5D-3L scores from the SF-12 and SF-36 summary scores enabled direct comparisons to be made between the results of the identified studies.

The QALYs gained by both the intervention and control groups in each study were calculated using area under the curve methods.¹⁴⁵ The incremental QALY gains were calculated by subtracting the total QALYs gained by the control group from that of the intervention group. In the event of a study comparing multiple interventions, the incremental QALY gains were calculated by subtracting the total QALYs gained by the control group from that of each of the intervention groups.

Dealing with missing data

Intention-to-treat analyses were conducted wherever possible. In the case of participant drop-outs, all participants who had contributed data for the relevant outcome measure were included.

Subgroup analysis

To enable meaningful comparisons to be made, the included studies were grouped together according to the setting in which the intervention was provided and the period of time over which quality of life was measured.

3.4 Results

3.4.1 Results of the search

Of the 532 abstracts obtained from the database searches, copies of 132 papers reporting on 127 studies were obtained for further eligibility assessment. Twelve of these papers, reporting on eleven different trials were deemed to meet the inclusion criteria for this review. The large number of ineligible papers was attributed to the broad range of search terms that were utilised in the search strategy which may have resulted in the retrieval of papers that met some, but not all of the inclusion criteria for this review.

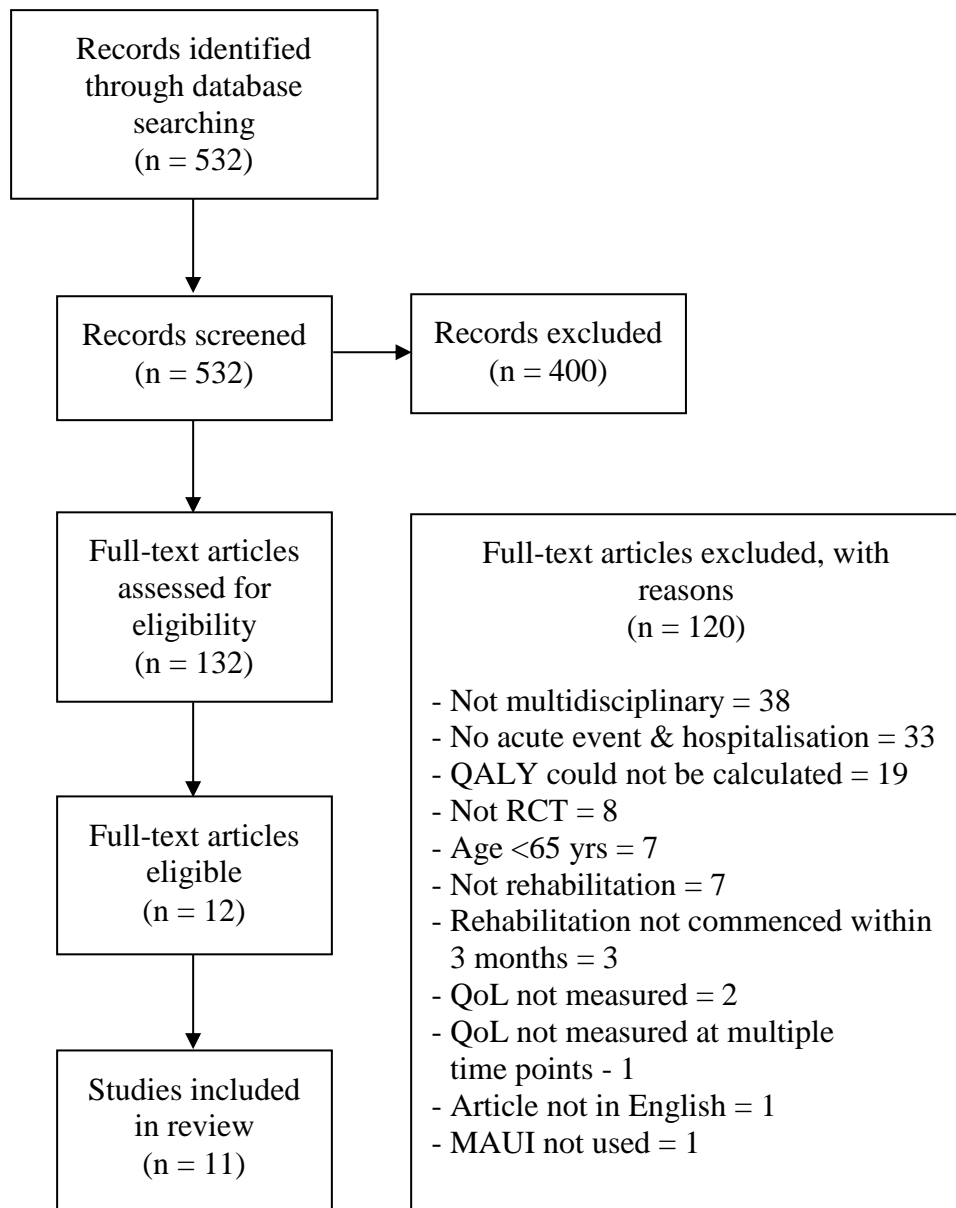
The authors of a further 19 papers reporting on 16 studies were contacted for clarification on the inclusion eligibility of their papers, mostly due to quality of life being measured, but the scores either not reported, or only summary scores provided. Two of the authors were able to provide the additional information requested, while seven were unable. Responses were not received from the remaining seven authors. These 14 studies were therefore excluded from the review because QALYs were not able to be calculated as insufficient information was presented in the published papers.

Although the focus was on QALYs estimated using instruments, studies reporting on QALYs estimated from valuation tasks were not specifically excluded from the review. Only 1 study that met the inclusion criteria reported on a valuation task (TTO), in addition to utilising a MAUI.¹⁵⁰ To ensure consistency with the other included studies, only the QALYs estimated from the MAUI in this study were included in the analysis.

3.4.2 Excluded studies

The main reasons for the exclusion of studies were that the intervention under consideration was not provided by a multidisciplinary team, followed by the intervention not being provided in response to an acute episode of ill-health and hospitalisation. However some of the excluded studies met more than one of the exclusion criteria. The study selection process is outlined in figure 3.1.

Figure 3.1 Study selection process



3.4.3 Trial selection and sample characteristics

The included trials had a sample size of 3,481 patients experiencing acute health events such as stroke,^{151, 152} cardiac diagnoses,^{150, 153, 154} hip fracture,^{155, 156} total joint replacements^{157, 158} and miscellaneous diagnoses.¹⁵⁹⁻¹⁶¹ The mean ages of the participants in the trials that reported this ranged from 58 to 79 years and the sample sizes ranged between 28 and 1,813 participants. Australia,^{151, 159} England^{154, 160, 161} and Taiwan^{155, 156} were the settings of two studies each, while the remaining five were conducted in Canada,¹⁵² Sweden,¹⁵⁰ Greece,¹⁵⁸ Copenhagen,¹⁵³ and the United States of America.¹⁵⁷ The characteristics of the included studies are presented in table 3.1.

Table 3.1 Characteristics of included studies (continued over page)

Study	Patient population	Setting	Experimental treatment	Control treatment	Outcome measure	Time period	Mean utility value	QALY gain	Incremental QALY gain
Anderson 2000 ¹⁵¹	Mean Age: 75 yrs Diagnosis: Stroke Country: Australia N = 86	Outpatient	Early discharge from acute setting and tailored multidisciplinary home-therapy sessions	Usual care in acute hospital ward or multidisciplinary stroke rehabilitation unit	SF-36	6 months	<i>Intervention</i> 6 months: 0.653 12 months: 0.662 Change: 0.009 <i>Control</i> 6 months: 0.698 12 months: 0.719 Change: 0.021 SF-36 converted to EQ-5D-3L scores	<i>Intervention</i> 0.329 <i>Control</i> 0.354	-0.025
Berg 2011 ^{153, 162}	Mean Age: 58 yrs (SD 13.2) Diagnosis: Implanted Cardioverter	Outpatient	12 week exercise program and psycho-educational intervention	Standard care comprising a medical follow-up and optional group meeting for patients to receive information and	SF-36	12 months	<i>Intervention</i> Baseline: 0.764 3 months: 0.853 6 months: 0.870	<i>Intervention</i> 0.854 <i>Control</i> 0.829	0.025

Study	Patient population	Setting	Experimental treatment	Control treatment	Outcome measure	Time period	Mean utility value	QALY gain	Incremental QALY gain
	Defibrillator recipients Country: Denmark N = 196			share experiences			12 months: 0.877 Change: 0.113 <i>Control</i> Baseline: 0.760 3 months: 0.828 6 months: 0.844 12 months: 0.843 Change:0.083 SF-36 converted to ED-5D-3L scores		
Evgeniadis 2008 ¹⁵⁸	Mean Age: 69 yrs Diagnosis: Knee arthroplasty for osteoarthritis	Inpatient and Outpatient	<i>Pre-operative group</i> Supervised 3 week pre-operative home exercise program to	Standard preoperative evaluation, inpatient rehabilitation program and follow-up controls	SF-36	4 weeks	<i>Pre-operative</i> Baseline: 0.178 4 weeks: 0.185 Change: 0.007 <i>Post-operative</i> Baseline: 0.171	<i>Pre-operative</i> 0.014 <i>Post-operative</i> 0.013 <i>Control</i> 0.014	<i>Pre-operative vs control</i> 0.000 <i>Post-operative vs control</i> -0.001

Study	Patient population	Setting	Experimental treatment	Control treatment	Outcome measure	Time period	Mean utility value	QALY gain	Incremental QALY gain
	Country: Greece		strengthen trunk and upper extremities				4 weeks: 0.172 Change: 0.001		
	N = 59		Or <i>Post-operative group</i> Supervised post-operative 8 week home exercise program to strengthen lower extremities.				<i>Control</i> Baseline: 0.181 4 weeks: 0.185 Change: 0.004 SF-36 converted to EQ-5D-3L scores		
Graves 2009 ^{159, 163}	Mean age: 79 yrs Diagnosis: Various Country: Australia N = 28	Inpatient and Outpatient	Exercise-based model of hospital and in-home nursing follow-up care	Routine care, discharge planning and rehabilitation advice	SF-12	24 wks	<i>Intervention</i> Baseline: 0.714 4 weeks: 0.844 12 weeks: 0.889 24 weeks: 0.901 Change: 0.187 <i>Control</i>	<i>Intervention</i> 0.400 <i>Control</i> 0.320	0.080

Study	Patient population	Setting	Experimental treatment	Control treatment	Outcome measure	Time period	Mean utility value	QALY gain	Incremental QALY gain
							Baseline: 0.732 4 weeks: 0.692 12 weeks: 0.701 24 weeks: 0.671 Change: -0.061		
							SF-12 converted to EQ-5D -3L scores		
Mayo 2000 ¹⁵²	Mean age: 70 yrs Diagnosis: Stroke Country: Canada N = 114	Outpatient	4 week tailored multidisciplinary home rehabilitation program including physical therapy, occupational therapy, speech therapy, dietary consultation and nursing	Standard discharge planning and referral for follow-up services	SF-36	2 months	<i>Intervention</i> 1 month: 0.688 3 month: 0.724 Change: 0.036 <i>Control</i> 1 month: 0.690 3 month: 0.670 Change: -0.020 SF-36 converted to EQ-5D-3L scores	<i>Intervention</i> 0.118 <i>Control</i> 0.113	0.004

Study	Patient population	Setting	Experimental treatment	Control treatment	Outcome measure	Time period	Mean utility value	QALY gain	Incremental QALY gain
O'Reilly 2006 ^{160, 161}	Mean age: "mid 80s" Diagnosis: Various acute illness Country: England N = 490	Inpatient	Post-acute hospital care with multidisciplinary assessment and treatment, individualized care plans, shared coverage between consultants and general practitioners	Extended stay in a general hospital with multidisciplinary care but could include transfer to other post-acute services according to existing local operational policies.	EQ-5D-3L	6 months	Not available	<i>Intervention</i> 0.340 <i>Control</i> 0.298	0.042
Sandström 2005 ¹⁵⁰	Mean age: Participants required to be ≥65 yrs Diagnosis: Coronary heart disease Country: Sweden	Outpatient	50 minute aerobic group training program 3 times a week for 3 months supervised by a physiotherapist with voluntary step-down period once a week for another 3 months	Verbal and written information about the importance of regular physical activity after an acute coronary event and recommended to take a daily	EQ-5D-3L	12 months	<i>Intervention</i> Baseline: 0.79 3 months: 0.85 12 months: 0.87 Change: 0.08 <i>Control</i> Baseline: 0.81 3 months: 0.84 12 months: 0.86	<i>Intervention</i> 0.850 <i>Control</i> 0.844	0.006

Study	Patient population	Setting	Experimental treatment	Control treatment	Outcome measure	Time period	Mean utility value	QALY gain	Incremental QALY gain
	N = 101		Verbal and written information about the importance of regular physical activity after an acute coronary event and recommendation to take a daily walk, gradually increasing time, length and speed	walk, gradually increasing time, length and speed. Monthly information meetings with cardiac rehabilitation team to discuss problems, heart disease and pharmacological therapy			Change: 0.05		
Shyu 2010 ^{156, 164, 165}	Mean age: 68yrs Diagnosis: Hip fracture	Inpatient and Outpatient	Inpatient geriatrician consultation, inpatient and outpatient physical therapy	Usual care including inpatient physical therapy	SF-36	12 months	<i>Intervention</i> 1 month: 0.534 3 months: 0.665 6 months: 0.720	<i>Intervention</i> 0.636 <i>Control</i> 0.522	0.114

Study	Patient population	Setting	Experimental treatment	Control treatment	Outcome measure	Time period	Mean utility value	QALY gain	Incremental QALY gain
	Country: Taiwan N=162		and discharge planning with follow-up by a geriatric nurse				12 months: 0.730 Change:0.196 <i>Control</i> 1 month: 0.474 3 months: 0.540 6 months: 0.578 12 months: 0.613 Change: 0.139 SF-36 converted to EQ-5D-3L scores		
Shyu 2013 ¹⁵⁵	Mean age: 76-77 (presented by group allocation) Diagnosis: Hip fracture	Inpatient and Outpatient	<i>Subacute Model:</i> Pre-surgery geriatric consultation, acute rehabilitation which continued at home post-	Usual care which included acute physical therapy but does not continue post-discharge	SF-36	12 months	<i>Comprehensive care</i> 1 month: 0.51 3 months: 0.64 6 months: 0.71 12 months: 0.79 Change: 0.28 <i>Subacute care</i>	<i>Comprehensive care</i> 0.639 <i>Subacute care</i> 0.663 <i>Control</i> 0.636	<i>Comprehensive care</i> 0.003 <i>Subacute care</i> 0.027

Study	Patient population	Setting	Experimental treatment	Control treatment	Outcome measure	Time period	Mean utility value	QALY gain	Incremental QALY gain
	Country: Taiwan N= 299		discharge, and early discharge-planning intervention <i>Comprehensive care:</i> All components of the subacute care model plus interventions focused on fall prevention, nutrition and depression identification and management.				1 month: 0.52 3 months: 0.68 6 months: 0.75 12 months: 0.79 Change: 0.27 <i>Control</i> 1 month: 0.51 3 months: 0.64 6 months: 0.73 12 months: 0.75 Change: 0.24 SF-36 converted to EQ-5D-3L scores		
Weaver 2003 ¹⁵⁷	Mean age: 72 Diagnosis: Elective total knee/hip replacement	Outpatient	1 preoperative home visit by a nurse and 1 by a physical therapist. 1 post-discharge nurse visit and 5-9 physical therapist visits	2 post-operative home visits and 9-45 post-operative home physical therapist visits	SF-36	5 months	<i>Intervention</i> 1 month: 0.684 6 months: 0.803 Change: 0.119 <i>Control</i> 1 month: 0.684	<i>Intervention</i> 0.310 <i>Control</i> 0.312	-0.002

Study	Patient population	Setting	Experimental treatment	Control treatment	Outcome measure	Time period	Mean utility value	QALY gain	Incremental QALY gain
	Country: USA N = 136						6 months: 0.814 Change: 0.130 SF-36 converted to EQ-5D-3L scores		
West 2012 ¹⁵⁴	Mean age: 64.2yrs (SD 11.2) Diagnosis: Myocardial infarction Country: England N = 1813	Outpatient	Weekly or bi-weekly exercise training and health education provided by a either a nurse, physiotherapist or occupational therapist plus at least one other discipline Usual care as provided to the control group	Usual care including routine advice and information booklet. Referral for further cardiac interventions or investigations as needed	SF-36	12 months	<i>Intervention</i> Baseline: 0.690 12 months: 0.748 Change: 0.058 <i>Control</i> Baseline: 0.692 12 months: 0.739 Change: 0.047 SF-36 converted to EQ-5D-3L scores	<i>Intervention</i> 0.719 <i>Control</i> 0.716	0.003

3.4.4 Interventions

The studies reported on a range of multidisciplinary interventions that were provided in settings that were either inpatient or outpatient in nature or a combination of the two. As shown in table 3.1, health professionals from a variety of disciplines provided the interventions.

Table 3.2 Health discipline providing interventions

Health professionals providing intervention	Number of studies
Counsellor	1
Dietitian	3
Health Promotion	1
Medical Practitioner	3
Nurse	8
Occupational Therapist	3
Orthopaedist	1
Pharmacy	1
Physiotherapist / physical therapist	9
Psychology	1
Social Worker	1
Speech Therapist	1

The included studies were mostly focused upon the provision of outpatient rehabilitation.^{150-154, 157} Physiotherapy or physical therapy-based interventions were the most commonly provided in the outpatient settings followed by nursing. Other health professionals involved in the interventions included medical practitioners, health

promotion officers, psychologists, social workers, occupational therapists, dietitians, speech therapists and pharmacists. Two of these studies compared outpatient rehabilitation post-stroke with usual care. Anderson and colleagues focused on stroke patients and compared usual care in an acute hospital ward or multidisciplinary stroke unit with early discharge from the acute setting followed by individualised multidisciplinary home visits from rehabilitation nursing, occupational therapy, social work and physiotherapy staff.¹⁵¹ Mayo and colleagues also focused on at home stroke rehabilitation but in the form of a four week tailored multidisciplinary home program consisting of nursing, physical therapy, occupational therapy, speech therapy and dietary consultation, and how this compared with standard discharge planning and referral for follow-up services.¹⁵²

Other studies focused on outpatient interventions for cardiac conditions. Sandström and Ståhle reported on an outpatient intervention following an acute coronary event.¹⁵⁰ This study explored the provision of information about the importance of physical exercise recommendations and monthly information sessions with a cardiac rehabilitation team. The intervention group additionally received 50 minute physiotherapist-supervised aerobic sessions three times a week for three months followed by a voluntary step-down program once a week for another three months. Berg and colleagues investigated the impact of a 12 week program combining exercise and psycho-educational interventions following a cardiac procedure.¹⁵³ The exercise component consisted of an individual physiotherapy consultation followed by twice weekly, individually tailored resistance and aerobic exercise program for 12 weeks. The program was performed either at home or in a group, outpatient setting depending on individual needs. The psycho-social educational component was conducted by a trained nurse and provided either in person

or over the telephone. The focus was on the impact of the procedure on the social and psychological aspects of recipients' lives. West and colleagues also investigated rehabilitation for post-acute coronary patients, focusing on myocardial infarction.¹⁵⁴ In addition to usual care, consisting of routine advice, an information booklet and referral for further interventions or investigations as needed, participants also received weekly or bi-weekly exercise training and health education. This was provided by either a nurse, physiotherapist, or occupational therapist in addition to a health professional from at least one other discipline.

The final outpatient study, by Weaver and colleagues, compared two groups of hip and knee replacement patients.¹⁵⁷ The intervention group received two pre-operative home visits from a nurse and physiotherapist and one post-operative home visit from a nurse and between five and nine post-operative physiotherapy home visits as needed. The control group received no pre-operative home visits, but two post-operative home nursing visits and between nine and forty-five post-operative physiotherapy home visits as needed.

Only one study, O'Reilly and colleagues, reported upon inpatient rehabilitation following an acute event.^{160, 161} Community hospital care including a multidisciplinary team assessment, development of an individual care plan and shared coverage between consultants and general practitioners was compared with an extended stay in the elderly care ward of a district general hospital for patients with acute illnesses.

The remaining four studies each provided a combination of inpatient and outpatient rehabilitation. Nurses were the most common health professional to provide these

interventions, followed by physiotherapists or physical therapists. Other disciplines that provided interventions in a combination of inpatient and outpatient settings included geriatricians, dietitians and orthopaedists. The trial reported on by Graves and colleagues compared routine care with the provision of a tailored exercise program, daily nurse visit and transitional care plan while an acute inpatient, followed by nursing visits and follow-up telephone calls post-discharge.¹⁵⁹ The second study, by Evgeniadis and colleagues, focused on patients undergoing total knee arthroplasty due to osteoarthritis patients and had two intervention arms.¹⁵⁸ Both intervention groups received standard inpatient rehabilitation; however the first group also received a supervised three week pre-operative home exercise program focusing on the trunk and upper extremities, while the second group instead received an eight week supervised home exercise program targeting lower extremities. The control group received standard inpatient rehabilitation.

The two studies by Shyu and colleagues both focused on interventions following hip fracture.^{155, 164} The 2010 study compared the outcomes of usual care with those of a subacute intervention including an inpatient geriatric assessment, both inpatient and outpatient physical therapy and discharge planning with follow-up by a geriatric nurse.¹⁶⁴ The 2013 study tested the impact of the same intervention and usual care, but with the addition of a second intervention option, that of comprehensive care. This included all aspects of the subacute model, with the addition of a fall prevention intervention, dietetic consultation and depression screening and management.¹⁵⁵

3.4.5 Outcomes

Three different instruments were used to measure quality of life in the included studies. The most commonly used instrument was the SF-36 which was administered in seven studies,¹⁵¹⁻¹⁵⁸ followed by the EQ-5D-3L which was utilised in 2 studies.^{150, 160, 161} The third instrument was the SF-12 which was utilised in one study.¹⁵⁹ Following the baseline assessments, quality of life was measured at various time points, ranging from one week to one year. Each of the included studies assessed HRQoL over time, enabling utility values, QALY gains and subsequently incremental QALY gains to be calculated. This data was then analysed according to the rehabilitation setting and the period over which quality of life was measured.

Incremental QALY gains

As previously stated, the QALYs gained were calculated based on the utility values using the area under the curve method.¹⁴⁵ The QALYs gained were then used to estimate the incremental QALY gains by calculating the difference in the QALY gained by the intervention and control groups. Drummond has previously indicated that a difference of 0.03 on the zero to one death full health QALY scale is usually considered to be important.¹⁶⁶ This threshold value was utilised to determine whether or not the mean incremental QALY gains demonstrated in the studies could be considered to be meaningful.

Because QALYs have a time dimension to them, it would have been beneficial for average comparisons to be presented in a meta-analysis, where time is controlled for. However a meta-analysis was not feasible to examine the impact of receiving a rehabilitation intervention as the information required namely both the mean QALY and

the standard deviation of change for both the intervention and control groups in the studies were not available for the majority of the included studies. This was because the data utilised in the analysis was derived from generated utility values. Therefore there was no measure of variability for each study to be utilised. A linear regression was performed with adjustment for the correlation in within each study. All respondents in each study were assigned the same QALY gain i.e. accounting for the fact that the QALY gain for each individual in each study is identical. An expanded dataset was utilised with each person having the same effect as the average effect for their group.

Aggregation of the findings from these studies was very difficult due to the diversity in the populations being considered, the time horizon of the respective studies, the wide variation in the interventions under consideration and the measurement instruments utilised. Accepting these difficulties, the data indicates that, on average, the control groups experienced a mean QALY gain of 0.431 while the intervention groups demonstrated a mean QALY gain of 0.453. Therefore subacute rehabilitation is associated with a mean incremental QALY gain of 0.022. However, based on the findings of Drummond this difference is not large enough to be considered meaningful.¹⁶⁶

As shown in table 3.3, a wide variation was noted in the incremental QALYs gained. The incremental QALYs gained ranged from -0.002,¹⁵⁷ to one study with no gain,¹⁵⁸ through to a study with an incremental QALY gain of 0.080.¹⁵⁹ In total, the interventions reported on in four studies resulted in incremental QALY gains equal to or above the threshold identified by Drummond.¹⁶⁶ No evidence of an incremental QALY gain was evident for patients recovering from stroke receiving early discharge from an

acute setting and tailored multidisciplinary home-therapy sessions compared to usual care in either an acute hospital ward or multidisciplinary stroke rehabilitation unit over a time period of six months.¹⁵¹ In contrast, the highest incremental QALY gain 0.080, was measured over 24 weeks in patients with a variety of diagnoses receiving an exercise-based model of hospital and in-home nursing follow-up care in comparison to routine care, discharge planning and rehabilitation advice.¹⁵⁹

In regard to the intervention setting, the only study reporting on an inpatient intervention resulted in a meaningful mean incremental QALY gain of 0.042.^{160, 161} This mean incremental QALY gain was higher than those achieved by the interventions provided in either an outpatient setting or in a combination of inpatient and outpatient settings. This supports the finding of a previous study, which discovered higher increases in HRQoL during the inpatient rehabilitation period compared to the post-discharge period.⁴⁸ As shown in table 3.3, this was followed by the studies that included a combination of inpatient and outpatient rehabilitation which demonstrated a meaningful mean incremental QALY gain of 0.037. The lowest mean incremental QALY gain was 0.002, achieved by the studies that reported on an outpatient interventions provided in an outpatient setting. This suggests that while the interventions provided in solely an inpatient setting or a combination of outpatient and inpatient settings resulted in meaningful mean incremental QALY gains, those provided on an outpatient basis did not result in meaningful mean incremental QALY gains.

Table 3.3 Incremental QALY gain by study setting

Studies by Setting	Incremental QALY gain
<i>Inpatient</i>	
O'Reilly 2006	0.042
<i>Outpatient</i>	
Anderson 2000	-0.025
Berg 2011	0.025
Mayo 2000	0.004
Sandstrom 2005	0.006
Weaver 2003	-0.002
West 2102	0.003
<i>Combination</i>	
Evgeniadis 2008	Pre-operative vs control: 0.000 Post-operative vs control: -0.001
Shyu 2010	0.114
Shyu 2013	Comprehensive care vs control: 0.003 Subacute care –vs control: 0.027
Graves 2009	0.080

As shown in table 3.4, when analysed according to study period, the studies measuring HRQoL over a longer period demonstrated a higher mean incremental QALY gain than those measuring it at earlier time points. The studies measuring HRQoL for a period of three months or less had a mean incremental QALY gain of 0.001. In contrast, the studies that measured HRQoL at a time of four months or more post-randomisation demonstrated a meaningful mean incremental QALY of 0.027. This suggests that

rehabilitation interventions provided over a longer time period may be associated with higher levels of quality of life.

Table 3.4 Incremental QALY gain by follow-up period

Study by Time-point	Incremental QALY gain
<i>≤ 3 months</i>	
Evgeniadis 2008	Pre-operative vs control: 0.000 Post-operative vs control: -0.001
Graves 2009	0.080
Mayo 2000	0.004
<i>≥ 4 months</i>	
Anderson 2000	-0.025
Berg 2011	0.025
O'Reilly 2006	0.042
Sandstrom 2005	0.006
Shyu 2010	0.114
Shyu 2013	Comprehensive care vs control: 0.003 Subacute care vs control: 0.027
Weaver 2003	-0.002
West 2012	0.003

3.5 Discussion

This review has examined the incremental QALY gains associated with participation in a course of subacute rehabilitation for patients aged 65 years and over. The objective was to examine studies focusing on rehabilitation provided to older adults in whom

HRQoL was measured using a utility instrument or an instrument from which a utility value could be calculated.

3.5.1 Summary of main results

A number of rehabilitation studies focusing on populations of older adults have used instruments which facilitate the generation of health state values and subsequent QALY estimation (e.g. individual responses to the SF-36 at multiple time points). Studies utilising these instruments have included both patients with a specific diagnoses such as stroke and joint replacements, hip fracture, cardiac conditions or patient populations with a variety of diagnoses. Multidisciplinary care was provided in either inpatient or outpatient settings, or a combination of these, with physiotherapy or exercise therapy the most common. Studies have typically either estimated and compared summary scores between different patient groups and/or service configurations at baseline and one subsequent time-point only or have provided a longitudinal assessment of changes in health and/or quality of life over time. However many of the studies included in this review have stopped short of calculating the costs of alternative rehabilitative therapies and applying the results within an economic evaluation framework.

The small number of studies meeting the inclusion criteria for this review has demonstrated an under-utilisation of MAUIs in subacute rehabilitation studies provided to older adults. The flow-on effect of this is that the potential for the conduct of economic analysis for the intervention under study is therefore limited. However, as demonstrated by the studies reviewed here, many studies relating to rehabilitation may report on effectiveness in terms of patient recovery, rather than cost. This may be due to

such studies being conducted with a primarily clinical rather than economic focus, or data pertaining to resource use being unavailable.

Although the intervention groups exhibited higher mean utility values at the study endpoints, it is difficult to determine whether the difference between the groups is significant or meaningful. Whilst the criteria reported by Drummond generally indicates a minimally importance difference of 0.03, work by Walters and Brazier has previously estimated that the minimally important difference for the EQ-5D-3L to be a somewhat higher 0.074.^{166, 167} While some of the patient groups that this estimate were derived from older patient populations, other groups included younger adults and those who were experiencing chronic illness. None of these groups were participating in trials that provided a rehabilitation intervention. This therefore makes it difficult to draw meaningful conclusions about the effectiveness of rehabilitation interventions based solely on the differences in utility values between the intervention and control groups demonstrated in the studies included in this review.

The findings of the review suggest that, in general, small incremental QALY gains are experienced by older adults receiving subacute rehabilitation interventions. It is apparent that whilst the results of some studies indicate that for some interventions the threshold defined by Drummond has been achieved, when interpreted as a whole, the mean incremental QALY gains would not be considered sufficient to pass the minimum thresholds.¹⁶⁶

The small incremental QALY gains may be influenced by other health outcomes and participant characteristics. Sociodemographic and clinical characteristics were generally

similar between the intervention and control groups at baseline.^{151, 154, 157, 158, 160, 161}

Therefore if these characteristics were influential on HRQoL (and therefore QALYs), the impact may be similar for both the intervention and control groups. In addition to this, the participants in some studies were generally quite independent in terms of self-care and mobility at baseline.^{155, 157} From this it could be concluded that only small utility gains could be expected given the relatively high levels of functioning in these aspects of health-related quality of life at baseline. The interventions reported on in the studies did not have a uniform impact on mobility-related outcomes, with some interventions resulting in an improvement in walking ability and range of movement and fewer falls, while other studies found no difference between the intervention and control groups.¹⁵⁶⁻¹⁵⁸

Another potentially influential health outcome was morbidity and associated symptoms. Two studies found that no significant difference existed between the intervention and control groups in terms of these aspects of health both at baseline and at post-intervention follow-ups.^{150, 157} Health service utilisation may also have influenced HRQoL, based upon the assumption that higher levels of service usage would be associated with poorer health outcomes and therefore lower levels of HRQoL and QALYs. The interventions provided in the studies reviewed here were associated with differing levels of health service utilisation. While the participants in some intervention groups had fewer health service encounters, readmissions or length of stay, others found no significant difference between the intervention and control groups.^{150-152, 156, 157, 159-161} Finally, the generally high HRQoL scores reported at baseline may have contributed to the low improvement over time along with the small difference between the intervention and control groups.

Where rehabilitation was provided in an inpatient environment, or a combination of inpatient and outpatient settings, a meaningful positive mean incremental QALY gain was demonstrated. This suggests that receiving the intervention in these settings resulted in a meaningful additional QALY gain. This may be due to a difference in therapy intensity between settings and the clinical condition of the study participants, with the less acute and dependent participants receiving care in outpatient settings only. However this finding must be interpreted with some caution as only one of the included studies provided rehabilitation solely in an inpatient setting.

It is also important to note that the average mean incremental QALYs gained over a longer time period by the intervention groups was shown to be meaningfully higher than those obtained over a shorter period. This suggests that longer follow-ups may be required to accurately assess quality of life in this patient population. A possible explanation for this finding is the observation that more time had passed since the initial acute event and the participants' hospitalisation; and consequently they may have achieved higher levels of recovery than the participants who were assessed at a shorter time point who had therefore had less recovery time. The passage of time may also account for the positive utility gain reported by both the intervention and control groups in all of the studies except for two, with the improvements being attributable to participants having had additional recovery time rather than being necessarily attributable to the provided intervention.

However it is also possible that the participants whose quality of life was measured over a longer time span had, over time, adapted to any ongoing limitations that they were experiencing as a result of their acute episode of ill-health, and redefined their concept

of quality of life. It has been suggested that people may respond to health changes by employing mechanisms that enable them to maintain a high quality of life.¹⁶⁸ These mechanisms, such as social support, spiritual practice, reframing expectations and amending goals, enable individuals to accommodate or adapt to their new health status.¹³¹ Additionally, these mechanisms may influence the way individuals evaluate their own quality of life. Known as response shift, this can occur due to an individual: re-defining their concept of quality of life, changing the value they place on particular quality of life domains and changing the internal standards by which they measure their quality of life.¹³¹ For example people experiencing mobility limitations may find that it does not negatively impact their quality of life as much as they had expected it would, or may begin to place less importance on the physiological function domains of quality of life, and instead place more emphasis on domains relating to social function.¹⁶⁸ These changes in the way quality of life is defined, whether consciously or unconsciously, allow the individual to maintain what they perceive to be a high quality of life despite their change in health status.

3.5.2 Quality of the evidence

It must be noted that the findings of this review are based on a small number of studies with a range of subacute populations using varying intervention approaches. Therefore the conclusions that can be drawn are somewhat limited.

The included studies were conducted in six different countries, included participants with a variety of diagnoses and provided a range of interventions in a combination of inpatient and outpatient settings for differing durations. Although this makes the

pooling of data difficult, it does mean that the findings of the review are based on a variety of forms of rehabilitation and the patients to which it is provided.

3.5.3 Potential bias in the review process

The possibility exists that the review was unable to identify some trials in this area.

Although a comprehensive search strategy was employed, it is possible that some trials may not have been published in full and were therefore not identified for inclusion in this review. While the authors of this review consider that studies have been appropriately included and excluded, the degree to which some interventions are deemed to be rehabilitation-based may be interpreted differently by others.

3.5.4 Agreements and disagreements with other studies or reviews

To our knowledge, no previous work has been conducted to review the average incremental QALY gained by older adults from a subacute rehabilitation intervention.

3.5.5 Implications for practice

Although the use of MAUIs are being routinely used to examine the outcomes of health care interventions in acute areas of medicine such as surgery, subacute care such as rehabilitation is typically a longer process associated with more incremental progress.⁴¹

This suggests that the instruments used to measure utility and therefore calculate QALY gains need to be sensitive to this. The incremental QALY gains experienced by older adults receiving subacute care interventions indicates that rehabilitation can result in a range of utility gains. The findings from this review have demonstrated rehabilitation interventions to generally have a small, but positive effect in terms of incremental QALY gains when HRQoL is measured over longer time periods and when

interventions are provided in either an inpatient or combination of inpatient and outpatient settings compared to the receipt of standard or routine care for older adults.

3.5.6 Implications for future research

The findings of this literature review suggest that while quality of life is a commonly used outcome measure in randomised controlled trials assessing rehabilitation for older adults, many of these have utilised instruments that are not appropriate for the calculation of health state values and the estimation of QALYs. While the findings of such studies can provide valuable insight in terms of HRQoL and physical function, the potential for this information to be incorporated within an economic evaluation framework remains limited. Whilst this review has identified largely positive incremental QALY gains for associated with the participation of older adults in rehabilitation services, the extent to which these gains could be considered to be clinically meaningful requires further investigation. It is important that further research is conducted to assess the minimal important difference in health state values and QALY gains for older adults participating in rehabilitation.

3.6 Conclusion

The literature reviewed in the previous chapter focused on the extent to which process of care has been measured in populations of older adults receiving subacute care. This chapter however reviewed literature focusing on the measurement and valuation of outcomes of subacute care for older adults. This enabled the extent to which HRQoL outcomes have been captured in published randomized controlled trials of rehabilitation, and the methods used to do so, to be determined.

Chapter 4

**Process of care: The application of DCE
methodology to investigate older adults'
preferences for subacute care**

Chapters 1 and 2 highlighted the importance and applicability of examining the process of care from the patient perspective, and found that little work has been conducted to do this using the DCE methodology in measuring and valuing the process of care exclusively in populations of older adults. Chapter 4 will address this gap in the literature, in relation to the first research objective, “to examine the process of subacute care from the patient perspective using a discrete choice experiment to determine the features of care that are important to older adults”. The findings presented in this chapter formed the basis of the first publication displayed in appendix 4.¹⁶⁹

4.1 Introduction

The quality of health care has been traditionally based on the views of health professionals and largely focused upon the measurement of clinical and health outcomes of patients.²⁵ The disadvantage of this approach lies in the possibility that the factors which are considered as most important to health professionals may not be the factors which are most important to patients themselves, and health outcomes may not be the only aspect of health care of importance to older adults and their families.^{2, 25} Elements of the process of receiving health care, for example waiting time, continuity of care, or treatment type may also be a highly important indicator of quality of care.^{41, 105, 114, 170}

Given the predicted increase in life expectancy and subsequent ageing population and increased demand on health and social care services, it is important for preference elicitation techniques to be available that are suitable for use with older adults. A preference elicitation method that is becoming more commonly utilised within the health care sector is the DCE. This methodology defines health care interventions or

services in terms of their key characteristics or attributes and their associated levels. Within a DCE, respondents are presented with a series of hypothetical scenarios describing different health care interventions from which they are asked to indicate their preferences. Each scenario is described in terms of its characteristics (attributes) which consist of varying levels. It is assumed that respondents will make trade-offs between the attributes and their associated levels in order to choose their preferred scenario. Their final choices can then be analysed to interpret the influence of each attribute on their overall decision.⁴⁶ The overall process utility or benefit that would be gained from alternative scenarios can also be determined. Another advantage of DCEs is that they enable the relative importance of multiple aspects of health care to be assessed simultaneously. Thus DCEs may include health-related outcomes such as mortality rate, non-health related outcomes including elements of health care process such as type of treatment, cost of treatment, or a combination of these elements.

Despite their increasing prevalence and widespread utilisation in the health care sector, DCEs have rarely been utilised in subacute care with populations of older adults.² Previous work has suggested that patients' current state of health may influence their assessment of quality of care and what components of care are important to them.⁴⁹ The main aim of this study was to examine and compare the preferences of older adults currently receiving either outpatient rehabilitation or residential Transition Care following an acute event for alternative configurations of rehabilitation programs.

4.2 Methods

4.2.1 Scenario development / Experiment design

To ensure the scenarios and attributes included in the DCE task were relevant and appropriate, a range of methods were used to identify the characteristics of subacute rehabilitation that were deemed important by patients. Initially, a literature review was conducted using keywords and MESH headings pertaining to patient preferences, patient satisfaction, rehabilitation and older adults in order to ascertain factors that patients value during the process of receiving health care. Additionally, published studies on DCEs were also reviewed to gain insight into the number of attributes to be included so as to minimise the complexity of the task. The findings of the literature review were then used to develop five potential attributes and associated levels which were presented to a focus group of clinicians specialising in rehabilitation and gerontology. The purpose of this consultation was to receive feedback on the relevance of the attributes and levels based on their clinical experience interacting with, and providing subacute care to older adults.

After incorporating the feedback from the clinicians, a series of recorded semi-structured interviews (n=20) were conducted with older subacute rehabilitation recipients (aged 65 years and over). The patient sample was consulted to ascertain the aspects of subacute rehabilitation of importance to older adults participating in rehabilitation following an acute hospital admission, to check the realism and relevance of the attributes and levels, and to check understanding and completion rates. The respondents were asked to complete the DCE task using a “think aloud” approach which involved verbalizing their thought process to the interviewer while completing the task.

¹⁷¹ The interviews were then transcribed and examined to assess whether the

respondents understood the DCE task, were making considered rather than dominant choices and were relying on the information provided in the scenarios rather than being influenced by additional factors. Respondents were also asked whether there were any aspects of subacute rehabilitation that were important to them that had not been covered in the DCE task. This was to ensure that characteristics that were valued by patients were not overlooked. A final series of five attributes were then developed, each consisting of three levels as shown in table 4.1. This resulted in 243 possible scenarios for presentation in the form of hypothetical rehabilitation programs with varying attribute levels. This was reduced to a more manageable number for the purposes of valuation using a fractional factorial design and the techniques described in Street and Burgess, resulting in 18 binary choice sets which were 100% efficient for estimating the main effects.¹⁷² The 18 binary choice sets were divided into four blocks or versions, two of which contained four choice sets and two consisting of five choice sets to reduce the cognitive burden upon respondents. An example of a choice set is presented to respondents is shown in figure 4.1. A within-experiment reliability test was included within the experiment, whereby respondents were presented with the same choice set twice, once near the beginning of the DCE task and then again at the end.

Table 4.1 Attribute descriptions and levels of DCE task (continued over page)

Attribute	Description	Levels
Involvement	Family and patient involvement in the decision to move from hospital to the next destination e.g. returning home, moving to a nursing home	<p>None: Clinicians make the decision and the family and patient are informed afterwards</p> <p>Shared: The family and patient make a joint decision with the clinicians</p> <p>Total: The family and patient make their own decision to move without any involvement from the clinicians</p>
Medical History	How the patient's medical history is transferred between the health care professionals who are caring for them	<p>No record: No written record or verbal communication is received about the patient</p> <p>A written summary: A written summary of the patient's condition and current medications is received within one week of the patient being transferred</p> <p>Full electronic record: A full electronic record of the patient's health background, previous health care usage and past and current medications is automatically transferred with the client</p>

Attribute	Description	Levels
Intensity	Intensity of rehabilitation program	Once weekly therapy: Once weekly group therapy delivered by a physiotherapist only
		Twice weekly therapy: Twice weekly physiotherapy and occupational therapy is delivered individually by skilled health care professionals (e.g. physiotherapists, psychologists, occupational health therapists and trained care workers)
		Daily therapy: Daily physiotherapy and occupational therapy is delivered individually by skilled health care professionals (e.g. physiotherapists, psychologists, occupational health therapists and trained care workers)
Information	How the patient will get information about their health and treatment whilst receiving care	Only if the patient asks: Patient will get information from health care professionals if they ask them.
		Social worker and junior doctor: A meeting for the patient and a family member with a social worker and junior doctor
		Senior doctor and specialist nurse with follow-up and summary: A meeting between the patient and a family member with a senior doctor and a specialist aged care nurse. The patient will be given a written summary, and a recording of the meeting on CD. They will also receive a follow up meeting and phone call from the specialist aged care nurse

Attribute	Description	Levels
Therapy duration	Duration of rehabilitation therapy provided	<p>A set period of 2 weeks: The care will finish after a set period regardless of how well the patient is at that time.</p> <p>Decided by medical team: The patient's medical team (doctor, physiotherapist etc) tells them that there is no more to be gained from continuing the therapy.</p>
		<p>Until the patient thinks they are well: However long the patient needs to have therapy for until they think they are well again</p>

Figure 4.1. Example of a DCE choice set presented to study respondents

	Program A	Program B
Patient and family involvement in the decision to move from hospital to the next destination	None	Shared
How your medical history is transferred between the health care professionals who are caring for you	Full electronic record	A written record
Intensity of rehabilitation program	Twice weekly therapy	Daily therapy
How you will get information about your health and treatment whilst receiving care	Senior doctor and specialist aged care nurse with follow up and summary	Social worker and junior doctor
Duration of rehabilitation therapy provided	Decided by team	Until you think you are well

4.2.2 Data collection

Optimum sample sizes for DCEs cannot be determined exactly a priori because knowledge of the true probabilities or model parameters is required. However, it has been demonstrated that large sample properties can be achieved with a minimum of 20 respondents per block or version.¹⁷³ The study was conducted on a very limited budget and this unfortunately constrained the sample size. However care was taken to ensure that the sample size was targeted to exceed the minimum number of respondents needed to achieve large sample properties.

Respondents were recruited from an outpatient day rehabilitation program at the Repatriation General Hospital, a 300 bed acute care hospital in metropolitan Adelaide, South Australia, and a residential Transition Care facility providing rehabilitation-type care to people aged 65 and over. These two groups were selected as together they are broadly representative of the subacute population of older adults in South Australia. The two groups also represent a range of subacute patients' levels of functional independence with the Transition Care group generally being functionally more dependent than the outpatient day rehabilitation group. Respondents were eligible for inclusion if they were currently receiving subacute care in the form of either outpatient day rehabilitation or the residential Australian National Transition Care Program within three months of an acute hospital admission, were aged 65 years or over and had adequate cognitive functioning as defined by a Mini Mental State Examination (MMSE) score of 24 or above.¹⁷⁴ Respondents were also required to not have communication or comprehension difficulties such as dysphasia or difficulties speaking or understanding English as determined by their treating health care team.

The study sample was obtained sequentially over a 17 month period from August 2009 to January 2011. Admission lists were monitored weekly by research staff for new subacute care recipients who met the study inclusion criteria. Eligible older adults were approached whilst attending either the outpatient day rehabilitation unit or the residential Transitional Care facility by the same research staff and provided with verbal and written information about the study. Each individual who went on to participate in the study provided informed, written consent to do so. The respondents completed a face-to-face, interviewer administered questionnaire shown in appendix 3 approximately four weeks after commencing rehabilitation or Transition Care. The questionnaire consisted of three sections. Section A contained a series of attitudinal statements related to the attributes of the DCE regarding aspects of health care and rehabilitation services for older adults (e.g. communication and involvement in decision making) in which respondents, using a likert-type scale, indicated their level of agreement or disagreement with each statement. The statements were included as a warm up exercise to familiarise the participants with the topic and the attributes to be presented in the DCE. Section B contained the DCE task on preferences for alternative configurations of rehabilitation programs. Section C included measures of self-reported health status, the quality of transition between health settings and a series of socio-demographic questions. Section C included socio-demographic questions such as age, gender and education level, the ICECAP-O and the EQ-5D-3L.^{32, 63}

4.2.3 Data analysis

A random effects regression model within the software package STATA version 11¹⁷⁵ was estimated to analyse the influence of the five attributes on respondents' choices whereby the scenario chosen by the respondent, hypothetical program A or B, was the

binary dependent variable and the levels of each attribute were the explanatory variables. The attribute levels were dummy coded and the base levels were excluded from the regression model.¹⁷⁶ Statistical significance of the coefficient attached to a particular attribute level indicates the relative importance of the attribute level in influencing respondents' choices. A positive coefficient indicates that the attribute level was associated with increased utility, whilst a negative coefficient indicates that the attribute level was associated with a reduction in utility.

Respondents may exhibit dominant preferences when completing DCEs in which they appear to make choices between scenarios based upon a single attribute alone rather than trading between all the of attribute levels presented.¹⁷⁷ As these responses are not necessarily invalid, excluding them may result in sample selection bias and statistical inefficiency.¹⁷⁸ For this reason, respondents who displayed dominant preferences were identified, but not excluded from the analysis. Respondents who did not pass the within-experiment reliability test were excluded from the analysis.

Approval to conduct the study was obtained from the Southern Adelaide Health Service/Flinders University Human Research Ethics Committee.

4.3 Results

Of the 96 eligible older adults approached to participate in the study, 86 (90%) agreed to participate. These respondents had a mean age of 77 years (SD 7.38), with the residential Transition Care group slightly older than the outpatient rehabilitation group (mean 81 years, SD 6.49 and mean 75 years, SD 7.05 respectively). As a whole, high

levels of cognitive functioning were evident (mean 27.86, SD 1.84), with little difference between the two groups (Transition Care mean 28.00, SD 1.59; outpatient rehabilitation mean 27.78, SD 1.97). The Transition Care group had been receiving subacute care for a longer period than the outpatient rehabilitation group (mean 42 days, SD 20.58 and mean 33 days SD 16.23 respectively). Respondents were quite evenly split in terms of gender, however when aggregated by care type, although the outpatient rehabilitation group had similar numbers of male and female participants (males n= 30, 55%, females n=25, 45%), the Transition Care group had a less even split (males n=12, 39%, females n=19, 61%). While the majority of respondents in both groups reported receiving assistance from an informal carer, discrepancies emerged in regard to residential status. A clear majority of the Transition Care group were living alone (n=23, 74%), while the majority of the outpatient rehabilitation group were living with others (n=40, 73%). Differences were also noted in the diagnoses of respondents. Those receiving Transition care were most commonly receiving subacute care for an orthopaedic condition (n=18, 58%), the outpatient rehabilitation group were mostly receiving care for a neurological condition (n=30, 55%). The respondent characteristics are presented in table 5.1 in chapter 5 in which they are contrasted to a general population sample of older adults.

Of these 86 respondents, 80 individuals completed the DCE task, however eleven (14%) respondents failed the within experiment reliability test and were therefore excluded from the DCE data analysis. The findings presented in this chapter are based on the remaining 69 respondents who successfully completed the DCE task. The demographics of the included respondents are presented in table 4.2. The respondents who completed the DCE had a mean age of 77 years (SD 0.86) As with the demographics of the larger

sample, the Transition Care group were slightly older than the outpatient day rehabilitation group (mean age 80 [range 65-89] and 75 [range 66-92] respectively). At the time of interview, the Transition Care respondents had been receiving subacute care for a longer duration than the outpatient day rehabilitation respondents (mean days 41 [SD 20.78] and 34 [SD 16.58] respectively). The most common reason for receiving subacute care for the Transition Care group was orthopaedic diagnoses such as fractures (n=15, 56%), while neurological diagnoses such as stroke were the most common reason for the outpatient day rehabilitation group (n=24, 57%).

Table 4.2 DCE task respondent characteristics (continued over page)

Characteristic	Outpatient rehabilitation n=42	Residential Transition Care n=27	All participants n=69
Age (mean years, sd)	74.79 (6.63)	80.30 (6.59)	76.94 (0.86)
Cognition (mean MMSE score, sd)	28.17 (1.81)	28.11 (1.58)	28
Subacute care duration (mean days, sd)	33.88 (16.58)	41.15 (20.78)	37
<i>Gender</i>			
Male	20 (48%)	11 (41%)	31 (45%)
Female	22 (52%)	16 (59%)	38 (55%)
<i>Has an informal carer</i>			
Yes	28 (67%)	19 (70%)	47 (68%)
No	14 (33%)	8 (30%)	22 (32%)
<i>Residential Status</i>			
Living alone	10 (24%)	19 (70%)	29 (42%)
Living with others	32 (76%)	8 (30%)	40 (58%)
<i>Country of Birth</i>			
Australia	32 (76%)	22 (81%)	54 (78%)
Other	10 (24%)	5 (19%)	15 (22%)
<i>Highest Education</i>			
Primary or secondary	21 (50%)	18 (72%)	39 (58%)
Tertiary	21 (50%)	7 (28%)	28 (42%)
<i>Reason for subacute care</i>			
Neurological	24 (57%)	1 (4%)	27 (39%)
Orthopaedic	7 (17%)	15 (56%)	24 (35%)

Characteristic	Outpatient rehabilitation n=42	Residential Transition Care n=27	All participants n=69
Functional decline/falls/mobility	7 (17%)	7 (26%)	14 (20%)
Other	4 (10%)	4 (15%)	4 (5%)

The results of the random effects regression models are presented in table 4.3. Both the Transition Care and outpatient rehabilitation recipient samples demonstrated very strong preferences for the transfer of a full electronic medical record between health professionals caring for an older adult (coefficient 0.93, $p \leq 0.001$ and coefficient 0.79, $p \leq 0.001$ respectively). Very strong preferences were also shown by both samples for the medical team determining rehabilitation therapy duration (Transition Care coefficient 0.63, $p \leq 0.001$; rehabilitation coefficient 0.80, $p \leq 0.001$).

Table 4.3. Results of random effects probit regression model (DCE) by subacute care type

Attribute	Outpatient Rehabilitation (n=42)			Residential Transition Care (n=27)		
	<i>Coefficient</i>	<i>Standard Error</i>	<i>P Value</i>	<i>Coefficient</i>	<i>Standard Error</i>	<i>P Value</i>
Shared**	0.89	0.24	≤0.001	0.40	0.30	0.19
Total	0.36	0.20	0.08	0.32	0.26	0.22
Written†	0.33	0.19	0.07	0.59	0.23	0.01
Full** ††	0.79	0.19	≤0.001	0.93	0.29	≤0.001
Twice	0.18	0.19	0.35	0.01	0.24	0.99
Daily†	0.18	0.18	0.30	0.67	0.28	0.02
Junior	0.19	0.20	0.39	0.28	0.23	0.22
Specialist*†	0.62	0.25	0.01	1.03	0.37	0.01
Team** ††	0.80	0.19	≤0.001	0.63	0.20	≤0.001
You* †	0.50	0.19	0.01	0.55	0.23	0.02

Number of obs = 189
 Number of groups = 42
 Wald Chi2 (10) = 36.09
 Log likelihood = -94.22

Number of obs = 122
 Number of groups = 27
 Wald Chi2 (10) = 26.21
 Log likelihood = -58.48

* = Significant at the 5% level for outpatient rehabilitation group
 ** = Significant at the 0.1% level for outpatient rehabilitation group
 † = Significant at the 5% level for residential Transition Care group
 †† = Significant at the 0.1% level for residential Transition Care group

Both subacute care samples displayed a strong preference for older adults to receive information about their treatment and progress with a meeting with senior specialist staff (medical and nursing) with follow-up and a take-home audio recording of the meeting the most preferred level. The Transition Care respondents demonstrated a stronger preference for this particular attribute level than the rehabilitation respondents (coefficient 1.03, $p=0.01$ and coefficient 0.62, $p=0.01$ respectively). Additionally, the outpatient day rehabilitation respondents exhibited very strong preference for shared decision making with medical staff regarding the post-acute discharge destination (coefficient 0.89, $p\leq 0.001$).

The majority of respondents ($n=44$, 64%) displayed non-dominant preferences as shown in table 4.4, suggesting that most respondents were trading between all the attributes rather than making choices based on one or more particular attribute. However, the Transition Care respondents were more likely than the outpatient day rehabilitation respondents to exhibit dominant preferences ($n=12$, 44% and $n=13$, 31% respectively). The attribute most commonly associated with dominance for both groups was the use of an electronic medical record to transfer patients' medical history between the staff caring for them at different sites (rehabilitation: $n=5$, 12%; Transition Care: $n=5$, 19%).

Table 4.4. Dominant preferences for attributes

Attribute	Participants (n, %)		
	<i>Rehabilitation</i> <i>n=42</i>	<i>Transition Care</i> <i>n=27</i>	<i>All Participants</i> <i>n=69</i>
Involvement	1 (2%)	-	1 (1%)
History	5 (12%)	5 (19%)	10 (14%)
Intensity	4 (10%)	0	4 (5%)
Information	0	3 (11%)	3 (4%)
Duration	3 (7%)	4 (15%)	7 (10%)
No dominance	29 (69%)	15 (56%)	44 (64%)

The responses to the attitudinal statements are presented in table 4.5. The outpatient day rehabilitation respondents were more likely than the Transition Care respondents to strongly agree that older adults should be involved in decisions about their own future care wherever possible (n=28, 67% vs. n=12, 44%). A greater percentage of the day rehabilitation respondents also strongly agreed that an intensive rehabilitation program can make a substantial difference to older adults' functioning and quality of life (n=26, 62% vs. n=11, 41%). The responses of the rehabilitation sample were found to be very similar to those of the Transition Care sample for all of the remaining attitudinal statements.

Table 4.5 Responses to attitudinal statements about rehabilitation and health care for older adults (continued over page)

	Outpatient Rehabilitation (n=42)					Transition Care (n=27)				
	<i>Strongly Agree</i> n (%)	<i>Agree</i> n (%)	<i>Neither agree nor disagree</i> n (%)	<i>Disagree</i> n (%)	<i>Strongly Disagree</i> n (%)	<i>Strongly Agree</i> n (%)	<i>Agree</i> n (%)	<i>Neither agree nor disagree</i> n (%)	<i>Disagree</i> n (%)	<i>Strongly Disagree</i> n (%)
Older people should be involved in decisions about their own future care wherever possible	28 (67%)	14 (33%)	0	0	0	12 (44%)	14 (52%)	1 (4%)	0	0
An intensive rehabilitation program can make a substantial difference to older people's functioning and quality of life	26 (62%)	14 (33%)	2 (5%)	0	0	11 (41%)	14 (52%)	2 (7%)	0	0
The immediate family (rather than the older person) is best placed to make decisions about the older person's future care	5 (12%)	15 (36%)	6 (14%)	16 (38%)	0	4 (15%)	7 (26%)	7 (26%)	7 (26%)	2 (7%)

	Outpatient Rehabilitation (n=42)					Transition Care (n=27)				
	<i>Strongly Agree</i> <i>n (%)</i>	<i>Agree</i> <i>n (%)</i>	<i>Neither agree nor disagree</i> <i>n (%)</i>	<i>Disagree</i> <i>n (%)</i>	<i>Strongly Disagree</i> <i>n (%)</i>	<i>Strongly Agree</i> <i>n (%)</i>	<i>Agree</i> <i>n (%)</i>	<i>Neither agree nor disagree</i> <i>n (%)</i>	<i>Disagree</i> <i>n (%)</i>	<i>Strongly Disagree</i> <i>n (%)</i>
The development of self-confidence is a key ingredient in improving older people's functioning	21 (50%)	20 (48%)	1 (2%)	0	0	11 (41%)	14 (52%)	2 (7%)	0	0
The communication between health care professionals in different settings is poor (e.g. between hospitals and nursing homes or GPs)	7 (17%)	7 (17%)	11 (26%)	14 (33%)	3 (7%)	0	11 (41%)	8 (30%)	8 (30%)	0
The communication between health care professionals and the older person and their family is poor	3 (7%)	4 (10%)	5 (12%)	27 (64%)	3 (7%)	2 (7%)	4 (15%)	2 (7%)	16 (59%)	2 (7%)

	Outpatient Rehabilitation (n=42)					Transition Care (n=27)				
	<i>Strongly Agree</i> n (%)	<i>Agree</i> n (%)	<i>Neither agree nor disagree</i> n (%)	<i>Disagree</i> n (%)	<i>Strongly Disagree</i> n (%)	<i>Strongly Agree</i> n (%)	<i>Agree</i> n (%)	<i>Neither agree nor disagree</i> n (%)	<i>Disagree</i> n (%)	<i>Strongly Disagree</i> n (%)
The health care services an older person requires should be made available to them regardless of the costs to the health service	12 (29%)	22 (52%)	5 (12%)	3 (7%)	-	10 (37%)	12 (44%)	1 (4%)	3 (11%)	1 (4%)
Currently there aren't enough rehabilitation services available for the older people who need them	7 (17%)	14 (33%)	11 (26%)	10 (24%)	-	6 (22%)	11 (41%)	8 (30%)	2 (7%)	-
Currently there aren't enough nursing home beds for the older people who need them	11 (26%)	19 (45%)	10 (24%)	2 (5%)	-	7 (26%)	11 (41%)	9 (33%)	-	-

4.4 Discussion

This study aimed to examine and compare the preferences of older adults receiving subacute care in the form of either outpatient day rehabilitation and residential Transitional Care following an acute event for alternative configurations of rehabilitation programs. Although the two patient groups differed in terms of their clinical characteristics, the elements of service provision that defined quality of health care proved to be very similar for both groups. The high rates of completion and respondents' understanding provides support for the practicality and face validity of the DCE approach in an older population. The preferences demonstrated in the DCE results also generally corresponded with the opinions expressed in the attitudinal statements demonstrating a high degree of convergent validity. The outpatient rehabilitation and Transition Care recipients both prioritised continuity of care and communication as a key feature of high quality subacute care which is consistent with UK reports on the hospital experiences of older adults with multiple health problems.¹⁷⁹

The only marked difference between the samples related to shared decision making, with the outpatient day rehabilitation recipients expressing much stronger preferences overall to be involved in decisions about their own future care. A possible explanation for this may be that the rehabilitation group were further along their recovery trajectory and may have felt more confident in participating in decisions regarding their future care. A previous study into autonomy in older rehabilitation recipients in an acute care setting demonstrates that, as their recovery progressed; older acute health care recipients began to exert more independence and control and tended to participate more fully in decisions regarding their own health care.¹⁸⁰

Previous studies have suggested that communication with health providers and the provision of information are two key basic principles for defining quality health care, with the ability to motivate patients and positively influence their recovery.^{181, 182} This includes health professionals spending additional time with patients, giving them an opportunity to speak honestly and the provision of written information which can also be shared with the patient's family.¹⁸³ The findings from this study concur with this viewpoint; in general respondents exhibited strong preferences for communication with health providers and the provision of information.

Very strong preferences were also shown in both the outpatient rehabilitation and residential Transition Care groups for the use of electronic medical records, suggesting the importance of communication between health care professionals. An electronic record was not available in South Australia in either acute or subacute care settings at the time of the study, yet despite the respondents having had no exposure to the approach, it was deemed to be important. However at the time of the study the Australian government was planning to introduce a personally controlled electronic health record system, which has since been implemented, participants may have had some exposure to this concept via the media.¹⁸⁴ The importance of inter-professional communication was also noted by Westby during focus groups conducted with rehabilitation recipients, which revealed that poor communication between health care settings may negatively impact on patient satisfaction, clinical outcomes, and service coordination.¹⁸⁵ Eldar has also identified the interaction between multidisciplinary professionals as a potential influence on quality of care.⁴¹

It is important to note that this study was essentially exploratory in nature and was conducted using a relatively small sample size, meaning the results should potentially be interpreted with some caution. However, the study has provided important preliminary evidence demonstrating the practicality and validity of the application of DCE methodology to determine older adults' preferences regarding what constitutes quality in the delivery of health programs.

4.5 Conclusion

In summary, this chapter has built on the lack of DCE methodology utilisation in populations of older adults established in chapter 2. This chapter has examined the process of subacute from the patient perspective by ascertaining which features of rehabilitation programs are most highly valued by older adults.

Given the predicted increase in health services that will be required due to an ageing population, involving older adults in research which incorporates their views and preferences relating to the optimal configuration of health services is an increasingly important issue. Future research is required into the application of DCEs with larger and more diverse samples of older adults in different health and aged care settings to gain a deeper understanding of their preferences for quality care. The potential also exists for the future incorporation of DCEs into an economic evaluation framework, for assessing the cost effectiveness of health care interventions and services targeted for older adults. This would allow for the process utility resulting from receiving rehabilitation programs to be determined.

Chapter 5

**Outcomes of care for older adults: Quality of life
comparisons between a subacute patient sample
and the general population**

The previous chapters have established the importance of measuring process of care in subacute care settings for older adults, the purposes for which this is done and the extent to which this has been reported on in the literature to date. However as noted in chapters 1 and 3, the outcomes of care are also important and have been shown to have a relationship with the process of care. Chapter 5 focuses on the outcomes of care experienced by a sample of older adults receiving subacute outpatient day rehabilitation or residential Transition Care. The findings of an observational study are presented in which the health-related and capability-based quality of life of the subacute care sample were measured and compared with that of a general population sample. This chapter addresses the third and fourth research objectives, “to examine the outcomes of subacute care for older adults by measuring and valuing both HRQoL and non-health related quality of life” and “to measure and value the quality of life of a general population sample of older adults to enable comparisons with that of a subacute care population, and obtain normative data for use in future research studies”. The findings presented in this chapter formed the basis of the second and third publications displayed in appendix 4.^{186, 187}

5.1 Introduction

Quality of life is increasingly being recognized as an important outcome measure of health and social care interventions, often being captured alongside traditional clinical outcomes such as mortality or re-admission rates. With an increasing focus being placed on improving quality of life at older ages, the advantages of measuring quality of life from the patients’ own perspective using Patient Reported Outcome Measures (PROMs) are also being recognized.²⁹ Typically PROMs are comprised of two main components. The first is a descriptive system of questions in which patients themselves (as opposed

to others e.g. health professionals) assess their own health and/or health-related quality of life. The second component is a scoring algorithm to provide summary scores relating to particular dimensions and/or overall quality of life. PROMs may be either specific to a particular condition such as the Oxford Hip Score¹⁸⁸ and the St George's Respiratory Questionnaire,¹⁸⁹ or generic, designed for use across all types of patient populations such as the SF-36⁵⁸ and EQ-5D-3L,⁶³ two of the most commonly used PROMS internationally.

While the 'measurement' of quality of life involves the completion of a PROM, which provides summary scores relating to specific dimensions or overall quality of life, the 'valuation' of quality of life typically requires the use of a specific type of PROM, a preference-based instrument. These preference-based instruments consist of a descriptive system and a valuation algorithm that represents the general population's preferences for the health and/or quality of life states defined by the instrument. In the case of the EQ-5D-3L, the values derived from this algorithm can be incorporated into QALYs.

The EQ-5D-3L, shown in figure 5.1, is a generic measure of health status which has been widely used internationally in a variety of patient populations.⁶³ The instrument consists of five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension contains three levels of increasing severity. The scoring algorithm allows for the calculation of a single index value representing quality of life on the zero to one death full health QALY scale.⁶³ It is envisaged that the recent routine incorporation of the EQ-5D-3L into the United Kingdom's National Health Service will enable patient perspectives to be considered in regard to the measurement

and regulation the performance, safety and quality of health care providers and services and also assist patients to make informed choices about their treatment and health care.²⁹

Figure 5.1 The EQ-5D-3L instrument ²⁹

By placing a tick in one box in each group, please indicate which statement best describes your health today.

Mobility	
I have no problems in walking about	<input checked="" type="checkbox"/>
I have some problems in walking about	<input type="checkbox"/>
I am confined to bed	<input type="checkbox"/>
Self-care	
I have no problems with self-care	<input type="checkbox"/>
I have some problems with self-care	<input checked="" type="checkbox"/>
I am unable to wash or dress myself	<input type="checkbox"/>
Usual activities	
I have no problems with performing my usual activities	<input type="checkbox"/>
I have some problems with performing my usual activities	<input type="checkbox"/>
I am unable to perform my usual activities	<input checked="" type="checkbox"/>
Pain/discomfort	
I have no pain or discomfort	<input type="checkbox"/>
I have moderate pain or discomfort	<input type="checkbox"/>
I have extreme pain or discomfort	<input checked="" type="checkbox"/>
Anxiety/depression	
I am not anxious or depressed	<input checked="" type="checkbox"/>
I am moderately anxious or depressed	<input type="checkbox"/>
I am extremely anxious or depressed	<input type="checkbox"/>

However, a recent review article by Lorgelly and colleagues highlighted that the QALY, with its narrow focus upon health utility gains may be inadequate in capturing other outcomes which are important to quality of life.¹⁹⁰ The outcomes of many public health

interventions may extend beyond health to encompass quality of life more broadly where this is assumed to encompass the broad range of factors that are important to people throughout the course of their life. For example, the provision of independent living accommodation for older adults may promote feelings of security while maintaining independence thereby improving their quality of life. A focus on QALYs which encapsulate “health-related” quality of life impacts alone would likely underestimate the relative benefits of this and many other public health interventions when compared to health care interventions.

The multi-faceted nature of health and well-being is reflected in Sen’s capability theory which suggests that well-being should be measured not according to what individuals actually do (i.e. their functionings) but what they are able to do (i.e. their capabilities).¹⁹¹ The approach is therefore based on a view of living as a combination of various ‘doings and beings’, with quality of life to be assessed in terms of the capability to achieve valuable functionings.¹⁹⁰ An example of the distinction between functionings and capabilities is to compare two people who are starving, one due to fasting and one because food is unavailable. Both have the same level of functioning (they are both starving). However, one person has the capability to obtain food whilst the other does not. Their capabilities are therefore different; Sen argues that their relative capabilities provide the most useful information for assessing the impact of a policy.¹⁹²

Methods for measuring capabilities in practice remain underdeveloped. However, the recent development of the ICECAP-O has provided a mechanism for the measurement of capability at both patient group and population levels.³² The ICECAP-O measures quality of life based upon an individual’s capabilities and is designed to be applicable in

economic evaluation across sectors including health, social and aged care for clinical and community based interventions. The potential for the instrument to be applied in providing guidance on the effectiveness and cost effectiveness of public health interventions is currently being investigated by the instrument developers in the UK.¹⁹³ The ICECAP-O incorporates five attributes (attachment, security, role, enjoyment, control); each consisting of four levels (figure 5.2). For each attribute, respondents indicate which level they believe most closely corresponds to their life at present. The attributes were developed according to the findings of qualitative interviews with older adults focusing on aspects of their lives that they valued and derived the most enjoyment from.¹⁹⁴

The ICECAP-O is also amenable to valuation as it has a preference-based scoring algorithm attached to it, which generates a single index value, ranging from zero (no capability) to one (full capability), to be calculated for all possible capability states defined by the instrument.¹⁹⁴ A scoring algorithm based on the Australian general population has recently been developed.¹⁹⁵ It is this capacity for both the *measurement* and *valuation* of quality of life which enables the ICECAP-O to be placed in an economic evaluation framework for estimating the cost effectiveness of interventions across sectors, including its potential for application in estimating the effectiveness and cost effectiveness of public health interventions. As the ICEpop CAPability measure for Adults (ICECAP-A) had not yet been developed, with the developers' permission the ICECAP-O was applied in this study with adults of all ages.¹⁹⁶ The findings indicate that it was acceptable in this context. Now that the ICECAP-A is publically available however the substitution of the ICECAP-O with the ICECAP-A is beneficial as the latter instrument is applicable for all adults.

The application of the ICECAP-O in the context of public health research remains in its infancy. To the candidate's knowledge, this is one of the first studies internationally to examine its potential for the measurement and valuation of quality of life in a community general population sample.

Figure 5.2 The ICECAP-O index of capability

ABOUT YOUR QUALITY OF LIFE

By placing a tick (✓) in ONE box in EACH group below, please indicate which statement best describes your quality of life at the moment.

1. Love and Friendship

I can have all of the love and friendship that I want	<input type="checkbox"/>	4
I can have a lot of the love and friendship that I want	<input type="checkbox"/>	3
I can have a little of the love and friendship that I want	<input type="checkbox"/>	2
I cannot have any of the love and friendship that I want	<input type="checkbox"/>	1

2. Thinking about the future

I can think about the future without any concern	<input type="checkbox"/>	4
I can think about the future with only a little concern	<input type="checkbox"/>	3
I can only think about the future with some concern	<input type="checkbox"/>	2
I can only think about the future with a lot of concern	<input type="checkbox"/>	1

3. Doing things that make you feel valued

I am able to do all of the things that make me feel valued	<input type="checkbox"/>	4
I am able to do many of the things that make me feel valued	<input type="checkbox"/>	3
I am able to do a few of the things that make me feel valued	<input type="checkbox"/>	2
I am unable to do any of the things that make me feel valued	<input type="checkbox"/>	1

4. Enjoyment and pleasure

I can have all of the enjoyment and pleasure that I want	<input type="checkbox"/>	4
I can have a lot of the enjoyment and pleasure that I want	<input type="checkbox"/>	3
I can have a little of the enjoyment and pleasure that I want	<input type="checkbox"/>	2
I cannot have any of the enjoyment and pleasure that I want	<input type="checkbox"/>	1

5. Independence

I am able to be completely independent	<input type="checkbox"/>	4
I am able to be independent in many things	<input type="checkbox"/>	3
I am able to be independent in a few things	<input type="checkbox"/>	2
I am unable to be at all independent	<input type="checkbox"/>	1

**Tick
one
box
only in
each
section**

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A recent health policy report by the Kings Fund in the United Kingdom noted that the process of completing a PROM and the information obtained from it has the potential to influence decision making by patients, clinicians and health service managers.²⁹ The approach can assist in the monitoring of disease and treatment progression and may identify problems that have been overlooked by patients or clinicians.²⁹ Completion of such instruments may also enhance communication between patients and clinicians and promote shared-decision making and clarify the priorities of patients and clinicians in terms of disease effects and treatment options and possible outcomes.^{29, 197} Where PROMs are generic and preference-based they may also facilitate resource allocation decision-making through the framework of economic evaluation which enables clinicians and health service managers to assess efficiency in regard to patient outcomes, service delivery and resource use.²⁹

Whilst it is undoubtedly useful to measure and value the quality of life of clinical patient groups in this context, it is beneficial to understand the relationship between the quality of life of patients and the quality of life of the general population. Normative data from the general population can be used as a reference with which to compare the quality of life of patient populations to investigate the impact of ill-health and treatments.^{198, 199} Such comparisons can assist in the interpretation of patient values by putting them into context in regard to what is considered to be a typical value from the general population.²⁰⁰⁻²⁰² This also provides a benchmark against which patient quality of life can be compared at varying time points ranging from diagnosis to post-treatment. By examining how the quality of life of specific patient groups compare to the general population, comparisons can also be made between patients experiencing different

conditions and treatments, assisting in the allocation of resources based on the needs and health outcomes of each patient group.^{29, 79}

The aims of the studies presented here were twofold. Firstly, to empirically examine the quality of life of older adults receiving subacute care in the form of outpatient rehabilitation or residential Transition Care, measured in terms of health status and capabilities. The second aim was to compare the quality of life of this patient group with that of a general population sample

5.2 Methods

Data were collected from two separate study populations: the clinical patient sample comprising of older adults receiving subacute outpatient day rehabilitation or residential Transition Care (n=86) reported on in chapter 4 and a general population sample aged 65 years and over (n=789). The data from the two study populations were then pooled to facilitate empirical comparisons between the subacute and general population samples.

The EQ-5D-3L data for the general population sample were collected via an online panel of survey respondents throughout Australia between February and June 2009. Data for this were collected as part of a larger study exploring preferences around EQ-5D-3L and SF-6D health states.²⁰³ Responses for the EQ-5D-3L were received from 2,249 respondents, 385 of whom were aged 65 years and over and included in the analysis reported on here. Additionally, data were also collected on socio-demographic

characteristics including age, gender, area of residence, marital status, country of birth, education level, household income and employment status.

The ICECAP-O data for the general population sample was generated from the inclusion of the ICECAP-O in the 2009 Health Omnibus survey. In addition to the ICECAP-O, respondents also answered socio-demographic questions relating to factors such as age and gender. The survey is conducted annually in South Australia to collect statistics for use in the planning, implementation and monitoring of health-related projects.²⁰⁴ Five thousand, two hundred households were randomly chosen via a multi-stage systematic area sample. The majority of households selected, 74%, were located in metropolitan areas with the remaining 26% located in regional areas. One person aged 15 years or older was randomly selected from each household to participate in the Health Omnibus Survey, however only those aged 65 years and over were included in the analysis reported on here. The interviews were conducted as face-to-face interviews in the respondents' own homes.

As the data was collected as part of three different studies, the socio-economic characteristic questions differed between the datasets. Of the socio-demographic categories that were investigated in the general population samples, only those that were also collected for the subacute and general population samples are presented here.

Data were analysed using the statistical software package STATA.¹⁷⁵ Descriptive tests were conducted to summarise the responses to the ICECAP-O and EQ-5D-3L, and socio-demographic characteristics. Wilcoxon rank-sum tests and Krussal Wallis rank tests were performed to analyse associations between ICECAP-O values and categorical

variables. Both the ICECAP-O and the EQ-5D-3L were scored using the recently developed Australian general population algorithms.^{195, 205} The data were dichotomised as patients or general population and also analyzed according to age (65-79 years and 80+ years) and gender.

The study was approved by the Southern Adelaide Health Service / Flinders University Human Research Ethics Committee.

5.3 Working hypotheses

It was anticipated that the subacute care sample would exhibit lower values for both the EQ-5D-3L and ICECAP-O instruments reflecting lower levels of health-related and capability-based quality of life than the general population given that they were recovering from a recent acute episode of ill-health. A relationship was also expected between quality of life and the type of subacute care being received. It was anticipated that respondents receiving outpatient rehabilitation would have higher EQ-5D-3L and ICECAP-O values on average than the respondents receiving the Australian National Transition Care Program as they had returned to the community to live, whilst the Transition Care recipients were still requiring institutional care and assistance with activities of daily living.

5.4 Results

Table 5.1 presents the characteristics of both the subacute care and general population samples. As a whole, the general population sample (n=1174) had a mean age of 73 (SD

6.81). However when disaggregated into sub-groups, those who completed the ICECAP-O, (n=789, 67%) and those who completed the EQ-5D-3L (n=385, 33%), differences began to emerge. The respondents in the ICECAP-O sample were slightly older (mean age 75, SD 7.07) than those in the EQ-5D-3L sample (mean age 69, SD 4.24) to a level of statistical significance ($p \leq 0.001$), with a much larger proportion aged 80 years or over (ICECAP-O: n=222, 25%; EQ-5D-3L: n=12, 3%). In regard to gender, 58% (n=677) of respondents in the general population sample were female. The percentage of each gender was found to differ between the two sub-groups, with a larger difference evident in the ICECAP-O sample (males n=299, 38%; females n=4901, 62%) than the EQ-5D-3L sample (males n=198, 51%; females n=187, 49%). The final socio-demographic that data was collected on from both general population sub-groups was the highest educational qualification. The highest educational qualification most commonly reported by the general population sample was secondary school or tertiary education (n=499, 63%), followed by primary school (n=278, 35%). When separated into sub-groups, this trend continued in the ICECAP-O sample (n=499, 63%), however the opposite was evident in the EQ-5D-3L group, with primary school being the most reported educational qualification (n=365, 95%).

The socio-demographic characteristics of the subacute care recipients have previously been discussed in chapter 4. The subacute care recipients (n=86) were older than the general population sample (n=1174) with mean ages of 77 (SD 7.38) and 73 (SD 6.81) years respectively. Just over half of the patient group was female (n=44, 51%), while the general population sample was mostly male (n=198, 51%). The subacute care respondents had been receiving subacute care for a mean number of 36.10 days (SD

18.33) at the time of interview, with the most common diagnoses being neurological (n=31, 36%) and orthopaedic (n=27, 31%) conditions.

Table 5.1 ICECAP-O and EQ-5D-3L respondent characteristics ^a (continued over page)

Variable	Patients (n=86)			General population (n=1174)		
	<i>Outpatient rehabilitation</i> (n=55)	<i>Transition care</i> (n=31)	<i>Total</i> (n=86)	<i>EQ-5D-3L general population</i> (n=385)	<i>ICECAP-O general population</i> (n=789)	<i>Total general population</i> (n=1174)
Subacute care type ^b	55 (64%)	31 (36%)	86 (100%)	N/A	N/A	N/A
Subacute care duration (days) ^b (mean, SD)	32.85 (16.23)	41.87 (20.58)	36.10 (18.33)	N/A	N/A	N/A
Cognitive score (mean, SD) ^b	27.78 (1.97)	28.00 (1.59)	27.86 (1.84)	N/A	N/A	N/A
<i>Age</i>						
Mean (SD)	74.95 (7.05)	80.77 (6.49)	77.05 (7.38)	69.41 (4.24)	74.99 (7.07)	73.16 (6.81)
65-79 years	40 (73%)	13 (42%)	53 (62%)	373 (97%)	567 (72%)	940 (75%)
80 years and over	15 (27%)	18 (58%)	33 (38%)	12 (3%)	222 (28%)	234 (19%)
<i>Gender</i>						
Male	30 (55%)	12 (39%)	42 (49%)	198 (51%)	299 (38%)	497 (42%)
Female	25 (45%)	19 (61%)	44 (51%)	187 (49%)	490 (62%)	677 (58%)
<i>Country of birth</i> ^b						
Australia	41 (75%)	25 (81%)	66 (77%)	N/A	477 (60%)	477 (60%)

Variable	Patients (n=86)			General population (n=1174)		
	<i>Outpatient rehabilitation (n=55)</i>	<i>Transition care (n=31)</i>	<i>Total (n=86)</i>	<i>EQ-5D-3L general population (n=385)</i>	<i>ICECAP-O general population (n=789)</i>	<i>Total general population (n=1174)</i>
Other	14 (25%)	6 (19%)	20 (23%)	N/A	310 (39)	310 (39)
Not answered / missing data	0	0	0	N/A	0	0
<i>Residential status^b</i>						
Living alone	15 (27%)	23 (74%)	38 (44%)	N/A	383 (49%)	383 (49%)
Living with others	40 (73%)	8 (26%)	48 (56%)	N/A	406 (51%)	406 (51%)
<i>Has an informal carer^b</i>						
Yes	33 (60)	23 (74)	56 (65)	N/A	N/A	N/A
No	22 (40)	8 (26)	30 (35)	N/A	N/A	N/A
<i>Highest Qualification</i>						
Primary school	13 (23%)	14 (45)	27 (31)	365 (95%)	278 (35%)	278 (35%)
Secondary school &/or tertiary	41 (75%)	15 (48)	56 (65)	16 (4%)	499 (63%)	499 (63%)
Currently studying	0	0	0	0	10 (1%)	10 (1%)
No education	1 (2%)	0	1 (1%)	-0	2 (1%)	2 (1%)
Not answered / missing data	-0	2 (6%)	2 (2%)	-0	-0	-0

Variable	Patients (n=86)			General population (n=1174)		
	<i>Outpatient rehabilitation</i> (n=55)	<i>Transition care</i> (n=31)	<i>Total</i> (n=86)	<i>EQ-5D-3L general population</i> (n=385)	<i>ICECAP-O general population</i> (n=789)	<i>Total general population</i> (n=1174)
<i>Diagnosis</i> ^b						
Neurological	30 (55%)	1 (3%)	31 (36%)	N/A	N/A	N/A
Orthopaedic	9 (16%)	18 (58%)	27 (31%)	N/A	N/A	N/A
Functional decline/falls/mobility	10 (18%)	8 (26%)	18 (21%)	N/A	N/A	N/A
Other	6 (11%)	4 (13%)	10 (12%)	N/A	N/A	N/A
<i>Instrument scores</i> ^b						
EQ-5D-3L (mean, SD)	0.597 (0.19)	0.592 (0.21)	0.595 (0.20)	0.789 (0.19)	N/A	0.789 (0.19)
ICECAP-O (mean, SD)	0.765 (0.18)	0.731 (0.17)	0.753 (0.18)	N/A	0.795 (0.17)	0.795 (0.17)

^a Percentages do not equal 100 due to rounding

^b Data not collected for EQ-5D-3L and/or ICECAP-O general population sample

5.4.1 Health-related quality of life

Of the 86 older adults in the subacute care sample, two did not complete the EQ-5D-3L in its entirety, giving a completion rate of 98% (n=84) for this instrument. The distribution of responses to the EQ-5D-3L instrument are presented in table 5.2. While 62% of the general population sample (n=239) reported no limitations in mobility, only 21% (n=18) of the subacute care participants reported no difficulty in walking. In regard to self-care, 94% (n=363) of the general population indicated that they had no problems washing or dressing themselves compared with only 55% (n=46) of the subacute care group. The two groups also differed in their ability to perform usual activities. While 70% (n=271) of the general population sample stated that they had no problems performing their usual activities, this level was reported by only 18% (n=15) of the subacute care participants. However a similar number of participants in both groups reported experiencing either pain/discomfort, or anxiety/depression.

Table 5.2 Distribution of responses to the EQ-5D-3L instrument *

EQ-5D-3L Domains	Patients (n=84)	General Population (n=385)	Total (n=469)
<i>Mobility</i>			
I have no problems walking around	18 (21%)	239 (62%)	257 (55%)
I have some problems walking around	65 (77%)	146 (38%)	211 (45%)
I am confined to bed	1 (1%)	0	1 (0%)
<i>Self Care</i>			
I have no problems washing or dressing myself	46 (55%)	363 (94%)	409 (87%)
I have some problems washing or dressing myself	35 (42%)	21 (5%)	56 (12%)
I am unable to wash or dress myself	3 (4%)	1 (0%)	4 (1%)
<i>Usual Activities</i>			
I have no problems performing my usual activities	15 (18%)	271 (70%)	286 (61%)
I have some problems performing my usual activities	45 (54%)	109 (28%)	154 (33%)
I am unable to perform my usual activities	24 (29%)	5 (1%)	29 (6%)
<i>Pain or Discomfort</i>			
I have no pain or discomfort	30 (36%)	152 (39%)	182 (39%)
I have moderate pain or discomfort	45 (54%)	216 (56%)	261 (56%)
I have extreme pain or discomfort	9 (11%)	17 (4%)	26 (6%)
<i>Anxiety or Depression</i>			
I am not anxious or depressed	53 (63%)	278 (72%)	331 (71%)
I am moderately anxious or depressed	27 (32%)	98 (25%)	125 (27%)
I am extremely anxious or depressed	4 (5%)	9 (2%)	13 (3%)

* Percentages do not equal 100 due to rounding

As shown in table 5.1, the EQ-5D-3L values of the outpatient day rehabilitation respondents were higher than that demonstrated by the residential Transition Care respondents, but not to a level of statistical significance. In terms of the socio-demographic characteristics, the only statistically significant difference in EQ-5D-3L values was according to gender, with males reporting higher levels of health-related quality of life than females (mean 0.639, SD 0.21 and mean 0.553, SD 0.18, $p < 0.05$ respectively).

When comparing the subacute patients with the general population sample, as shown in table 5.3, the mean EQ-5D-3L value for the general population respondents was significantly higher than that of the subacute care respondents (general population: mean 0.789, SD 0.19; patients: mean 0.595, SD 0.20, $p \leq 0.001$). This trend continued when the scores were analysed by age. Members of the general population sample aged between 65 and 79 years scored significantly higher than the subacute care sample in the same age group (general population: mean 0.790, SD 0.19; patients: mean 0.594, SD 0.19, $p \leq 0.001$). Of the respondents aged 80 years and over, respondents from the general population exhibited higher EQ-5D-3L values than those in the subacute care population (general population: mean 0.762, SD 0.14; patients: mean 0.596, SD 0.21, $p < 0.05$).

Table 5.3. Mean EQ-5D-3L scores and tests of association between EQ-5D-3L values and key variables by group and age group

(continued over page)

Age Group	Characteristic	Patients (n=84)				General population (n=385)				
		Mean	Lower 95% CI	Upper 95% CI	N	Mean	Lower 95% CI	Upper 95% CI	N	Significance (p value)
65-79 years (n=790)	<i>Gender</i>									
	Male**	0.631	0.550	0.712	26	0.790	0.761	0.819	189	≤0.001
	Female**	0.558	0.486	0.629	26	0.790	0.763	0.817	184	≤0.001
	<i>Education</i>									
	Primary School*	0.648	0.573	0.723	14	0.793	0.773	0.814	355	0.006
	Secondary School/Tertiary	0.571	0.505	0.638	37	0.689	0.591	0.787	14	0.061
	Currently studying	-	-	-	0	-	-	-	0	-
No education	-	-	-	0	0.887	0.665	1.109	2	-	
	<i>Age Group Total**</i>	0.594	0.541	0.648	52	0.790	0.770	0.810	373	≤0.001

Age Group	Characteristic	Patients (n=84)				General population (n=385)				
		Mean	Lower 95% CI	Upper 95% CI	N	Mean	Lower 95% CI	Upper 95% CI	N	Significance (p value)
80+ years (n=45)	<i>Gender</i>									
	Male	0.653	0.529	0.778	15	0.761	0.635	0.887	9	0.266
	Female	0.545	0.444	0.647	17	0.764	0.613	0.915	3	0.030
	<i>Education</i>									
	Primary School*	0.565	0.431	0.698	13	0.744	0.661	0.826	10	0.026
	Secondary School/Tertiary	0.612	0.516	0.708	17	0.853	0.564	1.142	2	0.162
	Currently studying	-	-	-	0	-	-	-	0	-
No education	-	-	-	1	-	-	-	0	-	
	<i>Age Group total*</i>	0.596	0.519	0.673	32	0.762	0.671	0.852	12	0.012
All Participants (n=471)	<i>All Ages Total**</i>	0.595	0.552	0.638	84	0.789	0.770	0.808	385	≤0.001

* Significant difference between patients and general population at the 5% level

** Significant difference between patients and general population at the 0.1% level

Members of the general population aged between 65 and 79 years continued to demonstrate significantly higher EQ-5D-3L values than the subacute care respondents when analysed by gender. As shown in figures 5.3 and 5.4, male members of the general population sample had significantly higher scores than those in the subacute sample (general population: mean 0.790, SD 0.20; patients: mean 0.631, SD 0.20, $p \leq 0.001$), as did the females (general population: mean 0.790, SD 0.19; patients: mean 0.558, SD 0.18, $p \leq 0.001$). No significant difference was evident between the subacute care respondents and general population respondents according to gender in participants aged 80 years and over.

Figure 5.3 Mean EQ-5D-3L scores: males by age group

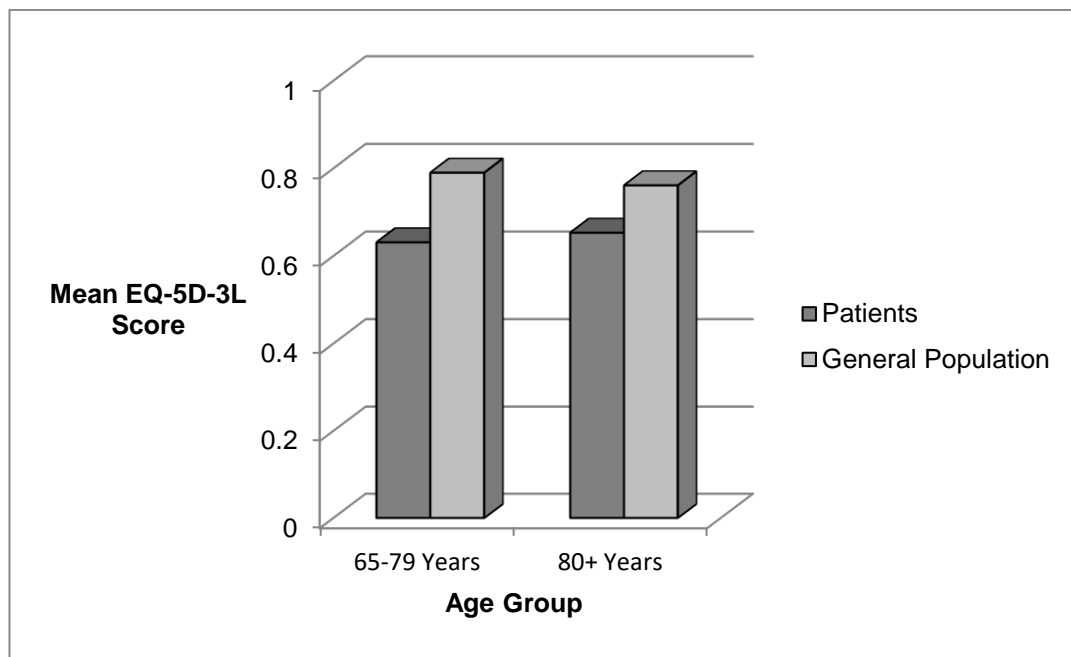
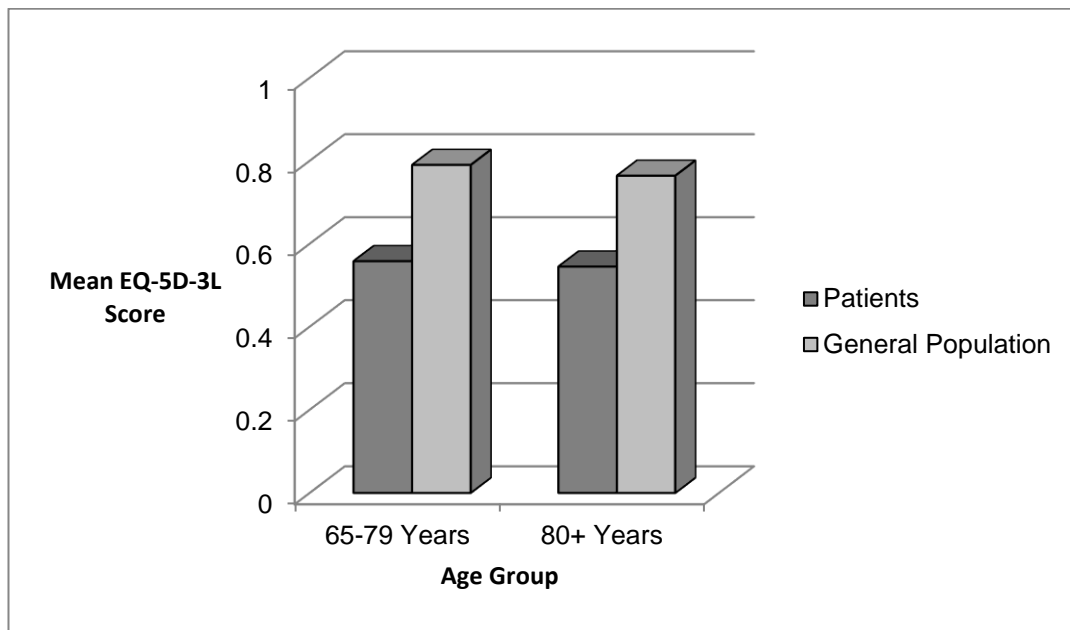


Figure 5.4 Mean EQ-5D-3L scores: females by age group



With respect to education level, the EQ-5D-3L values of both the subacute care and the general population samples differed. In both age groups, members of the general population who nominated primary school as being their highest educational qualification reported higher EQ-5D-3L values than the subacute care respondents with the same education level. The difference was more significant in the respondents aged 65 to 79 years (general population: mean 0.793, SD 0.19; patients: mean 0.648, SD 0.14, $p < 0.05$) than those aged 80 years and over (general population: mean 0.744, SD 0.13; patients: mean 0.565, SD 0.25, $p < 0.05$).

5.4.2 Capability-based quality of life

A total of four respondents had incomplete ICECAP-O data due to a refusal to answer particular questions or were unable to fully complete the interview giving a total useable response rate of 85% ($n=82$). The distribution of responses to the ICECAP-O is presented in table 5.4. A respondent was deemed to have a limitation in a particular

capability if they selected the second, third or fourth level for that particular question of the ICECAP-O instrument.

The results were found to be broadly similar across dimensions with the exception of the role (ability to do things that make an individual feel valued) and control (independence) dimensions. A smaller proportion of the subacute care recipient sample reported themselves in the highest two categories of the role dimension, indicating that they were able to do either all or many of the things that make them feel valued (patients: n=48, 59%; general population: n=610, 79%). In addition, 89% (n=684) of the general population reported being able to be either completely independent or independent in many things, compared with only 68% (n=56) of the subacute sample

Table 5.4 Distribution of responses to the ICECAP-O instrument * (continued over page)

	Outpatient rehabilitation (n=53)	Transition care (n=29)	All patients (n=82)	General Population (n=771)
<i>Attachment</i>				
I can have all of the love and friendship that I want	34 (64%)	13 (45%)	47 (57%)	448 (58%)
I can have some of the love and friendship that I want	13 (25%)	12 (42%)	25 (30%)	214 (28%)
I can have a little of the love and friendship that I want	5 (9%)	4 (14%)	9 (11%)	91 (12%)
I cannot have any of the love and friendship that I want	1 (2%)	0	1 (1%)	18 (2%)
<i>Security</i>				
I can think about the future without any concern	17 (32%)	14 (48%)	31 (38%)	229 (30%)
I can think about the future with only a little concern	21 (40%)	8 (28%)	29 (35%)	243 (32%)
I can only think about the future with some concern	9 (17%)	7 (24%)	16 (20%)	184 (24%)
I can only think about the future with a lot of concern	6 (11%)	0	6 (7%)	115 (15%)
<i>Role</i>				
I am able to do all of the things that make me feel valued	13 (25%)	7 (24%)	20 (24%)	296 (38%)
I am able to do many of the things that make me feel valued	20 (37%)	8 (28%)	28 (34%)	314 (41%)
I am able to do a few of the things that make me feel valued	15 (28%)	9 (31%)	24 (29%)	138 (18%)

	Outpatient rehabilitation (n=53)	Transition care (n=29)	All patients (n=82)	General Population (n=771)
I am unable to do any of the things that make me feel valued	5 (9%)	5 (17%)	10 (12%)	23 (3%)
<i>Enjoyment</i>				
I can have all of the enjoyment and pleasure that I want	18 (34%)	9 (31%)	27 (33%)	266 (35%)
I can have a lot of the enjoyment and pleasure that I want	22 (42%)	9 (31%)	31 (38%)	348 (45%)
I can have a little of the enjoyment and pleasure that I want	12 (23%)	9 (31%)	21 (26%)	139 (18%)
I cannot have any of the enjoyment and pleasure that I want	1 (2%)	2 (7%)	3 (4%)	18 (2%)
<i>Control</i>				
I am able to be completely independent	13 (25%)	2 (7%)	15 (18%)	380 (49%)
I am able to be independent in many things	25 (47%)	16 (55%)	41 (50%)	304 (39%)
I am able to be independent in a few things	13 (25%)	9 (31%)	22 (27%)	76 (10%)
I am unable to be at all independent	2 (4%)	2 (7%)	4 (5%)	11 (1%)

* Percentages do not equal 100 due to rounding

The general population sample exhibited higher ICECAP-O values on average than the subacute care sample (general population: mean 0.795, SD 0.17; patients: mean 0.753, SD 0.18), with the difference being statistically significant ($p = 0.023$). As predicted, the Transition Care respondents demonstrated lower levels of capability (mean 0.731, SD 0.17) than the rehabilitation respondents (mean 0.765 SD 0.18), although not to a statistically significant level.

Tests of association revealed no significant relationships between socio-demographic variables (age, gender and education) and the ICECAP-O values for the subacute care respondents according to care type (outpatient rehabilitation or Transition Care). However tests of association between the subacute and general population samples did reveal significant relationships. Table 5.5 shows the mean ICECAP-O scores for all participants and for sub-groups classified according to age. When disaggregated for age, the general population respondents aged 65 to 79 were found to have higher ICECAP-O values than the subacute care respondents in the same age group and the differences were statistically significant (general population: mean 0.809, SD 0.16; patients: mean 0.736, SD 0.17, $p < 0.05$). In contrast the difference in ICECAP-O values between the general population and subacute care respondents aged 80 years and over was much smaller and was not found to be statistically significant (general population: mean 0.759, SD 0.19; patients: mean 0.780, SD 0.20, $p = 0.370$).

Table 5.5 Mean ICECAP-O scores and tests of association between ICECAP-O values and key variables by group and age group

(continued over page)

Age Group	Socio-demographic Characteristics	Patients (n=82)				General population (n=771)				
		Mean	Lower 95% CI	Upper 95% CI	N	Mean	Lower 95% CI	Upper 95% CI	N	Significance (p value)
65-79 (n=605)	<i>Gender</i>									
	Male	0.794	0.730	0.858	25	0.807	0.783	0.830	217	0.328
	Female**	0.678	0.610	0.746	25	0.811	0.795	0.827	338	≤0.001
	<i>Education</i>									
	Primary School*	0.744	0.661	0.827	13	0.817	0.793	0.840	185	0.046
	Secondary School/Tertiary*	0.729	0.672	0.787	36	0.805	0.789	0.821	361	0.003
	Currently studying	-	-	-	0	0.839	0.804	0.874	9	-
No education	-	-	-	0	-	-	-	0	-	
	<i>Age Group Total*</i>	0.736	0.688	0.784	50	0.809	0.796	0.823	555	0.004

Age Group	Socio-demographic Characteristics	Patients (n=82)				General population (n=771)				
		Mean	Lower 95% CI	Upper 95% CI	N	Mean	Lower 95% CI	Upper 95% CI	N	Significance (p value)
80+ (n=248)	<i>Gender</i>									
	Male	0.780	0.661	0.899	16	0.764	0.721	0.807	72	0.445
	Female	0.779	0.693	0.866	16	0.757	0.725	0.789	144	0.672
	<i>Education</i>									
	Primary School	0.723	0.597	0.850	12	0.769	0.729	0.808	88	0.660
	Secondary School/Tertiary	0.803	0.722	0.883	18	0.753	0.720	0.787	127	0.305
	Currently studying	-	-	-	0	0.680	-	-	1	-
No education	0.910	-	-	1	-	-	-	0	-	
	<i>Age Group total</i>	0.780	0.710	0.849	32	0.759	0.734	0.785	216	0.370
All Participants (n=853)	<i>All Ages Total*</i>	0.753	0.714	0.792	82	0.795	0.783	0.807	771	0.023

* Significant difference between patients and general population at the 5% level

** Significant difference between patients and general population at the 0.1% level

When analysed according to gender, no significant difference was found between male subacute care respondents and male general population respondents in either age group as shown in figure 5.5. Although no significant differences were found between female subacute care respondents and female general population respondents aged 80 years and over, the difference in ICECAP-O values between female subacute care respondents and female general population respondents aged between 65 and 79 years was highly statistically significant. The general population were found to have higher scores than the subacute care respondents (general population: mean 0.811, SD 0.15; patients: mean 0.678, SD 0.16, $p \leq 0.001$), as shown in figure 5.6

Figure 5.5 Mean ICECAP-O scores: males by age group

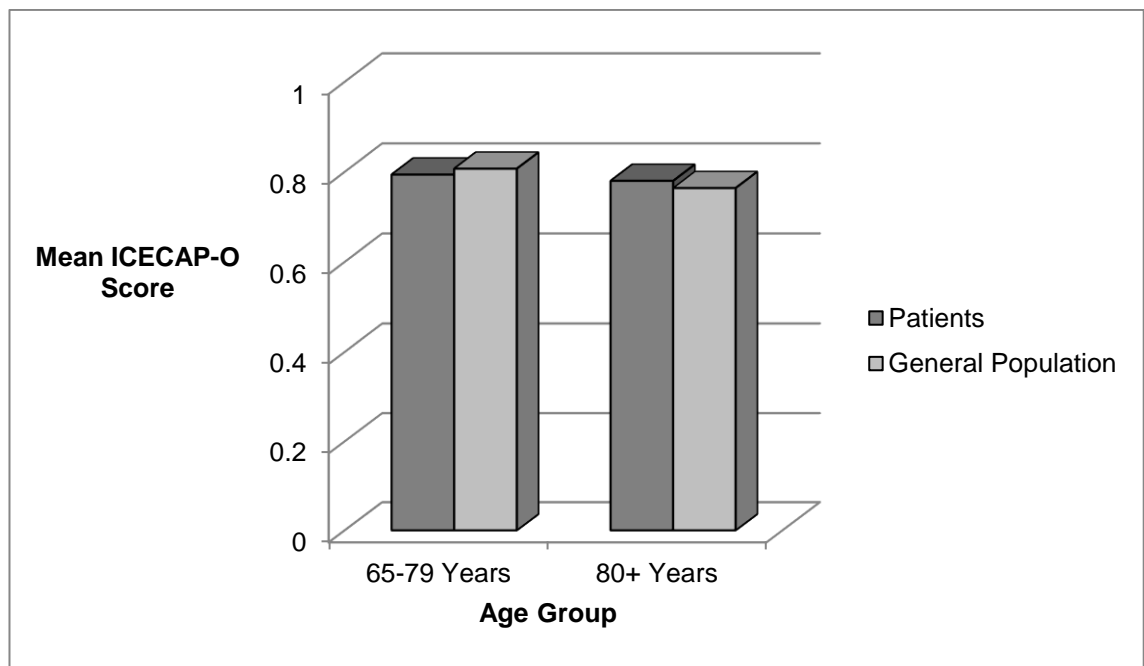
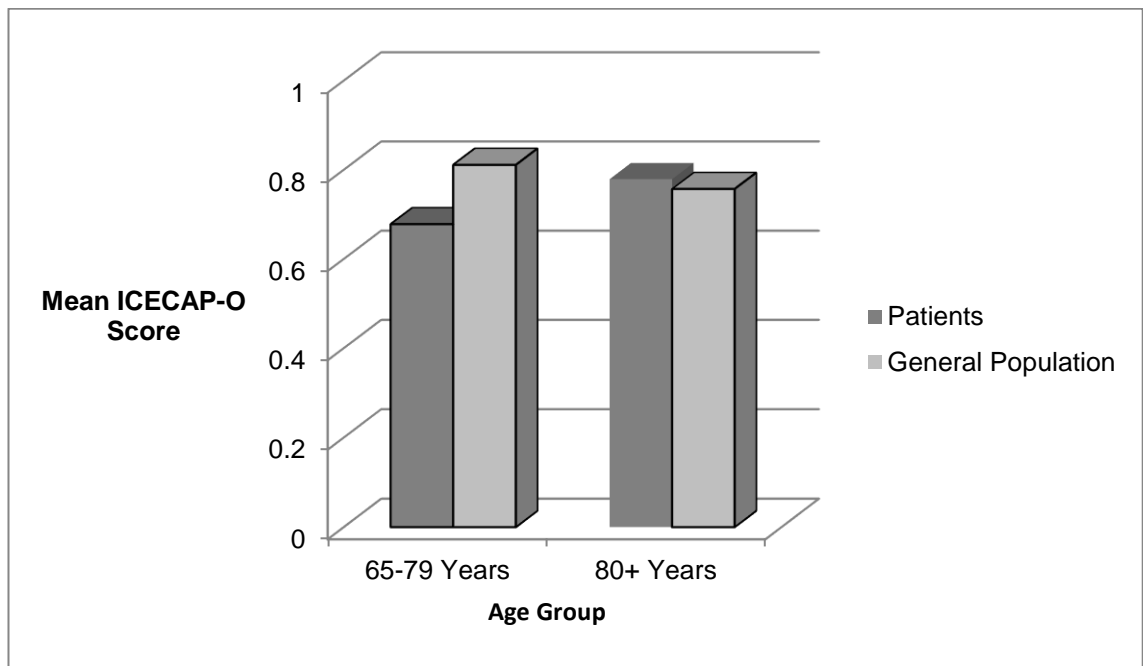


Figure 5.6 Mean ICECAP-O scores: females by age group



Education also proved important, as general population respondents aged between 65 and 79 with either primary school (general population: mean 0.817, SD 0.16; patients: mean 0.744, SD 0.15, $p \leq 0.05$) or secondary school/tertiary education (general population mean: 0.805, SD 0.16; patients 0.729, SD 0.18, $p < 0.05$) as their highest educational qualification exhibiting higher ICECAP-O values than the subacute care respondents with the same level of education. No significant association was evident for the older age group in regard to education.

5.4.3 Relationship between health-related and capability-based quality of life for older adults receiving subacute care

For older adults receiving subacute care, HRQoL and capability based quality of life were found to be positively associated when measured using the EQ-5D-3L and ICECAP-O respectively (spearman's $r = 0.426$; ≤ 0.001). This suggests that an increase in HRQoL may be accompanied by an increase in capability-based quality of life. The

relationship between these two forms of quality of life measurement was further supported by the highly significant association between the EQ-5D-3L and ICECAP-O values as shown in table 5.6.

When examined in greater detail, it became evident that while associations may exist between capability-based quality of life and *some* aspects of HRQoL, it was not associated with *all* aspects of HRQoL. Furthermore this influence differs in terms of the levels of significance across the domains. As shown in table 5.6, a highly significant association was evident between the ICECAP-O value and the EQ-5D-3L domain of usual activities ($p \leq 0.001$). While the EQ-5D-3L domain of self-care was also associated with the ICECAP-O value, the association was less significant ($p < 0.05$).

Similarly, HRQoL was found to be associated with *some*, but not *all* aspects of capability-based quality of life. As shown in table 5.6, the overall EQ-5D-3L values had a significant, positive associations with the ICECAP-O domains of security ($p \leq 0.05$), enjoyment ($p < 0.05$) and control ($p < 0.05$). Further to this, EQ-5D-3L mobility domain was significantly associated with the ICECAP-O domains of enjoyment and control ($p \leq 0.001$). The EQ-5D-3L domain of usual activities was strongly associated with the role and control domains of the ICECAP-O ($p \leq 0.001$). Lastly, the EQ-5D-3L self-care domain was associated with the ICECAP-O domains of role and control ($p < 0.05$).

Table 5.6 Tests of association (p values) between capabilities as measured by the ICECAP-O and EQ-5D-3L domains

EQ-5D-3L Domain	ICECAP-O Domain					Association with ICECAP-O tariff
	<i>Attachment</i>	<i>Security</i>	<i>Role</i>	<i>Enjoyment</i>	<i>Control</i>	
Mobility	0.377	0.127	0.784	≤0.001**	≤0.001**	0.067
Self-care	0.747	0.338	0.008*	0.106	0.002*	0.006*
Usual activities	0.640	0.583	≤0.001**	0.053	≤0.001**	≤0.001**
Pain/discomfort	0.096	0.127	0.539	0.109	0.272	0.891
Anxiety/depression	0.159	0.447	0.746	0.421	0.142	0.095
Overall value ^a	0.259	0.053*	0.202	0.006*	0.021*	≤0.001**

** Association is significant at the 0.1% level

* Association is significant at the 5% level

^a n=80, participants who completed both the EQ-5D-3L and ICECAP-O

5.5 Discussion

The findings reported here demonstrate a significant, positive relationship between quality of life when measured in terms of health and capability. As predicted, the subacute care recipients reported lower levels of HRQoL as measured by the EQ-5D-3L than the general population sample. Although the subacute care sample demonstrated lower levels of HRQoL than in another study of older adults, the respondents reported on here were older and recovering from an acute hospitalisation.²⁰⁶ The subacute care recipients were more likely than the general population sample to report experiencing

limitations in mobility, self-care and performing usual activities. These areas have previously been identified as aspects of life that may be influenced by acute illness for older adults.¹⁴³

Despite limitations in some domains of HRQoL differing between the subacute and general population samples, this was not the case for all of them. Little difference was evident between the groups in terms of the number of respondents reporting anxiety or depression, or pain or discomfort. This may potentially be attributed to the health care needs of the patient sample being addressed by the provision of subacute care. In contrast, the general population sample may not be accessing health services in relation to these issues meaning the problems may remain undetected and/or untreated and impacting on the respondents' HRQoL. Other studies have also found some, but not all domains of HRQoL to differ between patients and the general population.^{198, 199, 207, 208} Funk and colleagues demonstrated the quality of life experienced by pre-treatment head and neck cancer patients to be significantly lower than that of the general aged matched population US norms for the mental health dimension of the SF-36 only.¹⁹⁸ In comparison, Lindh and colleagues found older polyneuropathy patients to be more likely to report difficulties in the mobility, usual activity and pain/discomfort domains of the EQ-5D-3L than members of the general population, with the self-care and anxiety and depression dimensions being largely unaffected.¹⁹⁹ The same patient group was also significantly more likely to score lower on the general health and vitality domains of the SF-36, with male patients also more likely to score lower on the physical functioning, role-physical and bodily pain domains than the general population.¹⁹⁹

As hypothesized, capability was higher in older members of the general population than the subacute care sample. These differences were broadly consistent when the data were disaggregated according to age and gender sub-group classifications. Subacute care recipients were more likely than the general population to report limitations relating to, role, thinking about the future and independence, highlighting areas which may be affected by an acute illness in older adults.

The absence of a relationship between the capability-based quality of life and socio-demographic characteristics of the subacute care sample is in contrast to the findings of Coast and colleagues who found a strong association between capability and age.²⁰⁶ However those findings were based upon members of the United Kingdom general population, while this study focused on older Australian sample who were recovering from a recent acute illness.

It is important to note that the difference in capability-based quality of life between subacute care recipients and the general population was smaller than the difference in HRQoL. It may be that the subacute care being provided to the patient sample was having a larger impact on their capability than HRQoL, increasing the patient sample's levels of capability to a level that is closer that experienced by the general population. For example, the receipt of subacute care and consequent regular contact with health professionals may have increased the subacute care respondents' feelings of support, safety and security with the knowledge that assistance was available to them if needed. In contrast, members of the general population may not have had this reassurance or know where to obtain assistance in these areas if required. This difference in capability-based quality of life between the subacute care and general population samples and the

difference in HRQoL could also be attributed to the differences in the instruments used. While the EQ-5D-3L focuses on quality of life as determined solely by an individual's self-rated health the ICECAP-O addresses quality of life in a broader sense, relating to an individual's capabilities. Previous work comparing the EQ-5D-3L and ICECAP-O has suggested that these instruments be applied simultaneously as they each address unique aspects of quality of life, therefore providing complimentary information.²⁰⁹

These differences may also be due to the wider range of values produced by the EQ-5D-3L valuation algorithm, including negative values. The EQ-5D-3L values produced from the Australian scoring algorithm range from -0.217, corresponding to the most severe health state, through to 1.00 which pertains to full health. In comparison, the patient EQ-5D-3L values obtained in this study ranged from 0.08 to 1.00 (IQR 0.52-0.71, median 0.62). This suggests that although no values were at the lowest end of the scale, no basement or ceiling effects were evident. The general population EQ-5D-3L values were less evenly distributed along the theoretical range. The values ranged from 0.008 to 1.0 (IQR 0.71-1.00, median 0.80). This indicates a large portion of respondents were in a state equivalent to full health, with values at the maximum end of the scale.

In contrast, the values produced from the ICECAP-O Australian scoring algorithm range from zero to one. Although no patient respondents reported having no capability, some values were at the lower end of the scale, ranging from 0.28, through to 1.00, indicating full capability. The respondents' values were clustered towards the higher ~~not clustered at either~~ end of the scale, (IQR 0.68-0.88, median 0.80). The general population's values covered the entire scale, from 0.00 through to 1.00 (IQR 0.72-0.91,

median 0.84). As with the patient sample, the general population's values were clustered toward the higher end of the scale.

The mode of administration may also account for the difference in the range of HRQoL and capability based quality of life in the general population. Respondents may have been more hesitant to admit to limitations in particular domains such as love and friendship in the interviewer administered ICECAP-O compared to the EQ-5D-3L which was self-completed in an online format. However it is also possible that the clinical and general population samples reflected in this study simply differed more in terms of their health and HRQoL than their capability and quality of life in its broadest sense.

Despite these findings, some limitations of the study must be noted. It is difficult to make direct comparisons between the data presented here and that derived from previous studies as the ICECAP-O and EQ-5D-3L were scored using Australian algorithms in this study, while the other studies referred to applied the United Kingdom-developed scoring algorithm. Further to this, new Australian weights for the EQ-5D-3L have since been developed using a DCE approach since the conduction of the research presented here, which applied an algorithm based upon weights derived from a TTO approach.²¹⁰ While correlation between DCE and TTO-derived utility weights has been demonstrated, when compared, the DCE-derived weights provide a greater range of values than those obtained using TTO, with the DCE-based weights assigning higher scores to mild states and lower scores to worse states.²¹⁰ Therefore, it must be considered that the application of the newly derived DCE-based weights may have resulted in differing EQ-5D-3L scores, a wider range of EQ-5D-3L scores and

potentially a difference in the strength of the association between HRQoL and capability-based quality of life for the population studied here.

Due to the opportunistic sampling approach, although a range of socio-demographic data was collected within each of the study samples, few were common to both samples. This therefore limited the number of socio-demographic variables that could be included in the analysis. Further examination of the interaction between socio-demographic characteristics and HRQoL would benefit from the inclusion of factors such as residential status, country of birth and socio-economic details.

Additionally, the subacute care recipient sample that was used in this study was relatively small. It would be advantageous for future work to include larger samples of subacute older patients from other clinical populations, in addition to the measurement and valuation of HRQoL longitudinally at multiple time points rather than at a single time point as was performed here. Doing so would enable the re-test reliability of the ICECAP-O and its sensitivity to change over time to be established, and for the change in health-related quality of life over the patient trajectory from initial diagnosis to post-treatment to be examined, providing information useful in the planning and provision of health and social care services to older adults.

5.6 Conclusion

This chapter has built on chapter 2, which established not only the importance of measuring health outcomes from the patient perspective, but the extent to which this has been done in older adults receiving subacute care. The findings presented here

demonstrated the quality of life reported by older adults receiving subacute care to be lower than that of the older members of the general population. This disparity was evident regardless of whether quality of life was measured in terms of health or capability. However the difference was more prominent in HRQoL, highlighting the differences between the ICECAP-O and EQ-5D-3L, and the theoretical basis from which they were drawn. Additionally, particular aspects of quality of life were found to be affected, or be areas of greater concern to older adults receiving subacute care than older adults in the general population, suggesting that ill-health may be more influential on particular elements of quality of life than others.

Chapter 6

Transition between health care settings and quality of life: The relationship between process and outcomes of subacute health care

Chapter 5 reported on the measurement of health care outcomes based upon quality of life, measured in terms of both capability and health status. This chapter will focus on the association between processes and outcomes of care by examining the relationship between quality of life and the quality of transition between health care services.

Chapter 6 will address the fifth research objective, “to examine the relationship between the process and outcomes of subacute care for older adults by examining the association between quality of life and the quality of transition between care settings.” The findings presented in this chapter formed the basis of the fourth publication displayed in appendix 4.²¹¹

6.1. Introduction

The relationship between the process and outcomes of health care have been well documented, as have their place in the assessment of quality in health care. When examined separately, these concepts provide insight into the quality of the act of providing care and the effects of this care provision. However when these concepts are examined in conjunction with each other, an understanding of the overall quality of the care being provided can be developed. While Donabedian’s theoretical model of quality in health care establishes a causal relationship between the structure, process and outcomes of care, this relationship is not necessarily direct or uniform. It is therefore advantageous to measure both the process and outcomes of health care.^{26, 27, 30}

Chapter 4 presented one example of examining the process of health care provision by investigating patient preferences for care using a DCE methodology. Another element of the process of care that has recently been described as of importance in examining

the relationship between the process and outcomes of care is the quality of patients' transition between settings, for example moving from an acute health service to a subacute setting, or being discharged back into the community. This area is particularly pertinent to older Australian adults, who when compared with other age groups, tend to move more frequently between different health and aged care settings and tend to consume a disproportionate percentage of health care resources.¹³ During a period of ill-health, it is likely that older adults will receive care in multiple sites. A recent study of 920 community-dwelling older adults who were discharged from hospital to a subacute care facility demonstrated that almost half underwent four or more care transitions over the following 12 month period.⁵¹ For example during the acute period following a fractured hip, an older adult may receive care from orthopedic surgeons, and hospital-based medical practitioners, nurses and allied health staff. Following this, they may be treated by physicians, nurses and allied health staff in a subacute care setting such as an outpatient rehabilitation clinic, followed by nurses, personal care staff and allied health staff who provide community home care.⁵¹ However the receipt of multidisciplinary care in numerous settings, which is often not coordinated, and often for increasingly short periods, has the potential to put older adults at risk of care that is both fragmented and poorly executed.⁵² In order to assist older adult patients to achieve the maximum possible recovery, it is vital for the transition between care settings to be as seamless as possible.⁵¹

Despite multidisciplinary health care teams working towards shared goals, individual roles may be poorly defined due to staff working in different sites.⁵² Further to this, the successful transfer of patients from one setting to another is sometimes made more difficult due to health care staff being unfamiliar with the area of medicine that a patient

is being transferred to, and the capacity for care that will be available, resulting in inappropriate care transitions.²¹² A common outcome of this is the incomplete or inaccurate transfer of information regarding patients' medication regimen, health care needs and recovery goals. This is heightened by the fact that health care providers may not receive feedback relating to the outcomes of these care transitions.^{51, 52}

Quantitative studies have demonstrated that poorly executed care transitions can impact both the quality of care received and patient safety due to a variety of factors.⁵³ These include poor clinical outcomes, medication errors, incomplete or inaccurate information being transferred, unstable vital signs, service duplication and the provision or recommendation of inappropriate care. This is especially dangerous for older adult patients who often experience complex comorbid conditions and may have anxiety, pain, delirium or functional loss during the period of transition between care settings.⁵²⁻

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Patients' families, or informal caregivers, also report experiencing negative impacts due to poor transitions between health settings. With patients and their families often being the only common thread among the various health services providing care, the responsibility of coordinating the older adult's care may fall to them regardless of whether they possess the required confidence or skills to do so.⁵¹ This is exacerbated by the fact that the transition of older adults between health care environments is often in response to a new diagnosis, exacerbation of a chronic condition or change in functional status, meaning the transfer is often unplanned or urgent in nature.^{55, 213} Previous research involving focus groups and satisfaction questionnaires has shown that patients and their families have experienced anxiety due to feeling unprepared regarding the

transfer between settings, what to expect and how to respond to the patient's altered needs such as self-care. Patients and their families have also reported feeling abandoned due to not being able to contact appropriate health professionals for guidance, and feeling that their preferences were not taken into consideration and that they were not able to have input into the design of the care plan that was developed.^{51, 55, 213}

Unfortunately the impact of fragmented care resulting from poorly executed care transition is not limited to patients and their families, with health services also being affected. For example, the provision of duplicate tests and treatment results in higher costs of care, as does rehospitalisation and emergency department use which may have been avoidable with the provision of an adequate transition from inpatient care to other forms of care.^{52, 213} Additionally, fragmented care makes it difficult to trace responsibility when issues or mistakes arise. Further to this, lapses in the quality of care transitions places health care services at risk of patient complaints, negative publicity and litigation, all of which require time and resources to be dealt with.^{212, 213}

Although the area of Transition Care has previously remained under-investigated, recent research has enhanced the area's position to one of priority. Improving the transition of older adults between health care settings has recently gained recognition as being an area of importance to health policy makers as part of the overall strategy to meet the growing health care needs of an aging population.^{13, 52} It has been identified that the success of care transitions could be enhanced by a shift from care being institution-centred to patient-centred. Along with increased accountability, improvements in interdisciplinary communication and collaboration among health professionals working both within the same setting, and across different services would be beneficial to

promote the effective transition of older adults between health care environments.⁵²

However given that the patients themselves, and their families, are sometimes the only common link between the multitude of health professionals and services caring for an older adult it is vital that any endeavour to improve transitions in care incorporates the experiences and views of both patients and their families.⁵²

The aims of this study were to empirically examine, from the patient perspective, the relationship between quality of life and the quality of care transition in adults aged 65 and over whom were participating in outpatient day rehabilitation or receiving residential Transition Care utilising the CTM-3, EQ-5D-3L and the newly developed ICECAP-O instrument.

6.2 Methods

Data were collected from the clinical patient sample reported on in chapters 4 and 5 which was comprised of older adults receiving subacute outpatient day rehabilitation or residential Transition Care (n=86)

In addition to the ICECAP-O and EQ-5D-3L as discussed in chapter 5, respondents were also asked to complete the CTM-3, shown in figure 6.1. This instrument was designed to measure the quality of transitions between health care settings from the older patient's perspective. This can then be used in the evaluation of health service performance.⁵⁶ The instrument covers three domains: whether the patient understood what they were responsible for in managing their health, the purpose of their medications and whether their preferences and, those of their family, were taken into

consideration. Individual responses to the CTM-3 were used to calculate a score ranging from zero to 100, with higher scores indicating higher quality transitions.⁵⁰ The instrument has been used internationally by organisations involved in health care delivery, quality improvement and research.⁵⁰

Figure 6.1 The CTM-3 instrument ⁵⁰

CARE TRANSITIONS MEASURE® (CTM-3)				
Patient Name: _____		Date: _____		
1. The hospital staff took my preferences and those of my family or caregiver into account in deciding <i>what</i> my health care needs would be when I left the hospital.				
Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable
2. When I left the hospital, I had a good understanding of the things I was responsible for in managing my health.				
Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable
3. When I left the hospital, I clearly understood the purpose for taking each of my medications.				
Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/ Don't Remember/ Not Applicable

The data were analysed using the software package STATA.¹⁷⁵ Continuous measures included characteristics such as age, duration of subacute care, cognition and scores from the ICECAP-O, EQ-5D-3L and CTM-3 instruments. The categorical measures that were examined included the diagnoses, country of birth, residential status, education level and the domains of the previously mentioned instruments. The calculation of frequencies and means along with measures of dispersion and variability (standard deviation and range) were used to provide a summary of respondents' demographical characteristics. Spearman's rho was used to examine the association between continuous variables and chi-squared tests, Wilcoxon rank-sum and Kruskal-Wallis rank tests were performed to assess the associations between categorical variables.

The study was approved by the Southern Adelaide Health Service / Flinders University Human Research Ethics Committee and the South Australia Department of Health Ethics committee.

6.3 Working hypothesis

It was anticipated that there may be a positive relationship between the quality of care transitions and quality of life, with those individuals who scored more highly on the CTM-3 exhibiting higher levels of quality of life according to the ICECAP-O and EQ-5D-3L.

6.4 Results

6.4.1 Respondent Characteristics

The characteristics of the respondents are presented in table 6.1. All 86 respondents completed all three questions in the CTM-3 instrument. Of those, four respondents had incomplete ICECAP-O and/or EQ-5D-3L data due to a refusal to answer particular questions or were unable to fully complete the interview.

Table 6.1 CTM-3 respondent characteristics ^a (continued over page)

Variable	Participants (n=86)		
	<i>Outpatient rehabilitation</i> (n=55)	<i>Transition care</i> (n=31)	<i>Total</i> (n=86)
Age (mean, SD)	74.95 (70.5)	80.77 (6.49)	77.04 (7.37)
Cognitive score (mean, SD)	27.78 (1.97)	28.00 (1.59)	27.86 (1.84)
Subacute care duration (days) (mean, SD)	32.85 (16.23)	41.87 (20.58)	36.10 (18.33)
<i>Gender</i>			
Male	30 (55%)	12 (39%)	42 (49%)
Female	25 (45%)	19 (61%)	44 (51%)
<i>Country of birth</i>			
Australia	41 (75%)	25 (81%)	66 (77%)
Other	14 (26%)	6 (19%)	20 (23%)
<i>Residential status</i>			
Living alone	15 (27%)	23 (74%)	38 (44%)
Living with others	40 (73%)	8 (26%)	48 (56%)
<i>Has an informal carer</i>			
Yes	33 (60%)	23 (74%)	56 (65%)
No	22 (40%)	8 (26%)	30 (35%)
<i>Highest qualification</i>			
Primary school	13 (23%)	14 (45%)	27 (31%)
Secondary School/Tertiary	41 (75%)	15 (48%)	56 (65%)
No education	1 (2%)	0	1 (1%)
Not answered / missing data	0	2 (6)	2 (2)
<i>Diagnosis</i>			
Neurological	30 (55%)	1 (3%)	31 (36%)
Orthopaedic	9 (16%)	18 (58%)	27 (31%)
Functional decline/falls/mobility	10 (18%)	8 (26%)	18 (21%)
Other	6 (11%)	4 (13%)	10 (12%)

Variable	Participants (n=86)		
	<i>Outpatient rehabilitation</i> (n=55)	<i>Transition care</i> (n=31)	<i>Total</i> (n=86)
<i>Instrument scores</i>			
ICECAP-O (mean, SD) ^b	0.765 (0.18)	0.731 (0.17)	0.753 (0.18)
EQ-5D-3L (mean, SD) ^c	0.597 (0.19)	0.592 (0.21)	0.595 (0.20)
CTM-3 (mean, SD) [*]	75.45 (16.55)	63.44 (17.14)	71.12 (17.65)

^a Percentages do not equal 100 due to rounding

^b n=82

^c n=84

^{*} Significant difference between patient groups at the 5% level

6.4.2 Quality of life

As discussed in chapter 5, the quality of life demonstrated by the respondents was generally high when measured using the ICECAP-O (mean 0.753, SD 0.18) and EQ-5D-3L (0.595, SD 0.02). Although the outpatient day rehabilitation sample exhibited higher levels of quality of life when measured both in terms of health (rehabilitation: mean 0.597, SD 0.19; Transition Care: mean 0.592, SD 0.21) and capability (rehabilitation: mean 0.82, SD 0.15; Transition Care: mean 0.79, SD 0.16), neither of these were to a level of statistical significance

6.4.3 Quality of care transitions

The mean CTM-3 score for the total sample (n=86) was 71.12 (SD 17.65). The mean score of the rehabilitation respondents (mean 75.45, SD 16.55, n=55) was higher than that of the Transition Care respondents (mean 63.44, SD 17.14) to a level that was statistically significant ($p < 0.05$), as shown in table 6.1. The CTM-3 scores differed

according to a range of socio-demographic factors. Respondents who were aged 65-79 years had statistically higher CTM-3 scores than those aged 80 years and over to a level of statistical significance (mean 74.42, SD 16.64 and mean 65.82, SD 18.17 respectively, $p \leq 0.05$). Residential status also proved to be influential, with respondents who lived with others exhibiting significantly higher CTM-3 scores than those who lived alone (mean 75.46, SD 17.41 and mean 65.46, SD 16.58 respectively, $p < 0.05$). Respondents who reported not having an informal carer demonstrated higher CTM-3 scores (mean 77.22, SD 15.74) than those who received assistance from an informal carer (mean 67.86, SD 17.88) to a level of statistical significance ($p < 0.05$). Country of birth was also influential. CTM-3 scores were higher in respondents who were born in Australia (mean 73.57, SD 17.84) than those born in other countries (mean 63.06, SD 14.67) to a level that was statistically significant ($p < 0.05$).

Table 6.2 presents the distribution of responses to the CTM-3 instrument. The majority of respondents ($n=57$, 67%) either agreed or strongly agreed that their preferences were taken into account in regard to what their health care needs would be once leaving hospital. The majority ($n=70$, 82%) also agreed or strongly agreed that they had a good understanding of the things they were responsible for in managing their health. Finally, most participants ($n=74$, 86%) indicated that, upon hospital discharge, they understood the purpose for taking their medications. However it is important to note that, for each of the three questions, the percentage of participants who strongly agreed with the statement was higher in the outpatient day rehabilitation group than the residential Transition Care recipients.

Table 6.2 Distribution of responses to the CTM-3 instrument

CTM-3 Domains	Outpatient Transition		Total (n = 86)
	Rehab (n = 55)	Care (n = 31)	
<i>The hospital staff took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left the hospital</i>			
Strongly disagree	1 (2%)	1 (3%)	2 (2%)
Disagree	9 (16%)	7 (23%)	16 (19%)
Agree	26 (47%)	14 (45%)	40 (47%)
Strongly agree	14 (25%)	3 (10%)	17 (20%)
Don't know/not applicable	5 (9%)	6 (19%)	11 (13%)
<i>When I left the hospital I had a good understanding of the things I was responsible for in managing my health</i>			
Strongly disagree	0	2 (6%)	2 (2%)
Disagree	5 (9%)	5 (16%)	10 (12%)
Agree	24 (44%)	17 (55%)	41 (48%)
Strongly agree	25 (45%)	4 (13%)	29 (34%)
Don't know/not applicable	1 (2%)	3 (10%)	4 (5%)
<i>When I left the hospital I clearly understood the purpose for taking each of my medications</i>			
Strongly disagree	0	2 (6%)	2 (2%)
Disagree	6 (11%)	4 (13%)	10 (12%)
Agree	21 (38%)	14 (45%)	35 (41%)
Strongly agree	28 (51%)	11 (35%)	39 (45%)
Don't know/not applicable	0	0	0

As shown in table 6.3, a statistically significant, positive correlation was evident between the ICECAP-O and the CTM-3 (Spearman's $r=0.249$; $p\leq 0.05$), suggesting that higher quality care transitions are accompanied by higher levels of capability in support of the stated hypothesis. A significant relationship was found to exist between the CTM-3 score and the ICECAP-O role domain ($p<0.05$) indicating that some, but not all areas of capability are influenced by the quality of care transitions as shown in table 6.4. Additionally, a significant association was evident between the ICECAP-O attribute of attachment and the CTM-3 attribute of the patient understanding what they are responsible for in managing their health.

Table 6.3 Relationship between the CTM-3, ICECAP-O and EQ-5D-3L

	CTM-3
ICECAP-O^a	0.249*
EQ-5D-3L^b	0.204

* Association is significant at the 5% level

^a n=82

^b n=84

Table 6.4 Tests of association (p values) between capabilities and care transition as measured by the ICECAP-O and CTM-3

CTM-3 Domain	ICECAP-O Attributes				
	<i>Attachment</i>	<i>Security</i>	<i>Role</i>	<i>Enjoyment</i>	<i>Control</i>
Preferences considered	0.947	0.761	0.459	0.956	0.499
Understanding how to manage health	0.020*	0.912	0.097	0.191	0.510
Understanding purpose of medications	0.810	0.468	0.169	0.125	0.177
Overall value	0.170	0.221	0.037*	0.740	0.307

* Association is significant at the 5% level

No positive association was found to exist between the EQ-5D-3L and the CTM-3 (Spearman's $r=0.204$; $p=0.06$), as can be seen in table 6.3, suggesting no overall relationship between health-related quality of life and the quality of care transitions. However table 6.5 demonstrates that a highly significant relationship was evident between the overall CTM-3 score and the EQ-5D-3L usual activities attribute ($p \leq 0.001$) and to a lesser extent, the attribute of pain/discomfort ($p < 0.05$).

Furthermore, a significant relationship was found to exist between the EQ-5D-3L domain of usual activities and the CTM-3 domain of the respondent understanding what they are responsible for in managing their own health ($p < 0.05$). Additionally, significant relationships were also present between the CTM-3 domain of understanding the purpose of medications and the EQ-5D-3L domains of usual activities and pain/discomfort ($p < 0.05$). As with the ICECAP-O, this suggests a relationship between the quality of care transition and some, but not all aspects of HRQoL.

Table 6.5 Tests of association (p values) between HRQoL and care transition capabilities as measured by the EQ-5D-3L and CTM-3

CTM-3 Domain	EQ-5D-3L Domains				
	<i>Mobility</i>	<i>Self care</i>	<i>Usual activities</i>	<i>Pain/ discomfort</i>	<i>Anxiety /depression</i>
Preferences considered	0.911	0.948	0.108	0.236	0.171
Understanding health management	0.905	0.233	0.047*	0.463	0.606
Understanding purpose of medications	0.438	0.379	0.011*	0.030*	0.522
Overall value	0.789	0.324	≤0.001**	0.017*	0.636

** Association is significant at the 0.1% level

* Association is significant at the level 5% level

6.5 Discussion

As discussed in chapter 5, no significant difference in quality of life was evident between the outpatient day rehabilitation and residential Transition Care respondents when measured according to capability or health. The quality of life of the respondents in this study was lower than that reported in another recent study which compared the health-related and capability-based quality of life of older adults attending a Canadian falls prevention clinic using the EQ-5D-3L and ICECAP-O.²⁰⁹ However the respondents in the Canadian study were community dwelling and quite independent in terms of functional ability, while many of the respondents in the study presented here were requiring residential Transition Care to regain functional ability. It is also important to

note that the Canadian study scored the ICECAP-O and EQ-5D-3L instruments using algorithms based on the United Kingdom general population, while the study presented here applied algorithms developed based upon the Australian general population.^{195, 205}

The quality of care transitions experienced by the respondents was similar to that recorded in other studies of similar populations.^{15, 50} The respondents receiving outpatient day rehabilitation demonstrated higher quality care transitions than those who were receiving residential Transition Care. One explanation for this is that the rehabilitation respondents may have been more involved in their care transition than the Transition Care recipients seeing as they were further along in their recovery trajectory, having been discharged back into the community. Several socio-demographic characteristics were significantly associated with the quality of care transition. Higher quality care transitions were associated with being aged 65 to 79 years, living with others, not having an informal carer and being born in Australia. To date, little work has been undertaken into socio-demographic characteristics that may be associated with high quality transitions between health care settings making it difficult to make comparisons with the findings of other studies. To further understand the factors that influence the quality of care transitions, and therefore the process of subacute care for older adults, further investigations would be beneficial to highlight older adults who may be at risk of experiencing fragmented care and develop strategies to minimize the occurrence of this.

As hypothesized a priori, the findings of this empirical comparison suggest the existence of a relationship between the concepts of quality of life and the quality of care transitions when measured in a subacute setting. Of particular significance was the

relationship between the quality of care transitions and quality of life when measured in terms of capability, which demonstrated that increases in the quality of care transition was associated with increases in the capability-based quality of life.. In particular, the quality of care transition was associated with the ability to be independent and also perform activities that make an individual feel valued. This implies that a high quality of care transition was received by the respondents, as one of the main aims of care transition is the optimization of independence in terms of physical, social, emotional and cultural factors.¹⁴

However consideration must be paid to other factors that may have an impact on the quality of care transition experienced by older adults. For example time may be associated with the quality of care transition. Perceived quality of care transition may differ over time as the respondents' health improves and they become increasingly able to be involved in matters relating to their care, or they may feel that they receive a higher quality of care transition from services from which they have been received care from for a longer duration. There is also the possibility that respondents' recollection or perception of the quality of care transition may alter as time elapses, along with the potential influence of additional factors such as sociodemographic characteristics, motivation and cognitive impairment.⁴¹ As subacute care is often provided in a series of overlapping phases, this presents the opportunity to measure health outcomes such as the quality of care transition at set time-points along the recovery trajectory.⁴¹ It would therefore be beneficial for future work to measure the quality of care transition over multiple time points in order to examine whether time is an influential factor. This is particularly relevant to the domain regarding the level to which respondents understand

the purpose for their prescribed medications, as this is information that may be clear to them at the time of care transition, but may fade over time.

Transitioning between health care settings or being discharged back to the community has sometimes been associated with adverse drug events which may contribute to poor medication adherence among patients.²¹⁴ In contrast to this, the majority of the respondents in this study reported having an understanding of the purpose of their medications following hospital discharge, an indicator of quality care transitions. Previous work has indicated that understanding the reasons for a medication being prescribed can positively influence the adherence rates among older adults.²¹⁴ Further to this, patient-provider communication and the receipt of patient education about medications including potential benefits and side effects, has also been associated with patients taking medications as prescribed.²¹⁴⁻²²⁰ This is particularly pertinent for older adults, who are likely to be prescribed multiple medications due to comorbidities and often have low rates of medication adherence due to a variety of factors such as visual and cognitive impairments, and confusion regarding the medication regimen.^{214, 216, 220}

Understanding of the purpose of their prescribed medications following their transition between health care settings was associated the respondents' ability to perform usual day-to-day activities such as housework and leisure activities, and also with the level of pain and discomfort they experienced. Previous work has identified that correct medication usage not only assists in the management of disease and symptoms, but also has a positive impact on the lifestyle and the quality of life experienced by patients.^{214,}
²¹⁶ For example the effective management of chronic pain via analgesia regimes has been found to positively influence an individual's overall quality of life, as have

adherence to medication prescribed for epilepsy, hypertension and HIV.²²¹⁻²²⁴

Therefore, it may be deduced from the findings presented here, and those of previous work, that subacute care recipients' understanding of the purposes of their medications enables them to take their medications correctly, thereby assisting in the management of symptoms such as pain or discomfort and assisting them to undertake routine activities, both of which have beneficial impacts upon quality of life.

A relationship was also evident between subacute care recipients' understanding of how to manage their health and their relationships with others along with being able to perform their usual activities. The importance of educating patients about self-care including appropriate use of medication and adjusting lifestyle factors to improve symptoms has been associated with increases in empowerment and autonomy which in turn can positively influence physical health and quality of life.²²⁵⁻²²⁷ These concepts, empowerment and autonomy refer to feelings that an individual has the right and freedom to make decisions and have control over their life including the attainment of goals.²²⁷⁻²³⁰ In regard to older adults, Barkay and colleagues found autonomy to be associated with not only health status, but also with participation in daily activities such as dressing and bed making.²³⁰ It was theorized that individuals who felt unwell or that they had little control over their environment would forego participation in such activities. Additionally, autonomy and participation in activities were also associated with contact with friends and family members, with people who had more visitors experiencing higher levels of autonomy and demonstrating higher levels of activity participation.²³⁰ Social contact was also identified as important by Leenerts and colleagues, who associated it with levels of self-care, which in turn has been associated with increased confidence in one's own abilities.²²⁵

The findings presented here provide empirical evidence of the relationship between the process and outcomes of health care, verifying the Donabedian perspective that both of these elements are strongly interlinked and form a basis from which quality of care can be inferred.³⁰ These findings also provide support for the Campbell model which indicates that effective care is comprised of health outcomes and user evaluation, which may include the assessment of outcomes and processes of care.²⁶ When applied to the Donabedian model, relationships were evident between the process of care, in terms of the transition between health care settings, and outcomes of care in terms of quality of life. Specifically, relationships were shown between the following elements of processes of care: understanding the purpose of medications and understanding self-care responsibilities and the following outcomes of care: control (independence), attachment (relationships with others), ability to perform usual activities, and levels of pain.

Although the relatively small patient sample size is a limitation of this study, a high consent rate of 90% was achieved and the sample contained a diverse range of diagnoses broadly representative of older adults attending outpatient day rehabilitation and Transition Care programs. However, it is important that further research is conducted to verify these preliminary findings in larger clinical samples.

6.6 Conclusion

This chapter focused on examining the transition between health care settings for older adults. After establishing the importance of measuring the outcomes of health care in terms of quality of life in chapter 5, this chapter investigated the relationship between quality of life and the quality of care transition. The findings presented here provided

evidence for the relationship between the processes and outcome of care for older adults receiving subacute care following an episode of ill-health.

Chapter 7

Discussion

7.1 Introduction

The future ageing population is predicted to have higher expectations regarding their health care than previous generations. It is important that quality in health care is examined from the perspective of patients themselves, rather than based solely on factors considered to be important by health care professionals as it has been demonstrated that factors of importance of care delivery differ between patients and health care professionals, including in the area of subacute care.^{231, 232} This requires the participation of older adults in both the design and delivery of health care, areas in which they have traditionally had little involvement. Given that older adults typically have higher health service utilisation rates than other demographic groups, the large “baby boomer” population is expected to place increased future pressure on health and social care services whose operations are often restricted due to finite resources.^{3, 12} From this perspective, the importance of economic analysis to inform decision making regarding the allocation of these resources is becoming increasingly essential to ensure that the health care being provided to older adults is cost-effective.²

Theoretical models such as those developed by Donabedian, and Campbell have demonstrated that the process and outcomes of care are interconnected components in determining the overall quality of the health care provided.^{26, 30} Therefore, to effectively examine quality of care from the patient perspective, both the process and outcomes of care require investigation.²⁷ This involves firstly ascertaining, from the perspective of patients, what their needs and preferences are, and secondly whether these are being adequately met. It is also important that health care is examined using methodologies that are suitable for inclusion in the framework of economic evaluation.¹⁹⁰ To date there has been little investigation of preferences for the process and outcomes of care from

the perspective of populations of older adults participating in subacute care programs such as rehabilitation or Transition Care.

This thesis examined the quality of subacute care in the form of outpatient day rehabilitation and residential Transition Care for older adults, by investigating the process and outcomes of subacute care. A DCE methodology was applied to examine the process of care from the patient perspective, determining the features of subacute care that are important to older adult patients. Further to this, the utilisation of the CTM-3 instrument enabled specific aspects of the process of care relating to the quality of care transitions to be investigated from the perspective of older adults receiving subacute care. The outcomes of subacute care were examined via the measurement and valuation of quality of life based upon both health and capabilities which were contrasted with the findings of previously published studies. A comparison analysis of the health and quality of life of an older subacute care recipient population with a general older population sample was undertaken to facilitate empirical comparisons and the collection of normative data. The main findings of the thesis are summarised below.

7.2 Summary of major findings

7.2.1 DCE methodology is appropriate for use in populations of older adults receiving subacute care

The application of DCE methodology allowed for the process of subacute care to be examined via investigation into patient preferences. Previously little work has been conducted on the application of DCEs in samples comprised specifically of older adults. The findings of both the original DCE study presented in this thesis and the reviewed

literature, including the high completion rate and low prevalence of dominant preferences exhibited, demonstrate the methodology to be both acceptable and feasible for use in this population, which included adults aged up to 92 (original DCE study) 100 (reviewed literature) years of age respectively.

Previous studies have investigated the preferences of older adults for the screening, management and treatment of health ailments and also the configuration of health services. Aspects of care that proved to be significant to older adults have included the intensity, frequency, mode, setting and cost of a treatment, service or program along with the chance of experiencing adverse events such as treatment side effects and also benefits including recovery level.

The findings of the original DCE study presented in this thesis adds to the existing body of knowledge surrounding older adults' preferences for the process of health care. Involvement in decision making and the configuration of health services were also valued by the older adults who participated in the study presented in this thesis. Older adults who were receiving either subacute outpatient day rehabilitation or residential Transition Care displayed similar preferences for care despite the Transition Care recipients being older and having different clinical characteristics. This suggests a consistency in the factors considered to contribute to the quality of subacute care independent of patient characteristics.

Communication, both between health professionals and between patients and health professionals, was also highly valued by both the outpatient rehabilitation and residential Transition Care groups. In regard to subacute care recipients receiving

information about their treatment and progress, preferences were shown for a meeting with senior specialist staff (medical and nursing) with follow-up and a take-home audio recording of the meeting. Strong preferences were also demonstrated for the use of electronic medical records indicating the importance placed on the communication between health professionals in different settings. In regard to the input of health professionals, both groups highly valued continuity of care along with the health professionals determining the duration of rehabilitation therapy. However shared decision making was valued more highly by the outpatient day rehabilitation recipients who showed a stronger preference to be involved in decision making about their own future care, potentially due to being further along in their recovery trajectory.

The findings of both the present study, and those that were reviewed, demonstrate that older adults have clear preferences regarding the process of subacute care provision, and that these preferences are able to be successfully ascertained via a DCE methodology. The findings suggest that, from the perspective of older adults, the quality of subacute care is influenced by the duration and cost, patient knowledge of risk factors, the type of health professional providing treatment, health professional characteristics, financial incentives, participant involvement in decision making, patients receiving information about their treatment and progress, continuity of care and communication between the patient and health professionals and also between health care professionals.

Additionally, the outcomes of health treatments or programs were found to be an influential factor in older adult's preferences for subacute care in the reviewed literature, namely recovery levels and the risk of adverse events. This provides support for the theoretical models of both Donabedian and Campbell which highlight the

connection between the process and outcomes of health care.^{26, 30} Given the importance of acknowledging patient preferences, it would be beneficial for the aforementioned elements of the process of care to be incorporated into the design and delivery of health and social care services provided to older adults. Furthermore, given that the DCE methodology has been demonstrated as feasible for use with older adults, it follows that this approach could potentially be utilized in the development of PROMs to measure and value the outcomes of health and social services and interventions for older adults such as quality of life. Such an instrument could then be applied within the framework of economic evaluation to determine the cost-effectiveness of subacute care programs for older adults.

7.2.2 First empirical application of ICECAP-O with the CTM-3 and EQ-5D-3L in a subacute elderly population

The work presented here is, internationally, the first empirical application of the ICECAP-O alongside the EQ-5D-3L and CTM-3 instruments. This therefore provided the first empirical exploration in this context of the relationships between outcomes (as measured by the concepts of capability-based quality of life and health-related quality of life) and process (as measured by the quality of care transition).

Quality of care transitions

The assessment of the quality of transition between acute and subacute care settings allowed the process of care to be examined in regard to the consideration of patient preferences, and the provision of information. It also enabled the interaction between the process and outcomes of care to be examined. In general, the quality of care transition was shown to be similar to that reported for older adults in previous work.^{15, 50}

However comparison of the subacute care recipient samples revealed some notable differences in that the quality of transition reported by the outpatient day rehabilitation recipients was significantly higher than that identified by the residential Transition Care recipients. This could be due to the rehabilitation group being further along their recovery trajectory and therefore having greater capacity to be more involved in ensuring the quality of their transition between care settings. The finding that respondents in the outpatient day rehabilitation group reported a higher level of understanding of the purpose of their medications and responsibility in managing their own health relative to Transition Care recipients concurs with this view.

The quality of care transitions was also found to have a positive relationship with quality of life when measured in terms of capability, with increases in the quality of care transitions associated with increases in quality of life. This indicates a direct association between the process and outcome of outpatient day rehabilitation and residential Transition Care in terms of the domains included in the CTM-3 and ICECAP-O.

The outcomes of subacute care for older adults were examined in this thesis via the measurement and valuation of quality of life based upon health status and capability. This was then compared to the quality of life reported by a general population sample of Australian older adults and the findings of previously published studies.

Health related quality of life

The measurement and valuation of HRQoL enabled the outcomes of subacute rehabilitation and Transition Care to be examined in terms of outcome utility. The application of MAUIs in studies focusing on subacute rehabilitation for older adults

remains limited. The studies reviewed in this thesis indicated that although small incremental QALY gains were experienced by older adults receiving subacute care, the gains were, on average, not sufficient to pass the minimum thresholds suggested by Drummond.¹⁶⁶ In general, positive incremental QALY gains were achieved in the studies from subacute care which was provided in either an inpatient setting or a combination of inpatient and outpatient settings. Additionally, interventions that were provided over a longer time period resulted in higher mean incremental QALY gains on average than those that were shorter in duration.

The findings of the work presented in this thesis demonstrated that in general, the health-related quality of life reported by older adults receiving outpatient day rehabilitation was higher than that reported by older residential Transition Care recipients. This is not surprising and is likely due to the possibility that the outpatient rehabilitation recipients having achieved higher levels of recovery at the time of interview as they had been discharged back into the community and deemed medically stable enough to receive outpatient subacute care, whereas the Transition Care recipients were still requiring inpatient subacute care.

When compared with a sample of the general Australian population in the equivalent age group, the subacute care recipients exhibited significantly lower health-related quality of life regardless of educational level, gender or age (aged 65 to 79 years vs 80 years and over). However given that the respondents were recovering from a recent acute health episode, some degree of limitation is to be expected. The respondents were more likely than the general population to report limitations in regard to mobility, self-care and their ability to perform usual activities. Despite the subacute care group

experiencing lower levels of HRQoL than reported in other studies of older adults,²⁰⁶ little difference was shown in the levels of pain or discomfort, and anxiety or depression reported by the subacute and general population samples. However it has previously been acknowledged that the levels achieved in some domains of health-related quality of life may differ between patients and general population samples more than others.^{197,}

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Because the subacute care recipient sample were more likely than the general population sample to report limitations in mobility, self-care and the performance of usual activities, it could be deduced that these factors are negatively influenced by recent episodes of ill-health in older adults. It would therefore be beneficial to examine the process of care in regard to these areas. For example, the quality of transition between health care settings could be examined to determine whether the process of care that is being provided makes allowances for improvement in the areas in which the subacute care recipients in this study reported limitations. Recent DCE studies which focused on the provision of rehabilitation for older adults found levels of recovery in areas such as mobility to be of significant importance to older adults receiving rehabilitation.^{124, 125, 134} Thus, these factors are also important for health services to consider when providing subacute care to older adults.

The small number of studies which have examined quality of life of older adults utilizing instruments appropriate for inclusion in the framework for economic evaluations suggests an area for improvement. Although health outcomes are commonly measured in areas of subacute care such as rehabilitation and Transition Care, these are most often based on clinical outcomes such as the Functional Improvement Measure

and Barthel Index respectively which measure independence in activities of daily living. Increased inclusion of HRQoL measures which allow for the calculation of QALYs, would not only enable the cost-effectiveness of interventions to be calculated, but would also provide insight into the outcomes of care from the patients' perspective.

Capability-based quality of life

By measuring and valuing quality of life in terms of capability, the outcomes of care were able to be examined using an instrument that, whilst not a utility instrument designed for the calculation of QALYs, produces utility-like values suitable for inclusion in economic analysis.

When based on capability, the quality of life of older outpatient rehabilitation and residential Transition Care recipients was shown to be generally quite high. However, no significant difference was evident between the rehabilitation and Transition Care samples in terms of capability-based quality of life. Differences were evident however when comparing the subacute care sample with the general population. As in HRQoL, the subacute sample demonstrated lower capability-based quality of life than the general population sample. This suggests that an acute period of ill-health may have a negative influence on an older adult's capabilities.

Age proved to be an influential factor, with a significant difference evident between subacute and general population respondents aged between 65 and 79 years.

Importantly, control (independence), security (the level of concern associated with thinking about the future) and role (the ability to do things that make an individual feel valued) emerged as areas that may be affected by acute illness in older adults. This was

demonstrated by the fact that the subacute sample was more likely to report limitations in these domains than the general population sample.

The association between the quality of care transition and capability-based quality of life provides further support for the relationship between the process and outcomes of health care proposed by Donabedian. Although no significant relationship was shown to exist between care transition and HRQoL, the relationship between care transition and capability-based quality of life suggests that the quality of transition between care settings may be more influential in terms of patient capability than health status. This supports the recent findings reported in a Canadian study by Davis and colleagues that the EQ-5D-3L and ICECAP-O are designed to measure different outcomes of health care, and therefore should be used to complement, rather than replace each other.²³³

7.2.3 Relationship between the process and outcomes of subacute care for older adults

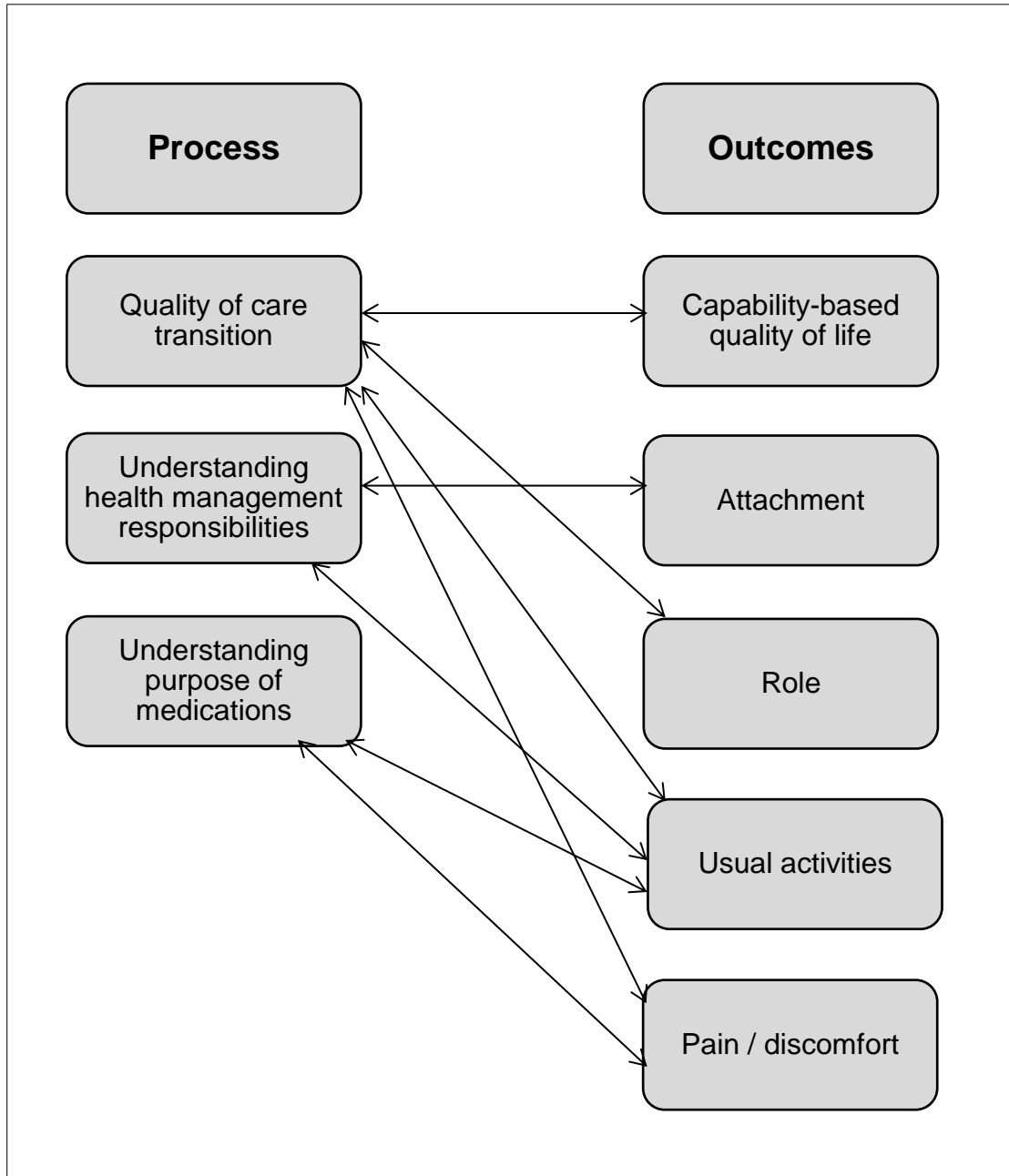
The findings presented here provide empirical support for the theoretical model of quality of care proposed by Donabedian, with associations found to exist between the process and outcomes of subacute care for older adults. Given that the process and outcomes of care combine to contribute to the overall quality of health care, the findings presented in this thesis demonstrate that the quality of subacute care is a combination of many factors for older adults. These include capability-based quality of life, the quality of care transition, HRQoL and individual elements of these concepts.

As shown in figure 7.1, the relationships between quality of care transition and the quality of life outcome domains (both capability and health-related) suggest that some,

but not all elements of the process and outcomes of care are related, and that some aspects are specifically related to each other. The positive correlation between the quality of care transition and capability-based quality of life suggests an increase in the process of care was accompanied by increases in the outcomes of care. Additionally, the quality of care transition was also related to the HRQoL domains of ability to perform usual activities and pain/discomfort along with the role (feeling valued) domain of capability-based quality of life.

In terms of the quality of care transition, process was related to a range of types of outcome elements relating to both social and physical functioning. The respondents' understanding of their responsibilities regarding their health was related to attachment and the ability to perform usual activities. The provision of knowledge, this time relating to the purpose of prescribed medications, was also influential on the outcome of performing usual activities, in addition to the level of pain or discomfort being experienced.

Figure 7.1 The relationship between the process and outcomes of subacute care for older adults



Additionally, previous work has reported that the levels of recovery achieved in areas such as mobility were found to be influential in the treatment decisions of older adults receiving subacute care.^{124, 125, 134} This provides further support for the connection between process and outcomes in defining quality of care.

The findings presented in this thesis demonstrate the interconnectedness between the process and outcomes of subacute care for older adults. Given the influence that these two concepts have on each other it is essential that the process by which subacute care is provided is to a high standard, and the maximum possible level of outcomes are achieved. As previously stated, it is advantageous if the processes and outcomes of care are examined from the patients' perspective using instruments that are suitable for inclusion in the framework of economic evaluations. This will not only allow the cost-effectiveness of health and social care interventions to be calculated, but will allow for investigation into whether the patients' needs and preferences, as they perceive them are being adequately met.

7.3 Limitations

The limitations pertaining to the individual studies reported on in this thesis are discussed within their associated chapters. One limitation common to each of the studies was that the methodologies that were used have had little previous application in populations specifically of older adults receiving subacute care. This therefore limited the degree to which comparisons could be made, and conclusions drawn between the findings presented here and those of other, previously conducted studies. A second common limitation was that the findings are based on an Australian specific population. Due to differences in health systems internationally, the experiences and preferences expressed by this Australian

population may differ to those expressed by older adults receiving subacute care in other countries. For example, the health care system in the United States is not publically funded which may influence the delivery of health care and the preferences of health care recipients.

The final common limitation relates to the sample size included in the studies. Although the size of the subacute care recipient sample was relatively small, the broad range of included diagnoses was representative of older adults receiving outpatient rehabilitation and residential Transition Care. In addition to this, a high consent rate was obtained further, suggesting the respondents were a representative sample. It is important to note that the studies presented here were essentially exploratory in nature and further investigation of these topics is needed using larger sample sizes. The opportunistic sampling approach that was utilized mean that, despite a range of socio-demographic data being collected within each of the study samples, few were common to the subacute care and two general population samples. This limited the extent to which the relationship between socio-demographic characteristics, patient preferences, quality of life and care transition could be examined.

Some limitations were particular to specific studies. A disadvantage of the DCE methodology lies in the need to reduce the number of included attributes to reduce the cognitive complexity of the task. This therefore limits the number of attributes or characteristics that can be included in a single DCE application. However, the process of attribute development for the DCE reported on in this thesis included a detailed literature review and consultation with experienced health professionals and subacute care. This process increased the likelihood that the attributes that were included in the experiment covered the most important factors relating to the preferences of older adults

receiving subacute care. An additional disadvantage is the possibility that respondents' preferences for the process of care may be biased towards the models of care that they are most familiar with, known as the "veil of experience".¹²⁹

The face-to-face administration of the ICECAP-O, EQ-5D-3L and CTM-3 instruments presents a limitation in terms of response bias. Respondents may have over-estimated their level of independence or satisfaction when answering the questions due to an optimism bias, in which individuals perceive themselves to be in a more positive position compared to others. When questioned about their health or wellbeing, respondents often answer using other individuals such as other patients, family or acquaintances as their point of reference. Typically, they will compare themselves to someone who they consider to be in a worse state than themselves, supporting their optimistic beliefs.²³⁴ Similarly, respondents may have provided responses that they deemed to be socially acceptable or desirable. Older adults have been identified as more likely than younger adults to give such responses, potentially due to being raised in a period that placed a large focus on propriety and maintaining social appearances, or in an attempt to seek approval.¹⁰² The provision of socially desirable response has been found to be slightly more prevalent when face-to-face administration methods are used as opposed to written approaches.²³⁴ Additionally, respondents may have adapted over time to any limitations they be experiencing as the result of ill-health, or their internal values or the importance they place on particular aspects of health and quality of life may have altered as part of this coping process, thereby influencing reporting higher levels of quality of than one may expect.^{131, 235, 236}

7.4 Implications for practice

The importance of incorporating patient preferences into the planning and provision of health and social care services has been well documented, although in practice it is not often performed.⁸⁹ Patient involvement has been associated with increases in health and quality of life, along with improvements in the accessibility and acceptability of health services.⁹¹ Given that older adults have shown both an ability and willingness to indicate their preferences for the provision of health and social care services, it would therefore be advantageous for these preferences to be taken into consideration.

In regard to subacute rehabilitation and Transition Care, factors of care that older adults have identified as being important included the use of electronic medical records, meetings to obtain information on treatment progress, shared decision making, continuity of care and health care professionals determining the duration of therapy. The value placed on these areas highlight factors in the process of subacute care that are important to recipients, and therefore may be beneficial to incorporate into the future provision of care.

The review of the literature indicated that positive effects can be obtained for older adults from the receipt of subacute rehabilitation, suggesting the importance of the provision of this area of medicine. Given that several aspects of life have been identified as being impacted on by the experience of an acute health event for older adults,¹⁴³ increased focus on improving function in these areas may result in improved outcomes in rehabilitation and Transition Care. Compared to the general population, subacute care recipients reported limitations in their independence, ability to do things that make them feel valued, and the level of concern associated with thinking about the future. Mobility,

self-care and performing usual activities were other areas that the subacute care recipients reported limitations in. These limitations highlight areas that may need to be taken into consideration in the provision of subacute care to older adults in order to assist them to achieve the best possible levels of recovery.

7.5 Future research directions

In order to gain an increased understanding of older adults' preferences for health care, further research is required into the application of DCEs in particular. The use of DCEs in larger samples and varying clinical populations and settings would not only be beneficial, but also provide further evidence of the validity and practicality for the use of the DCE methodology in older adults. Additionally, potential exists for the exploration of administration of DCEs in populations of older adults with mild cognitive impairment, given that it is a common experience among older adults receiving health care.

The potential also exists for the future incorporation of DCEs, such as the one presented in this thesis, into an economic evaluation framework to calculate the cost-effectiveness of subacute care for older adults. This could be achieved utilising the method developed by Benning and colleagues which involves deriving the cost data for preferred models of subacute care, and combining their total cost estimates with the utility values ascertained via a DCE.⁷³ While an increase in the application of DCE methodologies would assist in ascertaining the preference of patients for subacute care, it would also be favourable to increase the examination of the process of care patients are experiencing. This can be achieved by utilising instruments such as the CTM-3 which would not only

provide insight into what is actually occurring in regard to the provision of care, but it would also assist in assessing whether the various elements of process of care are enabling the desired outcomes of the intervention, treatment or service to be achieved.

While quality of life is commonly measured as an outcome of health care, many of these studies have utilised instruments that are not appropriate for the calculation of health state values and the estimation of QALYs. Despite providing insight into quality of life and physical function, the potential for this information to be incorporated within an economic evaluation framework remains limited. The increased incorporation of MAUIs into studies evaluating subacute care such as rehabilitation interventions would facilitate the ability to conduct an economic evaluation. Further to this, future work assessing the minimal important health state values and QALY gains for older adults participating in rehabilitation would assist in outcomes of care being able to be measured in a way that is suitable for incorporation into economic analysis.

The introduction of the routine measurement and valuation of patient quality of life in Australia would be especially beneficial, as has commenced in the United Kingdom with the introduction of routine PROMs data collection for patients undergoing particular interventions.²⁹ This would not only provide data with which comparisons can be made regarding the provision and outcomes of subacute health care from the patient perspective, but if MAUIs are routinely utilised, it would facilitate an examination of the HRQoL benefits of any new interventions in comparison with those already being provided.

It would also be advantageous for HRQoL and capability-related quality of life to continue to be measured and valued longitudinally at multiple time points rather than at a single time point as was performed here. This would allow for the identification of changes in quality of life over the recovery period to be examined, and considered in the planning and provision of health care services for older adults. Given that the ICECAP-O is a relatively new instrument, longitudinal application would aid in establishing the re-test reliability of the instrument and its sensitivity to change over time. Further research should also be conducted to compare the ICECAP-O with other instruments also designed to measure quality of life in a broader sense in older adults such as the recently developed OPQOL (Older People's Quality of Life) instrument.²³⁷

7.6 Conclusions

The main findings of this thesis relate to the factors that contribute to the quality of subacute care for older adults. Although their use has been limited thus far, instruments exist for the examination of the process and outcomes of subacute rehabilitation for older adults that have been shown to be suitable for inclusion in the framework of economic evaluation. The application of such instruments holds the potential to provide insight into the preferences and experiences of patients themselves, rather than decisions and planning being based solely on the views of health professionals, the importance of which is becoming increasingly important given the increased pressure expected to be placed on health and aged care services in the future.

The main contributions of the research presented here are the concurrent application of the ICECAP-O, EQ-5D-3L and CTM-3 instruments, resulting in demonstrated

relationships between the provision and outcomes of subacute care for older adults.

Additionally, the feasibility of the DCE methodology in populations of frail older adults has also been demonstrated. In summary, the thesis provides support for the future application of innovative approaches including DCEs and the application of PROMs to measure the broader aspects of quality of life beyond health status alone and for the measurement and valuation of quality in the provision of subacute care for older adults.

REFERENCES

1. Australian Government Treasury. Australia to 2050: Future challenges. Intergenerational Report. Canberra: Commonwealth of Australia; 2010. Available: http://archive.treasury.gov.au/igr/igr2010/report/pdf/IGR_2010.pdf. Accessed 9.11.16.
2. Ratcliffe J, Laver K, Couzner L, Cameron I, Gray L, Crotty M. Not just about costs: The role of health economics in facilitating decision making in aged care. *Age & Ageing*. 2010;39(4):426-9.
3. Australian Institute of Health and Welfare. Older Australia at a glance. 4th Edition. Canberra: AIHW; 2007. Available: <http://www.aihw.gov.au/publication-detail/?id=6442468045>. Accessed 9.11.16. Report No.: AGE 52.
4. Eagar K. ABF Information Series No. 6: Subacute Care: Centre for Health Service Development, University of Wollongong; 2010. Available: <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/documents/doc/uow082638.pdf>. Accessed 9.11.16.
5. Eagar K. The Australian National Sub-Acute and Non-Acute Patient casemix classification. *Aust Health Rev*. 1999;22(3):180-96.
6. Australian Institute of Health and Welfare. National Health Data Dictionary. Version 16. Canberra: AIHW; 2012. Available: <http://www.aihw.gov.au/publication-detail/?id=10737422826>. Accessed 9.11.16. Report No.: HWI 119.
7. Australian Institute of Health and Welfare. Development of nationally consistent subacute and non-acute admitted patient care data definitions and guidelines. Canberra: AIHW; 2013. Available: <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129543218>. Accessed 9.11.16. Report No.: HSSE 135.
8. Eagar K, Cromwell D, Kennedy C, Lee L. Classifying sub-acute and non-acute patients: Results of the New South Wales Casemix Area Network Study. *Aust Health Rev*. 1997;20(2):26-42.
9. Simmonds F, Stevermuer T. The AROC annual report: The state of rehabilitation in Australia 2005. *Aust Health Rev*. 2007;31(Suppl 1):S31-S53.
10. Productivity Commission. Trends In Aged Care Services: Some Implications. Commission Research Paper. Canberra: Australian Government; 2008. Available: http://www.pc.gov.au/data/assets/pdf_file/0004/83380/aged-care-trends.pdf. Accessed 9.11.16.
11. Productivity Commission. Disability Care and Support. Canberra: Australian Government; 2011. Available: <http://www.pc.gov.au/inquiries/completed/disability-support/report>. Accessed 9.11.16. Report No.: 54.
12. Ratcliffe J, Laver K, Couzner L, Crotty M. Health Economics and Geriatrics: Challenges and Opportunities. In: Atwood C, editor. *Geriatrics: InTech*; 2012. Available: <http://www.intechopen.com/books/geriatrics/health-economic-evaluation-and-geriatrics-challenges-and-opportunities>. Accessed 9.11.16.
13. Gray LC, Peel NM, Crotty M, Kurrle SE, Giles LC, Cameron ID. How effective are programs at managing transition from hospital to home? A case study of the Australian transition care program. *BMC Geriatrics*. 2012;12:6.
14. Department of Health and Ageing. Transition Care Program: Program Guidelines. Canberra: Department of Health and Ageing; 2005. Available:

- <https://agedcare.health.gov.au/programs-services/flexible-care/transition-care-programme-guidelines>. Accessed 9.11.16.
15. Giles L, Halbert J, Stepien-Hulleman J, Eckermann S, Masters S, Prendergast J, et al. National Evaluation of the Transition Care Program: Final Evaluation Report. Adelaide: Flinders Partners,2008. Available: <https://agedcare.health.gov.au/ageing-and-aged-care-publications-and-articles-ageing-and-aged-care-reports/national-evaluation-of-the-transition-care-program-full-report>. Accessed 9.11.16. Report No.: RFT 206/0506.
 16. Australian Institute of Health and Welfare. Older people leaving hospital: A statistical overview of the Transition Care Program 2009-10 and 2010-11. Canberra: AIHW; 2012. Report No.: AGE71.
 17. Poulos CJ, Eagar K, Faux SG, Estell JJ, Crotty M. Subacute care funding in the firing line. *Med J Aust*. 2013;199(2):92-3.
 18. Australasian Faculty of Rehabilitation Medicine. Standards for the provision of inpatient adult rehabilitation medicine services in public and private hospitals 2011. Sydney: The Royal Australasian College of Physicians, 2011. Available: <https://www.racp.edu.au/docs/default-source/default-document-library/afm-standards-2011.pdf?sfvrsn=2>. Accessed 9.11.16.
 19. Simmonds F, Stevermuer T. The AROC annual report: the state of rehabilitation in Australia 2006. *Aust Health Rev*. 2008;32(1):85-110.
 20. Australasian Rehabilitation Outcomes Centre. AROC Ambulatory Report. Wollongong, University of Wollongong; 2015. Available: <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@aroc/documents/doc/uow213025.pdf>. Accessed 9.11.16.
 21. Australasian Rehabilitation Outcomes Centre. The AROC Annual Report: The State of Rehabilitation in Australia in 2015. Wollongong, University of Wollongong; 2015. Available: <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@aroc/documents/doc/uow221359.pdf>. Accessed 9.11.16.
 22. Australasian Rehabilitation Outcomes Centre. The AROC annual report: The state of rehabilitation in Australia in 2010. Wollongong: University of Wollongong; 2010. Available: <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@aroc/documents/doc/uow106153.pdf>. Accessed 9.11.16.
 23. South Australia Department of Health. Statewide Rehabilitation Service Plan 2009–2017/South Australia. Adelaide: Government of South Australia; 2009. Available: <http://www.sahealth.sa.gov.au/wps/wcm/connect/97db9d0042632bfebce5beb44d317729/serviceplan09-17-clinicalnetworks-sahealth-0911.pdf?MOD=AJPERES&CACHEID=97db9d0042632bfebce5beb44d317729>. Accessed 9.11.16.
 24. Quine S, Carter S. Australian baby boomers' expectations and plans for their old age. *Australas J Ageing*. 2006;25(1):3-8.
 25. Brown CR. Where are the patients in the quality of health care? *Int J Qual Health Care*. 2007;19(3):125-6.
 26. Campbell SM, Roland MO, Buetow SA. Defining quality of care. *Soc Sci Med*. 2000;51:1611-25.
 27. Hoenig H, Lee J, Stineman M. Conceptual overview of frameworks for measuring quality in rehabilitation. *Top Stroke Rehabil*. 2010;17(4):239-51.

28. Berwick DM, Nolan TW. Physicians as leaders in improving health care: a new series in *Annals of Internal Medicine*. *Ann Intern Med*. 1998;128(4):289-92.
29. Devlin NJ, Appleby J. Getting the most out of PROMs: Putting health outcomes at the heart of NHS decision-making. London, The King's Fund; 2010. Available: <https://www.kingsfund.org.uk/publications/getting-most-out-proms>. Accessed 9.11.16.
30. Donabedian A. The quality of care. How can it be assessed? *JAMA*. 1997;260(12):1743-8.
31. Donabedian A. The quality of medical care. *Science*. 1978;200(4344):856-64.
32. Coast J, Flynn TN, Natarajan L, Sproston K, Lewis J, Louviere J, et al. Valuing the ICECAP capability index for older people. *Soc Sci Med*. 2008;67(5):874-82.
33. Crawford V, Dinsmore J, Sout R, Donnellan C, O'Neill D, McGee H. Stroke presentation and hospital management: comparison of neighboring healthcare systems with differing health policies. *Stroke*. 2009;40(6):2143-8.
34. Pound P, Ebrahim S. Rhetoric and reality in stroke patient care. *Soc Sci Med*. 2000;51(10):1437-46.
35. Pound P, Sabin C, Ebrahim S. Observing the process of care: A stroke unit, elderly care unit and general medical ward compared. *Age Ageing*. 1999;28(5):433-40.
36. Ryan M. Using conjoint analysis to take account of patient preferences and go beyond health outcomes: An application to in vitro fertilisation. *Soc Sci Med*. 1999;48(4):535-46.
37. Mooney G. *Economics, Medicine and Health Care*. New Jersey: Harvester Wheatsheaf; 2003.
38. Donabedian A. Promoting quality through evaluating the process of patient care. *Med Care*. 1968;VI(3):181-202.
39. Larson JS, Muller A. Managing the quality of health care. *J Health Hum Serv Adm*. 2002;25(3/4):261-80.
40. Bishop M. Quality of life and psychosocial adaptation to chronic illness and disability: Preliminary analysis of a conceptual and theoretical synthesis. *Rehabil Couns Bull*. 2005;48:219-31.
41. Eldar R. Quality of care in rehabilitation medicine. *Int J Qual Health Care*. 1999;11(1):73-9.
42. Masters S, Halbert J, Crotty M. Innovations in aged care: What are the first quality reports from the transition care program in Australia telling us? *Australas J Ageing*. 2008;27(2):97-102.
43. Masters S, Giles L, Halbert J, Crotty M. Development and testing of a questionnaire to measure older people's experience of the Transition Care Program in Australia. *Australasian Journal on Ageing*. 2010;29(4):172-8.
44. Crow R, Gage H, Hampson S, Hart J. The measurement of satisfaction with healthcare: Implications for practice from a systematic review of the literature. *Health Technol Assess*. 2002;6(32):1-244.
45. Lancaster KJ. A new approach to consumer theory. *J Pol Econ*. 1966;74(2):132-57.
46. Lanscar E, Louviere J. Conducting discrete choice experiments to inform healthcare decision making: A user's guide. *PharmacoEconomics*. 2008;26(8):661-77.
47. Bachmann S, Finger C, Huss A, Egger M, Stuck AE, Clough-Gorr KM. Inpatient rehabilitation specifically designed for geriatric patients: Systematic review and meta-analysis of randomised controlled trials. *BMJ*. 2010;340:1718.

48. Hopman W, Verner J. Quality of life during and after inpatient stroke rehabilitation. *Stroke*. 2003;34(3):801-5.
49. Grøndahl VA, Karlsson I, Hall-Lord ML, Appelgren J, Wild-Larsson B. Quality of care from patients' perspective: Impact of the combination of person-related and external objective care conditions. *J Clin Nurs*. 2011;20(17-18):2540-51.
50. Coleman EA, Parry C, Chalmers SA, Chugh A, Mahoney E. The central role of performance measurement in improving the quality of Transitional Care. *Home Health Care Serv Q*. 2007;26(4):93-104.
51. Coleman EA. Falling through the cracks: Challenges and opportunities for improving transitional care for people with complex care needs. *J Am Geriatr Soc*. 2003;51(4):549-55.
52. Parry C, Coleman EA, Smith JD, Frank JC, Kramer AM. The care transitions intervention: A patient-centred approach to facilitating effective transfers between sites of geriatric care. *Home Health Care Serv Q*. 2003;22(3):1-18.
53. Coleman EA, Parry C, Chalmers S, Min SJ. The care transitions intervention: results of a randomized controlled trial. *Arch Intern Med*. 2006;166(17):1822-8.
54. Coleman EA, Boulton C, American Geriatrics Society Health Care Systems Committee. Improving the quality of transitional care for persons with complex care needs. *J Am Geriatr Soc*. 2003;51(4):556-7.
55. Coleman EA, Mahoney E, Parry C. Assessing the quality of preparation for posthospital care from the patient's perspective: The Care Transitions Measure. *Med Care*. 2005;43(3):246-55.
56. Coleman EA, Smith JD, Frank JC, Eilertsen TB, Thiare JN, Kramer AM. Development and testing of a measure designed to assess the quality of care transitions. *Int J Integr Care*. 2002;2:e02.
57. Brazier J, Roberts J, Deverill M. The estimation of a preference-based measure of health from the SF-36. *J Health Econ*. 2002;21(2):271-92.
58. Ware JE, Sherbourne CD. The MOS 36-Item Short Form Health Survey (SF-36). I. Conceptual framework and item selection. *Med Care*. 1992;30(6):473-83.
59. Sintonen H, Pekurinen M. A fifteen-dimensional measure of health-related quality of life (15D) and its applications. In: Walker SR, Rosser RM, editors. *Quality of Life Assessment : Key Issues in the 1990s*. London: Kulwer Academic Publishers; 1993.
60. Hawthorne G, Richardson J, Osborne R. The Assessment of Quality of Life (AQoL) instrument: A psychometric measure of health-related quality of life. *Qual Life Res*. 1999;8(3):209-24.
61. Kaplan RM, Anderson JP, Ganiats TG. The Quality of Well-being Scale: Rationale for a single quality of life index. In: Walker SR, Rosser RM, editors. *Quality of Life Assessment : Key Issues in the 1990s*. London: Kulwer Academic Publishers; 1993.
62. Horsman J, Furlong W, Feeny D, Torrance G. The Health Utilities Index (HUI): Concepts, measurement properties and applications. *Health Qual Life Outcomes*. 2003;1:54.
63. Rabin R, de Charro F. EQ-5D: A measure of health status from the EuroQol Group. *Ann Med*. 2001;33(5):337-43.
64. Drummond MF, Sculpher MJ, Torrance GW, O'Brien BJ, Stoddart GL. *Methods for the Economic Evaluation of Health Care Programmes*. Oxford: Oxford University Press; 2005.

65. Sullivan PW, Ghushchyan V. Mapping the EQ-5D Index from the SF-12: US general population preferences in a nationally representative sample. *Med Decis Making*. 2006;26(4):401-9.
66. Ara R, Brazier J. Predicting the Short Form-6D preference-based index using the eight mean Short Form-36 Dimension Scores: Estimating preference-based health-related utilities when patient level data are not available. *Value Health*. 2009;12(2):346-53.
67. Ara R, Brazier J. Deriving an algorithm to convert the eight mean SF-36 dimension scores into a mean EQ-5D preference-based score from published studies (where patient level data are not available). *Value Health*. 2008;11(7):1131-43.
68. Nichol MB, Sengupta N, Globe DR. Evaluating Quality-Adjusted-Life Years: Estimation of the Health Utility Index (HUI2) from the SF-36. *Med Decis Making*. 2001;21(2):105-12.
69. Fryback DG, Lawrence WF, Martin PA, Klein R, Klein BEK. Predicting Quality of Well-being scores from the SF-36: Results from the Beaver Dam Health Outcomes Study. *Med Decis Making*. 1997;17(1):1-9.
70. Hanmer J. Predicting an SF-6D preference-based score using MCS and PCS scores from the SF-12 or SF-36. *Value Health*. 2009;12(6):958-66.
71. Rowen D, Brazier J, Roberts J. Mapping SF-36 onto the EQ-5D index: How reliable is the relationship? *Health Qual Life Outcomes*. 2009;7:27.
72. Ratcliffe J, Buxton M. Patients' preferences regarding the process and outcomes of life-saving technology. *Int J Technol Assess Health Care*. 1999;15(2):340-51.
73. Benning T, Kimman M, Dirksen C, Boersma L, Dellaert B. Combining individual-level discrete choice experiment estimates and costs to inform health care management decisions about customized care: The case of follow-up strategies after breast cancer treatment. *Value Health*. 2012;15(5):680-9.
74. McIntosh E. Using discrete choice experiments within a cost-benefit analysis framework: Some considerations. *PharmacoEconomics*. 2006;24(9):855-68.
75. Brazier J, Ratcliffe J, Salomon JA, Tsuchiya A. *Measuring and Valuing Health Benefits for Economic Evaluation*. New York: Oxford University Press; 2007.
76. Kernick DP. Introduction to health economics for the medical practitioner. *Postgrad Med J*. 2003;79(929):147-50.
77. Scott RD, 2nd, Solomon SL, McGowan JE, Jr. Applying economic principles to health care. *Emerg Infect Dis*. 2001;7(2):282-5.
78. McPake, B., Kumaranayake L, Normand C. *Health Economics: An International Perspective*. London: Routledge; 2002.
79. Cunningham SJ. An introduction to economic evaluation of health care. *J Orthod*. 2001;28(3):246-50.
80. Scuffham PA, Whitty JA, Mitchell A, Viney R. A review of industry submissions requesting listing on the Australian Pharmaceutical Benefits Scheme 2002-2004. *PharmacoEconomics*. 2008;26(4):297-310.
81. Pharmaceutical Benefits Advisory Committee. Guidelines for preparing submissions to the Pharmaceutical Benefits Advisory Committee. Version 4.5. Canberra: Australian Government Department of Health; 2015. Available: <http://www.pbac.pbs.gov.au/content/information/printable-files/pbacg-book.pdf>. Accessed 9.11.16.
82. National Institute for Health and Clinical Excellence. Guide to the methods of technology appraisal. 2013. Available: <http://nice.org.uk/process/pmg9>. Accessed 9.11.16.

83. Makai P, Brouwer WB, Koopmanschap MA, Stolk EA, Nieboer AP. Quality of life instruments for economic evaluations in health and social care for older people: a systematic review. *Soc Sci Med*. 2014;102:83-93.
84. Hunt SM, McKenna SP, McEwen J, Backett EM, Williams J, Papp E. A quantitative approach to perceived health status: a validation study. *J Epidemiol Community Health*. 1980;34(4):281-6.
85. Bergner M, Bobbitt RA. The Sickness Impact Profile: development and final revision of a health status measure. *Med Care*. 1981;xix(8):787-805.
86. Giles L, Hawthorne G, Crotty M. Health-related quality of life among hospitalized older people awaiting residential aged care. *Health Qual Life Outcomes*. 2009;7:71.
87. Milte C, Walker R, Crotty M, Luszcz M, Lancaster E, Kaambwa B, et al. What's important in defining quality of life for older people? An exploratory study of the views of older South Australians. Adelaide: Flinders Centre for Clinical Change and Health Care Research, Flinders University; 2013. Available: http://www.flinders.edu.au/fms/documents/test/Working%20Paper_01_131.pdf. Accessed 9.11.16. Report No.: 01/13.
88. Coast J, Smith R, Lorgelly P. Should the capability approach be applied in health economics? *Health Econ*. 2008;17(6):667-70.
89. Ryan M, Farrar S. Using conjoint analysis to elicit preferences for health care. *BMJ*. 2000;320(7248):1530-33.
90. Johnson A. An outline of consumer participation in health. *Collegian*. 2001;8(2):25-7.
91. Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, et al. Systematic review of involving patients in the planning and development of health care. *BMJ*. 2002;325(7375):1263-7.
92. Foster MM, Earl PE, Haines TP, Mitchell GK. Unravelling the concept of consumer preference: Implications for health policy and optimal planning in primary care. *Health Policy*. 2010;97(2-3):105-12.
93. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. A national study of public preferences. *J Gen Intern Med*. 2005;20(6):531-5.
94. Benbassat J, Pilpel D, Tidhar M. Patients' preferences for participation in clinical decision making: A review of published surveys. *Behav Med*. 1998;24(2):81-8.
95. Kenealy T, Goodyear-Smith F, Wells S, Arroll B, Jackson R, Horsburgh M. Patient preference for autonomy: Does it change as risk rises? *Fam Pract*. 2011;28(5):541-4.
96. Ekdahl AW, Andersson L, Friedrichsen M. "They do what they think is the best for me." Frail elderly patients' preferences for participation in their care during hospitalization. *Patient Educ Couns*. 2010;80(2):233-40.
97. Ekdahl AW, Andersson L, Wirehn AB, Friedrichsen M. Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey. *BMC Geriatr*. 2011;11:46.
98. Frosch DL, Kaplan RM. Shared decision making in clinical medicine: Past research and future directions. *Am J Prev Med*. 1999;17(4):285-94.
99. Ryan J, Sysko J. The contingency of patient preferences for involvement in health decision making. *Health Care Manage Rev*. 2007;32(1):30-6.

100. Amalraj S, Starkweather C, Nguyen C, Naeim A. Health literacy, communication, and treatment decision-making in older cancer patients. *Oncology*. 2009 Apr 15;23(4):369-75.
101. Breemhaar B, Visser AP, Kleijnen JGVM. Perceptions and behaviour among elderly hospital patients: Description and explanation of age differences in satisfaction, knowledge, emotions and behaviour. *Soc Sci Med*. 1990;31(12):1377-85.
102. Ross CE, Mirowsky J. Socially-desirable responses and acquiescence in a cross-cultural survey of mental health. *J Health Soc Behav*. 1984;25(2):189-97.
103. Propper C. Contingent valuation of time spent on NHS waiting lists. *The Economic Journal*. 1990;100:193-9.
104. de Bekker-Grob EW, Ryan M, Gerard K. Discrete choice experiments in health economics: A review of the literature. *Health Econ*. 2012;21(2):145-72.
105. Ryan M, Major K, Skåtun D. Using discrete choice experiments to go beyond clinical outcomes when evaluating clinical practice. *J Eval Clin Pract*. 2005;11(4):328-38.
106. Coast J, Horrocks S. Developing attributes and levels for discrete choice experiments using qualitative methods. *J Health Serv Res Policy*. 2007;12(1):25-30.
107. Rubin G, Bate A, George A, Shackley P, Hall N. Preferences for access to the GP: A discrete choice experiment. *Br Gen Pract*. 2006;56(531):743-8.
108. Muhlbacher AC, Nubling M. Analysis of physicians' perspectives versus patients' preferences: Direct assessment and discrete choice experiments in the therapy of multiple myeloma. *Eur J Health Econ*. 2011;12(3):193-203.
109. Payne K, Fargher EA, Roberts SA, Tricker K, Elliot RA, Ratcliffe J, et al. Valuing pharmacogenetic testing services: A comparison of patients' and health professionals' preferences. *Value Health*. 2011;14(1):121-34.
110. McNamara A, Chen C, George S, Walker R, Ratcliffe J. What factors influence older people in the decision to relinquish their driver's licence? A discrete choice experiment. *Accid Anal Prev*. 2013;55:178-84.
111. Morton R, Snelling P, Webster A, Rose J, Masterson R, Johnson D, et al. Dialysis modality preference of patients with CKD and family caregivers: A discrete-choice study. *Am J Kidney Dis*. 2012;60(1):102-11.
112. Ryan M, McIntosh E, Shackley P. Methodological issues in the application of conjoint analysis in health care. *Health Econ*. 1998;7(4):373-8.
113. Milte R, Ratcliffe J, Chen G, Lanscar E, Miller M, Crotty M. Cognitive overload? An exploration of the potential impact of cognitive functioning in discrete choice experiments with older people in health care. *Value Health*. 2014;17(5):655-59.
114. Amaya-Amaya M, Gerard K, Ryan M. Discrete choice experiments in a nutshell. In: Ryan M, Gerard K, Amaya-Amaya M, editors. *Using Discrete Choice Experiments to Value Health and Health Care*. Dordrecht: Springer; 2008.
115. Louviere JJ, Flynn TN, Carson RT. Discrete choice experiments are not conjoint analysis. *Journal of Choice Modelling*. 2011;3(3):57-72.
116. Louviere JJ. *Random Utility Theory-Based Stated Preference Elicitation Methods: Applications in Health Economics with Special Reference to Combining Sources of Preference Data*. Sydney: Centre for the Study of Choice, University of Technology; 2004. Available:

<http://citeseerx.ist.psu.edu/viewdoc/summary?doi=10.1.1.137.3803>. Accessed 9.11.16. Report No.: 04-001.

117. Ryan M. Discrete choice experiments in health care: NICE should consider using them for patient centred evaluations of technologies. *BMJ*. 2004;328:360-1.
118. Grutters JPC, Kessels AGH, Dirksen CD, van Helvoort-Postulart D, Anteunis LJC, Joore MA. Willingness to accept versus willingness to pay in a discrete choice experiment. *Value Health*. 2008;11(7):1110-9.
119. Ratcliffe J. The use of conjoint analysis to elicit willingness-to-pay values. Proceed with caution? *Int J Technol Assess Health Care*. 2000;16(1):270-5.
120. de Bekker-Grob EW, Essink-Bot ML, Meerding WJ, Pols HAP, Koes BW, Steyerberg EW. Patients' preferences for osteoporosis drug treatment: A discrete choice experiment. *Osteoporosis Int*. 2008;19:1029-37.
121. de Bekker-Grob EW, Essink-Bot ML, Meerding WJ, Koes BW, Steyerberg EW. Preferences of GPs and patients for preventative osteoporosis drug treatment: A discrete choice experiment. *Pharmacoeconomics*. 2009;27(3):211-19.
122. Kaambwa B, Lanscar E, McCaffrey N, Chen G, Gill L, Cameron ID, et al. Investigating consumers' and informal carers' views and preferences for consumer directed care: A discrete choice experiment. *Soc Sci Med*. 2015;140:81-94.
123. King MT, Viney R, Smith DP, Hossain I, Street D, Savage E, et al. Survival gains needed to offset persistent adverse treatment effects in localised prostate cancer. *Br J Cancer*. 2012;106(4):638-45.
124. Laver K, Ratcliffe J, George S, Lester L, Walker R, Burgess L, et al. Early rehabilitation management after stroke: What do stroke patients prefer? *J Rehabil Med*. 2011;43(4):354-58.
125. Milte R, Ratcliffe J, Miller M, Whitehead C, Cameron ID, Crotty M. What are frail older people prepared to endure to achieve improved mobility following hip fracture? A discrete choice experiment. *J Rehabil Med*. 2013;45(1):81-6.
126. Yeo S, Edwards R, Fargher E, Luzio S, Thomas R, Owens D. Preferences of people with diabetes for diabetic retinopathy screening: A discrete choice experiment. *Diabet Med*. 2012;29(7):869-77.
127. Robling MR, Ingledew DK, Greene G, Sayers A, Shaw C, Sander L, et al. Applying an extended theoretical framework for data collection mode to health services research. *BMC Health Serv Res*. 2010;10:180.
128. Bowling A. Mode of questionnaire administration can have serious effects on data quality. *J Public Health*. 2005;27(3):281-91.
129. Salkeld G, Ryan M, Short L. The veil of experience: Do consumers prefer what they know best? *Health Econ*. 2000;9(3):267-70.
130. Loomes G, Sugden R. Regret Theory: An alternative theory of rational choice under uncertainty. *The Economic Journal*. 1982;92(368):805-24.
131. Sprangers MAG, Schwartz CE. Integrating response shift into health-related quality of life research: A theoretical model. *Soc Sci Med*. 1999;48(11):1507-15.
132. Hong SH, Liu J, Wang J, Brown L, White-Means S. Conjoint analysis of patient preferences on Medicare medication therapy management. *J Am Pharm Assoc*. 2011;51(3):378-87.
133. Kistler CE, Hess TM, Howard K, Pignone MP, Crutchfield TM, Hawley ST, et al. Older adults' preferences for colorectal cancer-screening test attributes and test choice. *Patient Prefer Adherence*. 2015;9:1005-16.

134. Laver K, Ratcliffe J, George S, Burgess L, Crotty M. Is the Nintendo Wii Fit really acceptable to older people?: A discrete choice experiment. *BMC Geriatr.* 2011;11:64.
135. Tversky A, Kahneman D. Loss aversion in riskless choice: A reference-dependent model. *The Quarterly Journal of Economics.* 1991;106(4):1039-61.
136. Tinelli M, Ryan M, Bond C. What, who and when? Incorporating a discrete choice experiment into an economic evaluation. *Health Econ Rev.* 2016;6(1):31.
137. Kaambwa B, Bryan S, Barton P, Parker H, Martin G, Hewitt G, et al. Costs and health outcomes of intermediate care: Results from five UK case study sites. *Health Soc Care Community.* 2008;16(6):573-81.
138. Smith R, Darzins P, Steel C, Murray K, Osborne D, Gilsenan B. Outcome Measures in Rehabilitation. Project Report. Melbourne, National Ageing Research Institute; 2001. Available: <http://docplayer.net/543270-Outcome-measures-in-rehabilitation.html>. Accessed 9.11.16.
139. Kidd D, Stewart G, Baldry J, Johnson J, Rossiter D, Petruckevitch A, et al. The Functional Independence Measure: A comparative validity and reliability study. *Disabil Rehabil.* 1995;17(1):10-4.
140. Cournan M. Use of the Functional Independence Measure for outcomes measurement in acute inpatient rehabilitation. *Rehabil Nurs.* 2011;36(3):111-7.
141. Sainsbury A, Seebass G, Bansal A, Young JB. Reliability of the Barthel Index when used with older people. *Age Ageing.* 2005;34(3):228-32.
142. Shah S, Vanclay F, Cooper B. Improving the sensitivity of the Barthel Index for stroke rehabilitation. *J Clin Epidemiol.* 1989;42(8):703-9.
143. Hahn EA, Cella D, Chassany O, Fairclough DL, Wong GY, Hays RD, et al. Precision of health-related quality of life data compared with other clinical measures. *Mayo Clin Proc.* 2007;82(10):1244-54.
144. Netten A, Burge P, Malley J, Potoglou D, Towers AM, Brazier J, et al. Outcomes of social care for adults: Developing a preference-weighted measure. *Health Technol Assess.* 2012;16(16):1-166.
145. Matthews JNS, Altman DG, Campbell MJ, Royston P. Analysis of serial measurements in medical research. *BMJ.* 1990;300(6719):230-5.
146. Sintonen H. The 15-D measure of health related quality of life: reliability, validity and sensitivity of its health state descriptive system. Working paper 41, Centre for Health Program Evaluation; 1994. Available: http://business.monash.edu/_data/assets/pdf_file/0009/391374/wp41-1.pdf. Accessed 9.11.16.
147. Seiber WJ, Groessl EJ, David KM, Ganiats TG, Kaplan RM. Quality of well being self-administered (QWB-SA) scale. San Diego: Health Services Research Centre, University of California; 2008. Available: <https://hoap.ucsd.edu/qwb-info/QWB-Manual.pdf> Accessed 9.11.16.
148. Kharroubi SA, Brazier JE, Roberts J, O'Hagan A. Modelling SF-6D health state preference data using a nonparametric Bayesian method. *J Health Econ.* 2007;26(3):597-612.
149. Higgins JPT, Green S, editors. *Cochrane Handbook for Systematic Reviews of Interventions: The Cochrane Collaboration*; 2011. Available: www.handbook.cochrane.org. Accessed 9.11.16.
150. Sandström L, Ståhle A. Rehabilitation of elderly with coronary heart disease - Improvement in quality of life at a low cost. *Advances in Physiotherapy.* 2005;7(2):60-6.

151. Anderson CS, Rubenach S, Ni Mhurchu C, Clark M, Spencer C, Winsor A. Home or hospital for stroke rehabilitation? Results of a randomised controlled trial: I: Health outcomes at 6 months. *Stroke*. 2000;31(5):1024-31.
152. Mayo NE, Wood-Dauphinee S, Côté R, Gayton D, Carlton J, Buttery J, et al. There's no place like home: An evaluation of early supported discharge for stroke. *Stroke*. 2000;31(5):1016-23.
153. Berg SK, Svendsen JH, Zwisler AD, Pedersen BD, Preisler P, Siersbæk-Hansen, et al. COPE-ICD: A randomised clinical trial studying the effects and meaning of a comprehensive rehabilitation programme for ICD recipients - Design, intervention and population. *BMC Cardiovasc Disord*. 2007;11:33.
154. West RR, Jones DA, Henderson AH. Rehabilitation after myocardial infarction trial (RAMIT): Multi-centre randomised controlled trial of comprehensive cardiac rehabilitation in patients following acute myocardial infarction. *Heart*. 2012;98(8):637-44.
155. Shyu YIL, Liang J, Tseng MY, Li HJ, Wu CC, Yang CT. Comprehensive and subacute care interventions improve health-related quality of life for older patients after surgery for hip fracture: A randomised controlled trial. *Int J Nurs Stud*. 2013;50(8):1013-24.
156. Shyu YL, Liang J, Wu CC, Su JY, Cheng HS, Chou SW, et al. Two-year effects of interdisciplinary intervention for hip fracture in older Taiwanese. *J Am Geriatr Soc*. 2010;58(6):1081-9.
157. Weaver FM, Hughes SL, Almagor O, Wixson R, Manheim L, Fulton B, et al. Comparison of two home care protocols for total joint replacement. *J Am Geriatr Soc*. 2003;51(4):523-8.
158. Evgeniadis G, Beneka A, Malliou P, Mavromoustakos S, Godolias G. Effects of pre- or postoperative therapeutic exercise on the quality of life, before and after total knee arthroplasty for osteoarthritis. *J Back Musculoskelet Rehabil*. 2008;21(3):161-9.
159. Graves N, Courtney M, Edwards H, Chang A, Parker A, Finlayson K. Cost-effectiveness of an intervention to reduce emergency re-admissions to hospital among older patients. *PLoS ONE*. 2009;4(10):e7445.
160. O'Reilly J, Lawson K, Green J, Young JB, Forster A. Post-acute care for older people in community hospitals—a cost-effectiveness analysis within a multi-centre randomised controlled trial. *Age Ageing*. 2008;37(5):513-20.
161. O'Reilly J, Lawson K, Young A, Young J, Forster A, Green G, et al. A cost effectiveness analysis within a randomised controlled trial of post-acute care of older people in a community hospital. *BMJ*. 2006;333(7561):228.
162. Berg SK, Pedersen PU, Zwisler AD, Winkel P, Gluud C, Pedersen BD, et al. Comprehensive cardiac rehabilitation improves outcome for patients with implantable cardioverter defibrillator. Findings from the COPE-ICD randomised clinical trial. *Eur J Cardiovasc Nurs*. 2015;14(1):34-44.
163. Courtney M, Edwards H, Chang A, Parker A. Fewer emergency readmissions and better quality of life for older adults at risk of hospital readmission: A randomized controlled trial to determine the effectiveness of a 24-week exercise and telephone follow-up program. *J Am Geriatr Soc*. 2009;57(3):395-402.
164. Shyu YL, Liang J, Wu CC, Cheng HS, Chen MC. An interdisciplinary intervention for older Taiwanese patients after surgery for hip fracture improves health-related quality of life. *BMC Musculoskelet Disord*. 2010;11:225.

165. Shyu YIL, Liang J, Wu CC, Su JY, Cheng HS, Chou SW, et al. Interdisciplinary intervention for hip fracture in older taiwanese: Benefits last for 1 year. *J Gerontol A Biol Sci Med Sci*. 2008;63(1):92-7.
166. Drummond M. Introducing economic and quality of life measurements into clinical studies. *Ann Med*. 2001;33(5):344-9.
167. Walters SJ, Brazier JE. Comparison of the minimally important difference for two health state utility measures: EQ-5D and SF-6D. *Qual Life Res*. 2005;14(6):1523-32.
168. Western H. Altered living: Coping, hope and quality of life after stroke. *Br J Nurs*. 2007;16(20):1266-70.
169. Couzner L, Crotty M, Walker R, Ratcliffe J. Examining older patient preferences for quality of care in postacute transition care and day rehabilitation programs. *Health*. 2013;5(6A2):128-35.
170. Mainz J. Defining and classifying clinical indicators for quality improvement. *Int J Qual Health Care*. 2003;15(6):523-30.
171. Boren T, Ramey J. Thinking aloud: Reconciling theory and practice. *IEEE: Transactions on Professional Communication*. 2000;43(3):261-78.
172. Street D, Burgess L. *The Construction of Optimal Stated Choice Experiments: Theory and Methods*. New Jersey: Wiley; 2007.
173. Louviere JJ, Hensher DA, Swait JD. *Stated Choice Methods: Analysis and Applications*. Cambridge: Cambridge University Press; 2000.
174. Folstein MF, Folstein SE, McHugh PR. "Mini Mental State" A practical method for grading the cognitive state of patients for the clinician. *J Psychiat Res*. 1975;12(3):189-98.
175. StataCorp. *Stata Statistical Software: Release 11*. Texas: StataCorp LP; 2009.
176. Ryan M, Watson V, Gerard K. Practical issues in conducting a discrete choice experiment. In: Ryan M, Gerard K, Amaya-Amaya M, editors. *Using Discrete Choice Experiments to Value Health and Health Care*. Dordrecht: Springer; 2008.
177. Ryan M, Gerard K, Amaya-Amaya M, editors. *Using discrete choice experiments to value health and health care*. Dordrecht: Springer; 2008.
178. Lanscar E, Louviere J. Deleting 'irrational' responses from discrete choice experiments: A case of investigating or imposing preferences? *Health Econ*. 2006;15(8):797-811.
179. Cornwell J, Levenson R, Sonola L, Poteliakhoff E. *Continuity of care for older hospital patients: A call for action*. London, The King's Fund; 2012. Available: http://www.kingsfund.org.uk/publications/continuity_of_care.html. Accessed 9.11.16.
180. Jacelon CS. Older adults and autonomy in acute care: Increasing patients' independence and control during hospitalization. *J Gerontol Nurs*. 2004;30(11):29-36.
181. Lothian K, Philp I. Maintaining the dignity and autonomy of older people in the healthcare setting. *BMJ*. 2001;322(7287):668-70.
182. Atwal A, Tattersall K, Murphy S, Davenport N, Craik C, Caldwell K. Older adults experiences of rehabilitation in acute health care. *Scand J Caring Sci*. 2007;21(3):371-8.
183. Lui MHL, Mackenzie AE. Chinese elderly patients' perceptions of their rehabilitation needs following a stroke. *J Adv Nurs*. 1999;30(2):391-400.
184. Australian Government Department of Health. *Personally Controlled Electronic Health Record (PCEHR) Review*. Australian Government; 2013. Available:

<http://www.health.gov.au/internet/main/publishing.nsf/content/ehealth-record>.

Accessed 9.11.16.

185. Westby MD, Backman CL. Patient and health professional views on rehabilitation practices and outcomes following total hip and knee arthroplasty for osteoarthritis: A focus group study. *BMC Health Serv Res.* 2010;10:119.
186. Couzner L, Crotty M, Norman R, Ratcliffe J. A comparison of the EQ-5D-3L and ICECAP-O in an older post-acute patient population relative to the general population. *Appl Hlth Econ Health Policy.* 2013;11(4):415-25.
187. Couzner L, Ratcliffe J, Lester L, Flynn T, Crotty M. Measuring and valuing quality of life for public health research: Application of the ICECAP-O capability index in the Australian general population. *Int J Public Health.* 2013;58(3):367-76.
188. Dawson J, Fitzpatrick R, Carr A, Murray D. Questionnaire on the perceptions of patients about total hip replacement. *J Bone Joint Surg Br.* 1996;78(2):185-90.
189. Jones PW, Quirk FH, Baveystock CM. The St George's Respiratory Questionnaire. *Respir Med.* 1991;85(Suppl B):25-31.
190. Lorgelly P, Lawson KD, Fenwick EAL, Briggs AH. Outcome measurement in economic evaluations of public health interventions: A role for the capability approach? *Int J Environ Res Public Health.* 2010;7(5):2274-89.
191. Sen A. Capability and well-being. In: Nussbaum M, Sen A, editors. *The Quality of Life.* New York: Oxford University Press; 1993.
192. Robeyns I. Sen's capability approach and gender inequality. Selecting relevant capabilities. *Feminist Economics.* 2003;9(2-3):61-92.
193. Flynn T, Chan P, Coast J, Peters TJ. Assessing quality of life among British older people using the ICECAP-O capability measure. *Appl Hlth Econ Health Policy.* 2011;9(5):317-29.
194. Grewal I, Lewis J, Flynn T, Brown J, Bond J, Coast J. Developing attributes for a generic quality of life measure for older people: Preferences or capabilities? *Soc Sci Med.* 2006;62(8):1891-901.
195. Flynn T, Louviere J, Huynh E, Terlich F. What are Australian preferences for quality of life? Results from best-worst scaling studies to value the ICECAP instruments. *Australian Health Economics Society Meeting; 30 Sept - 1 Oct 2010; Sydney, Australia; 2010.*
196. Al-Janabi H, Flynn TN, Coast J. Development of a self-report measure of capability wellbeing for adults: The ICECAP-A. *Qual Life Res.* 2012;21(1):167-76.
197. Greenhalgh J, Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review. *J Eval Clin Pract.* 1999;5(4):401-16.
198. Funk GF, Hynds Karnell L, Dawson CJ, Means ME, Colwill ML, Gliklich RE, et al. Baseline and post-treatment assessment of the general health-status of head and neck cancer patients compared with United States population norms. *Head Neck.* 1997;19(8):675-83.
199. Lindh J, Tondel M, Persson B, Vrethem M. Health-related quality of life in patients with cryptogenic polyneuropathy compared with the general population. *Disabil Rehabil.* 2011;33(7):617-23.
200. Gralnek IM, Hays RD, Kilbourne A, Naliboff B, Mayer EA. The impact of irritable bowel syndrome on health-related quality of life. *Gastroenterology.* 2000;119(3):654-60.

201. March LM, Cross MJ, Lapsley H, Brnabic A, Tribe KL, Bachmeier C, et al. Outcomes after hip or knee replacement surgery for osteoarthritis. A prospective cohort study comparing patients' quality of life before and after surgery with age-related population norms. *Med J Aust.* 1999;171(5):235-8.
202. Sørensen J, Davidsen M, Gudex C, Pedersen KM, Brønnum-Hansen H. Danish EQ-5D population norms. *Scand J Public Health.* 2009;37(5):467-74.
203. Whitehurst DGT, Norman R, Brazier JE, Viney R. Comparison of contemporaneous EQ-5D and SF-6D responses using scoring algorithms derived from similar valuation exercises. *Value Health.* 2014;17(5):570-77.
204. Harrison Research. Health Omnibus Survey. 2010. Available: http://www.harrisonresearch.com.au/health_omnibus.php. Accessed 9.11.16.
205. Viney R, Norman R, King MT, Cronin P, Street DJ, Knox S, et al. Time trade-off derived EQ-5D weights for Australia. *Value Health.* 2011;14(6):928-36.
206. Coast J, Peters TJ, Natarajan L, Sproston K, Flynn T. An assessment of the construct validity of the descriptive system for the ICECAP capability measure for older people. *Qual Life Res.* 2008;17(7):967-76.
207. Brucker PS, Yost K, Cashy J, Webster K, Cella D. General population and cancer patient norms for the Functional Assessment of Cancer Therapy - General (FACT-G). *Eval Health Prof.* 2005;28(2):192-211.
208. Loge JH, Abrahamsen AF, Ekeberg Ø, Kaasa S. Reduced health-related quality of life among Hodgkin's disease survivors: a comparative study with general population norms. *Ann Oncol.* 1999;10(1):71-7.
209. Davis JC, Liu-Ambrose T, Richardson CG, Bryan S. A comparison of the ICECAP-O with EQ-5D in a falls prevention clinical setting: Are they complements or substitutes? *Qual Life Res.* 2012;22(5):969-77.
210. Viney R, Norman R, Brazier J, Cronin P, King MT, Ratcliffe J, et al. An Australian Discrete Choice Experiment to value EQ-5D health states. *Health Econ.* 2014;23(6):729-42.
211. Couzner L, Ratcliffe J, Crotty M. The relationship between quality of life, health and care transition: an empirical comparison in an older post-acute population. *Health Qual Life Outcomes.* 2012;10(69).
212. Coleman EA, Berenson R. Lost in transition: Challenges and opportunities for improving the quality in transitional care. *Ann Intern Med.* 2004;140(7):533-36.
213. Coleman EA, Fox PD, HMO Care Management Workgroup. One patient, many places: Managing health care transitions. Part 1: Introduction, accountability, and information transfer. *Ann Longterm Care.* 2004;12(9):25-32.
214. Hastings S, Kosmoski J, Moss J. Special considerations of adherence in older adults. In: Bosworth H, editor. *Improving Patient Treatment Adherence: A Clinician's Guide.* London: Springer; 2010.
215. Balkrishnan R. Predictors of medication adherence in the elderly. *Clin Ther.* 1998;20(4):764-71.
216. Banning M. Older people and adherence with medication: A review of the literature. *Int J Nurs Stud.* 2008;45(10):1550-61.
217. Conrad P. The meaning of medications: Another look at compliance. *Soc Sci Med.* 1985;20(1):29-37.
218. Lowe C, Raynor D, Purvis J, Farrin A, Hudson J. Effects of a medicine review and education programme for older people in general practice. *Br J Clin Pharmacol.* 2000;50(2):172-5.
219. Osterberg L, Blaschke T. Adherence to medication. *N Engl J Med.* 2005;353(5):497-97.

220. Ryan A. Medication compliance and older people: A review of the literature. *Int J Nurs Stud.* 1999;36(2):153-62.
221. McCarberg B, Barkin R. Long-acting opioids for chronic pain: Pharmacotherapeutic opportunities to enhance compliance, quality of life, and analgesia. *Am J Ther.* 2001;8(3):181-6.
222. Holt E, Munter P, Joyce C, Webber L, Krousel-Wood M. Health-related quality of life and antihypertensive medication adherence among older adults. *Age Ageing.* 2010;39(4):481-7.
223. Hovinga C, Asto M, Manjunath R, Wheless J, Phelps S, Sheth R, et al. Association of non-adherence to antiepileptic drugs and seizures, quality of life, and productivity: Survey of patients with epilepsy and physicians. *Epilepsy Behav.* 2008;13(6):316-22.
224. Carballo E, Cadarso-Suárez C, Carrera I, Fraga J, de la Fuente J, Ocampo A, et al. Assessing relationships between health-related quality of life and adherence to antiretroviral therapy. *Qual Life Res.* 2004;13(3):587-99.
225. Leenerts M, Teel C, Pendleton M. Building a model of self-care for health promotion in aging. *J Nurs Scholarsh.* 2002;34(4):355-61.
226. Holman H, Lorig K. Overcoming barriers to successful aging: Self-management of osteoarthritis. *West J Med.* 1997;167(4):265-8.
227. Tu Y, Wang R, Yeh S. Relationship between perceived empowerment care and quality of life among elderly residents within nursing homes in Taiwan: A questionnaire survey. *Int J Nurs Stud.* 2006;43(6):673-80.
228. Clark P. The philosophical foundation of empowerment: Implications for geriatric health care programs and practice. *J Aging Health.* 1989;1(3):267-85.
229. Hage A, Lorensen M. A philosophical analysis of the concept empowerment; The fundament of an education-programme to the frail elderly. *Nurs Philos.* 2005;6(4):235-46.
230. Barkay A, Tabak N. Elderly residents' participation and autonomy within a geriatric ward in a public institution. *Int J Nurs Pract.* 2002;8(4):198-209.
231. Montgomery AA, Fahey T. How do patients' treatment preferences compare with those of clinicians? *Qual Health Care.* 2001;10(Suppl 1):i39-i43.
232. Laver K, Ratcliffe J, George S, Lester L, Crotty M. Preferences for rehabilitation service delivery: A comparison of the views of patients, occupational therapists and other rehabilitation clinicians using a discrete choice experiment. *Aust Occup Ther J.* 2013;60(2):93-100.
233. Davis JC, Bryan S, McLeod R, Rogers J, Khan K, Liu-Ambrose T. Exploration of the association between quality of life, assessed by the EQ-5D and ICECAP-O, and falls risk, cognitive function and daily function, in older adults with mobility impairments. *BMC Geriatrics.* 2012;12:65.
234. Cummins RA, Nistico H. Maintaining Life Satisfaction: The Role of Positive Cognitive Bias. *J Happiness Stud.* 2002;3(1):37-69.
235. Groot W. Adaptation and scale of reference bias in self-assessments of quality of life. *J Health Econ.* 2000;19(3):403-20.
236. Fuhrer MJ. Subjectifying quality of life as a medical rehabilitation outcome. *Disabil Rehabil.* 2000;22(11):481-9.
237. Bilotta C, Bowling A, Nicolini P, Case A, Pina G, Rossi SV, et al. Older people's quality of life (OPQOL) scores and adverse health outcomes at a one-year follow-up. A prospective cohort study on older outpatients living in the community in Italy. *Health Qual Life Outcomes.* 2011;9:72.

Appendices

APPENDIX 1 - MEDLINE SEARCH STRATEGY

- 1 Quality of Life.mp. or "Quality of Life"/
- 2 Quality-Adjusted Life Years.mp. or Quality-Adjusted Life Years/
- 3 Health/ or health.mp. or Health Status Indicators/ or Health Status/
- 4 Recovery of Function/
- 5 "health status".mp.
- 6 self-reported health.mp.
- 7 or/1-6
- 8 ("EQ-5D" or "EQ5D" or "EuroQoL").mp.
- 9 AQoL.mp.
- 10 ("SF-12" or "SF12").mp.
- 11 ("15D" or "15-D").mp.
- 12 ("SF-6D" or "SF6D").mp.
- 13 ("SF-36" or "SF36").mp. or Short Form 36/
- 14 ("quality of well-being scale" or "QWB").mp.
- 15 ("Health utility index" or "HUI").mp.
- 16 or/8-15
- 17 rehabilitation.mp. or Rehabilitation/
- 18 exp "Outcome and Process Assessment (Health Care)"/ or exp Treatment Outcome/
- 19 health facilities/ or ambulatory care facilities/ or community health centers/ or outpatient clinics, hospital/ or Rehabilitation Centres.mp.
- 20 Hospitals, Convalescent/ or Hospitals/ or Hospitals, Community/

- 21 comprehensive health care/ or "continuity of patient care"/ or patient care team.mp.
- 22 Rehabilitation Nursing/
- 23 Community Health Services/ or Community Health Nursing/ or Counselling/ or Home Care Services, Hospital-Based/ or Health Services For The Aged/ or Social Work/ or exp Nursing Care/ or Home Care Services/ or Home Nursing/ (215749)
- 24 ((geriatric or interdisciplinary or inter-disciplinary or inter disciplinary or multi-disciplinary or multidisciplinary or multi disciplinary or early or post-operative or post operative or postoperative or post-surgical or post surgical or postsurgical or home* or intensive or accelerated or intervention or functional) adj2 (intervention or care or rehabilitation or program* or approach or group or recovery)).tw.
- 25 Patient Care Team/ or multidisciplinary.mp.
- 26 rehabilitation/ or early ambulation/ or exp exercise therapy/ or occupational therapy/ or "rehabilitation of speech and language disorders"/ or rehabilitation, vocational/
- 27 postoperative period/
- 28 outpatients/
- 29 or/17-28
- 30 acute.mp.
- 31 ("subacute" or "sub-acute" or "sub acute").mp. or Subacute care/
- 32 ("post-acute" or "post acute" or "postacute").mp.
- 33 or/30-32
- 34 exp Aged/
- 35 older people.mp.
- 36 geriatr*.mp.

37 or/34-36

38 7 and 16 and 29 and 33 and 37

39 randomized controlled trial.pt.

40 controlled clinical trial.pt.

41 randomized.ab.

42 randomly.ab.

43 trial.ab.

44 groups.ab.

45 or/39-44

46 (animals not (humans and animals)).sh.

47 45 not 46

48 38 and 47

49 limit 48 to (english language and humans and ("all aged (65 and over)" or "aged (80 and over)"))

50 from 49 keep 1-203

APPENDIX 2 - EXAMPLE OF CONVERSION OF SF-36 VALUES TO EQ-5D-3L INDEX SCORES AS USED IN CHAPTER 3

Mean SF-36 subscale values reported in Mayo et al.¹⁵²

Physical function index (PF) – 54.3

Social function (SF) – 59.6

Role: physical (RP) – 23.7

Role: emotional (RE) – 53.6

Mental health index (MH) – 67.1

Vitality (VT) – 53.1

Bodily pain (BP) – 73.5

General health perceptions (GH) – 62.6

Algorithm used to convert from SF-36 subscale values to EQ-5D-3L index score.⁶⁷

$$\text{EQ-5D-3L} = 0.03256 + 0.0037 \times \text{PF} + 0.00111 \times \text{SF} - 0.00024 \times \text{RP} + 0.00024 \times \text{RE} + \\ 0.00256 \times \text{MH} - 0.00063 \times \text{VT} + 0.00286 \times \text{BP} + 0.00052 \times \text{GH}$$

$$\text{EQ-5D-3L} = 0.03256 + 0.0037 \times 54.3 + 0.00111 \times 59.6 - 0.00024 \times 23.7 + 0.00024 \times \\ 53.6 + 0.00256 \times 67.1 - 0.00063 \times 53.1 + 0.00286 \times 73.5 + 0.00052 \times 62.6$$

$$\text{EQ-5D-3L} = 0.688$$

**APPENDIX 3 - QUESTIONNAIRE ADMINISTERED TO PATIENT
PARTICIPANTS REPORTED ON IN CHAPTERS 4, 5 AND 6**

Client V1

**A survey of client preferences for rehabilitation services
following a hospital stay for older people**

We would like to invite you to participate in a research project that seeks to obtain client preferences concerning rehabilitation services following a hospital stay for older people.

The results of this survey will be used to write a report and publications that will help guide policy makers and health care professionals in making decisions about the future planning and organisation of rehabilitation services for older people.

Your participation in this survey is entirely voluntary. All of the information you provide will be confidential. It will be used for research purposes only and will not be used in any way in which you can be identified.

Thank you for your co-operation.

Ms Leah Couzner¹

Associate Professor Julie Ratcliffe¹

Professor Maria Crotty¹

Dr Ruth Walker²

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Client V1

Section A

In this section of the questionnaire we are interested in obtaining your views about a number of statements relating to the administration and delivery of rehabilitation services following a stay in hospital. We would like you to read through each of the statements below and indicate the extent to which you agree or disagree with each statement by placing a tick (✓) in the relevant box next to each statement.

Please note there are no wrong or right answers to any of these statements. We are interested in your views.

Strongly Agree Agree Neither agree nor disagree Disagree Strongly disagree

1. Older people should be involved in decisions about their own future care wherever possible					
2. An intensive rehabilitation programme can make a substantial difference to older people's functioning and quality of life					
3. The immediate family (rather than the older person) is best placed to make decisions about the older person's future care					
4. The development of self confidence is a key ingredient in improving older people's functioning					
5. The communication between health care professionals in different settings is poor (e.g. between hospitals and nursing homes or G.Ps)					
6. The communication between health care professionals and the older person and their family is poor					
7. The health care services an older person requires should be made available to them regardless of the costs to the health service					
8. Currently there aren't enough rehabilitation services available for the older people who need them					
9. Currently there aren't enough nursing home beds for the older people who need them					

Client V1

Section B

In this section we would like you to choose between two hypothetical scenarios. Below is an example that you may encounter in your every day life.

Example

If you imagine that you are going shopping. The first column shows things that you may consider when deciding which shop you will go to. The other two columns show the information you may use to make your decision. In some ways Shop A may seem like the best option, but in others, Shop B may seem better.

Which shop would you visit?

Please note there is no right or wrong answer to this. We are interested in your views

Characteristics	Shop A	Shop B
Variety of products	A lot of products	Few products
Location	Far away from home	Close to home
Parking	A lot of car parks	Few car parks
Price of products	Cheaper	More expensive
Quality of service	Poor service	Good service

The next scenarios are about rehabilitation for older people after a hospital stay. We will now give you 6 pairs of hypothetical rehabilitation programmes for you to choose between. Each programme is described in terms of its characteristics. The possible differences between the programmes are:

1. **Family and patient involvement in the decision to move from hospital to the next destination** e.g. returning home, moving to a nursing home
 - **None:** Clinicians make the decision and the family and patient are informed afterwards
 - **Shared:** The family and patient make a joint decision with the clinicians
 - **Total:** The family and patient make their own decision to move without any involvement from the clinicians

2. How your medical history is transferred between the health care professionals who are caring for you

- **No record:** No written record or verbal communication is received about the patient
- **A written summary:** A written summary of the patient's condition and current medications is received within one week of the patient being transferred
- **Full electronic record:** A full electronic record of the patient's health background, previous health care usage and past and current medications is automatically transferred with the client

3. Intensity of rehabilitation programme

- **Once weekly therapy:** Once weekly group therapy delivered by a physiotherapist only
- **Twice weekly therapy:** Twice weekly physiotherapy and occupational therapy is delivered to you individually by skilled health care professionals (e.g. physiotherapists, psychologists, occupational health therapists and trained care workers)
- **Daily therapy:** Daily physiotherapy and occupational therapy is delivered to you individually by skilled health care professionals (e.g. physiotherapists, psychologists, occupational health therapists and trained care workers)

4. How you will get information about your health and treatment whilst receiving care

- **Only if you ask:** You will get information from health care professionals if you ask them.
- **Social Worker and Junior Doctor:** A meeting for you and a family member with a social worker and junior doctor
- **Senior Doctor and Specialist Nurse with follow-up and summary:** A meeting held at your convenience between you and a family member with a senior doctor and a specialist aged care nurse. You will be given a written summary, and a recording of the meeting on CD. You will also receive a follow up meeting and phone call from the specialist aged care nurse

Client V1

5. Duration of rehabilitation therapy provided

- **A set period of 2 weeks:** The care will finish after a set period regardless of how well you are at that time.
- **Decided by medical team:** Your medical team (doctor, physiotherapist etc) tells you that there is no more to be gained from continuing the therapy.
- **Until you think you are well:** However long you need to have therapy for until you think you are well again

Six pairs of choices are presented on the cards. Some of the characteristics of each choice change in every pair. Imagine you are offered the choice between two programmes with different characteristics. For each of the choices on the cards which programme would you choose? Would you prefer the program you have chosen to the rehabilitation that you are currently receiving?

Please note there are no right or wrong answers to these choices. We are interested in your views

1. How difficult did you find these questions to complete?

Very difficult	
Moderately difficult	
Slightly difficult	
Not difficult	

If you found them difficult, what do you think made them difficult to answer?

Section C

We would be grateful if you could provide a few details about yourself. All of the information you provide will be treated in complete confidence and used for research purposes only.

1. What is your age?
(years)

2. Are you? *(Please tick appropriate box):*

Male	
Female	

3. Do you live? *(Please tick appropriate box):*

On your own	
With spouse	
With other family	
With others – not relatives	
In a nursing home	

4. What is the highest educational qualification you have?

Primary school	
Some secondary school	
Completed high school	
Some additional training (eg TAFE, apprenticeship)	
Undergraduate university	
Postgraduate university	

5. Were you born in Australia?

Yes	
No	

If No please can you tell us what country you were born in?

.....

6. What is your post-code?

.....

7. Do you have a family member who acts as your carer?

Yes	
No	

8. How long ago did you last stay in hospital overnight?

Less than 1 month	
1-2 months	
2-3 months	

Client V1

9. What was the reason for your last stay in hospital?
.....

10. What date did you begin receiving your current rehabilitation?
.....

11. What is the medical condition that you are currently receiving rehabilitation for?
.....

Here are some simple questions about the time you were in hospital. By ticking one answer in each group below, please indicate which statements best describes your own experiences.

12. The hospital staff took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left the hospital

(Please tick appropriate box):

Strongly disagree	
Disagree	
Agree	
Strongly agree	
Don't know/Not applicable	

13. When I left the hospital I had a good understanding of the things I was responsible for in managing my health

(Please tick appropriate box):

Strongly disagree	
Disagree	
Agree	
Strongly agree	
Don't know/Not applicable	

14. When I left the hospital I clearly understood the purpose for taking each of my medications

(Please tick appropriate box):

Strongly disagree	
Disagree	
Agree	
Strongly agree	
Don't know/Not applicable	

Client V1

Here are some simple questions about your health quality of life in general. By ticking one answer in each group below, please indicate which statements best describes your health and quality of life today.

Please tick one

15. Mobility
- I have no problems in walking about
 - I have some problems in walking about
 - I am confined to bed
16. Self-care
- I have no problems with self-care
 - I have some problems washing or dressing myself
 - I am unable to wash or dress myself
17. Usual Activities
- I have no problems with performing my usual activities
(e.g. work, study, housework, family or leisure activities)
 - I have some problems with performing my usual activities
 - I am unable to perform my usual activities
18. Pain/Discomfort
- I have no pain or discomfort
 - I have moderate pain or discomfort
 - I have extreme pain or discomfort
19. Anxiety/Depression
- I am not anxious or depressed
 - I am moderately anxious or depressed
 - I am extremely anxious or depressed
20. Attachment
- I can have all of the love and friendship that I want
 - I can have a lot of the love and friendship that I want
 - I can have a little of the love and friendship that I want
 - I cannot have any of the love and friendship that I want

8

Client V1

21. Security

- I can think about the future without any concern
- I can think about the future with only a little concern
- I can only think about the future with some concern
- I can only think about the future with a lot of concern

22. Role

- I am able to do all of the things that make me feel valued
- I am able to do many of the things that make me feel valued
- I am able to do a few of the things that make me feel valued
- I am unable to do any of the things that make me feel valued

23. Enjoyment

- I can have all of the enjoyment and pleasure that I want
- I can have a lot of the enjoyment and pleasure that I want
- I can have a little of the enjoyment and pleasure that I want
- I cannot have any of the enjoyment and pleasure that I want

24. Control

- I am able to be completely independent
- I am able to be independent in many things
- I am able to be independent in a few things
- I am unable to be at all independent

Do you have any comments that you would like to make about this questionnaire *(please write these in the space provided below)*

.....
.....
.....

Thank you for taking the time to complete this questionnaire.

Appendix 4: Peer reviewed publications arising from this research

The findings from these publications are reported on in chapters 4, 5 and 6 of this thesis.

Examining older patient preferences for quality of care in postacute transition care and day rehabilitation programs

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ABSTRACT

Background: Quality in health care has traditionally been determined based on clinical or health outcomes. However, these factors may not be the only aspects of health care that are important to patients. Within rehabilitation factors related to the process of care, the way in which rehabilitation services are delivered, may also be important to patients when defining quality of care. **Objective:** The purpose of this study was to examine and compare the preferences of older people receiving post-acute outpatient rehabilitation or residential intermediate (transition) care for alternative configurations of rehabilitation programs. **Methods:** A discrete choice experiment (DCE) was designed to elicit the preferences of older people for the design and delivery of post-acute rehabilitation programs. The participants were older adults (≥65 years) receiving post-acute outpatient rehabilitation or residential intermediate (transition) care in South Australia. Each participant was presented with a series of choice questions involving two hypothetical programs, the characteristics of which varied in every choice. Participants were then asked to select their preferred program. **Results:** Despite marked differences in case-mix and dependency levels, the preferences of the two groups were very similar, focusing on relationships and communication with health care professionals. Both groups demonstrated very strong preferences for the use of an electronic medical record and for receiving information about their treatment and

progress via a meeting with a specialist physician and nurse. The outpatient rehabilitation group also exhibited a strong preference for a shared decision making model in relation to their future care needs. **Conclusions:** The findings highlight the commonality of preferences of older patients receiving post-acute services for the optimal configuration of rehabilitation services. Issues prioritised were service integration and access to senior medical and nursing staff. The study demonstrates the practicality and validity of DCEs to determine older people's preferences in defining quality of care.

Keywords: DCE; Patient Preferences; Aged; Rehabilitation; Intermediate Care Facilities

1. INTRODUCTION

Quality in health care has been traditionally based upon the views of health professionals and largely focused upon the measurement of clinical and health outcomes of patients [1]. The disadvantage of this approach lies in the possibility that the factors which are considered as most important to health professionals may not be the factors which are most important to patients themselves. Health outcomes may not be the only aspect of health care of importance to older people and their families [1,2]. The process of receiving health care, for example waiting time, continuity of care, or treatment type may also be a highly important indicator of quality of care [3-6].

To date, the quality of health care from the patient's perspective has typically been measured using methods such as patient satisfaction surveys. However, several

studies using patient satisfaction surveys have found older people are more likely than younger participants to give socially-desirable responses, are less inclined to complain and more likely to express gratitude [7,8]. A systematic review by Crow and colleagues on patient satisfaction revealed that older people are generally more likely to agree with questions worded in a positive way, thereby bringing the accuracy of their responses into question, and also more likely to report high levels of satisfaction, potentially due to lower expectations of health care [8,9].

Given the predicted increase in life expectancy, subsequent ageing population and increased demand on health and social care services, it is important for preference elicitation techniques to be available that are suitable for use with older adults. A preference elicitation method that is becoming more commonly utilised within the health care sector is the discrete choice experiment (DCE). This approach defines health care interventions or services in terms of their key characteristics or attributes and their associated levels. Within a DCE, respondents are presented with a series of hypothetical scenarios describing different health care interventions from which they are asked to indicate their preferences. Each scenario is described in terms of its characteristics (attributes) which consist of varying levels. For example an attribute of "chance of complete recovery" may have corresponding levels of 50%, 75% and 100%. It is assumed that respondents will make trade-offs between the attributes in order to choose their preferred scenario. Their final choices can then be analysed to interpret the influence of each attribute on their overall decision [10]. The overall utility or benefit that would be gained from alternative scenarios can also be determined. An additional advantage of DCEs is that they enable the relative importance of multiple aspects of health care to be assessed simultaneously. Thus DCEs may include health-related outcomes such as mortality rate, non-health related outcomes including cost of treatment, or elements of health care process such as type of treatment, or a combination of these elements.

Despite their increasing prevalence and widespread utilisation in the health care sector, DCEs have rarely been utilised in rehabilitation medicine with populations of older people [2,11,12]. Previous work has suggested that patients' current state of health may influence their assessment of quality of care and what components of care are important [5,13]. Therefore, we hypothesised that depending on the stage of recovery, older people in post-acute care programs would prioritise different issues. For example those in day rehabilitation who had recovered well enough to go home and return for outpatient treatment might have a higher interest in the approach to therapy delivery than in factors relating to medical man-

agement and service integration. Once identified these differences might allow changes in service models. The main aim of this study was to examine and compare the preferences of older people currently receiving either outpatient rehabilitation or transition care following an acute event for alternative configurations of rehabilitation programs.

2. METHOD

2.1. Scenario Development/Experiment Design

The selection and description of the key attributes and levels was developed via consultation with a panel of clinicians, a literature review and a series of qualitative interviews ($n = 20$) with older rehabilitation patients (aged 65 years and over) to ascertain the aspects of post-acute rehabilitation of importance to patients following an acute hospital stay. Five attributes were developed, each consisting of 3 levels as shown in **Table 1**. This resulted in 243 possible scenarios for presentation in the form of hypothetical rehabilitation programs with varying attribute levels. This was reduced to a more manageable number for the purposes of valuation using a fractional factorial design and the techniques described in Street and Burgess [14] resulting in 18 binary choice sets which were 100% efficient for estimating the main effects. The 18 binary choice sets were divided into 4 blocks or versions, 2 of which contained 4 choice sets and 2 consisting of 5 choice sets to reduce the cognitive burden upon respondents. An example of a choice set is presented in **Table 2**.

Prior to the main DCE study, a small pilot study was conducted with older people receiving outpatient rehabilitation ($n = 20$), firstly to check the realism and relevance of the attributes and levels presented from the participants' perspective and secondly to check understanding and completion rates. A within-experiment reliability test was also included within the experiment, whereby participants were presented with the same choice set twice, once near to the beginning of the DCE task and then again at the end.

2.2. Data Collection

Participants were recruited from an outpatient day rehabilitation program at the Repatriation General Hospital, a 300 bed acute care hospital in metropolitan Adelaide, South Australia, and a residential post-acute intermediate care (transition care) facility providing rehabilitation type care to people aged 65 and over. These two groups were selected as they represent differing levels of independence and forms of post-acute care after being discharged from an acute health care setting. Inclusion cri-

Table 1. DCE attributes and levels.

Attributes	Levels
Family and patient involvement in the decision to move from hospital to the next destination e.g. returning home, moving to a nursing home	Clinicians make the decision and the family and patient are informed afterwards
	Shared decision making with clinicians
	The family and patient make their own decision to move without any involvement from the clinicians
How the patient's medical history is transferred between the health care professionals who are caring for them	No record is received about the patient
	A written summary of the patient's condition and current medications is received within one week of the patient being transferred
	A full electronic record of the patient's health background, previous health care usage and past and current medications is automatically transferred with the patient
Intensity of rehabilitation programme	Once weekly group therapy delivered by a physiotherapist
	Twice weekly individual physiotherapy and occupational therapy delivered by skilled health care professionals
	Daily individual physiotherapy and occupational therapy delivered by skilled health care professionals
How the patient will get information about their health and treatment whilst receiving care	Patient will get information from health care professionals if they ask them.
	A meeting for the patient and a family member with a social worker and junior doctor
	A meeting between the patient and a family member with a senior doctor and specialist aged care nurse with take home written summary and audio recording, and follow up meeting and phone call from the nurse
Duration of rehabilitation therapy provided	A set period of 2 weeks
	Decided by medical team
	Until the patient thinks they are well

Teria were: aged ≥ 65 years, Mini Mental Sate Examination (MMSE) score of ≥ 24 [16], receiving outpatient day rehabilitation or residential intermediate (transition) care following an acute hospital admission; absence of communication or comprehension difficulties, e.g. dysphasia or non-English speaking background as determined by the treating health care team.

The participants completed the questionnaire via a face-to-face interview approximately 4 weeks after commencing rehabilitation or transition care. The questionnaire contained 3 sections. Section A comprised a series of attitudinal statements regarding rehabilitations services and health care for older people. The statements were accompanied by a likert-type scale in which participants indicated the level to which they agreed or disagreed with each statement. Section B contained the DCE task. Section C included measures of self-reported health status, the quality of transition between health

Table 2. Example choice set.

	Program A	Program B
Patient & family involvement in the decision to move from hospital to the next destination	None	Shared
How your medical history is transferred between the health care professionals who are caring for you	Full electronic record	A written record
Intensity of rehabilitation programme	Twice weekly therapy	Daily therapy
How you will get information about your health and treatment whilst receiving care	Senior doctor and specialist aged care nurse with follow up and summary	Social worker and junior doctor
Duration of rehabilitation therapy provided	Decided by team	Until you think you are well

settings and a series of socio-demographic questions.

2.3. Data Analysis

A random effects regression model within the software package STATA version 11 [16] was estimated to analyse the influence of the 5 attributes on participants' choices whereby the scenario chosen by the participant, hypothetical program A or B, was the binary dependent variable and the levels of each attribute were the explanatory variables. The attribute levels were dummy coded [17] and the base levels were excluded from the regression model. Statistical significance of the coefficient attached to a particular attribute level indicates the relative importance of the attribute level in influencing participants' choices. A positive coefficient indicates that the attribute level was associated with increased utility, whilst a negative coefficient indicates that the attribute level was associated with a reduction in utility.

Participants may exhibit dominant preferences when completing DCEs in which they appear to make choices between scenarios based upon a single attribute alone rather than trading between all the of attribute levels presented. As these responses are not necessarily invalid, excluding them may result in sample selection bias and statistical inefficiency [18]. For this reason, participants who displayed dominant preferences were identified, but not excluded from the analysis. Participants who did not pass the within-experiment reliability test were excluded from the analysis.

Approval to conduct the study was obtained from the Southern Adelaide Health Service/Flinders University Human Research Ethics Committee.

3. RESULTS

A total of 80 participants completed the DCE task. The participants had a mean age of 76.94 years (SD 0.86),

with the intermediate (transition) care group being slightly older than the outpatient day rehabilitation group [mean age 80.30 (range 65 - 89) and 74.79 (range 66 - 92) respectively]. At the time of interview, the intermediate (transition) care recipients had been receiving post-acute care for a longer duration than the outpatient rehabilitation recipients [mean days 41.15 (SD 20.78) and 33.88 (SD 16.58) respectively]. The most common reason for receiving post-acute care for the intermediate (transition) care group was orthopaedic diagnoses such as fractures ($n = 15$, 56%), while neurological diagnoses such as stroke were the most common reason for the outpatient rehabilitation group ($n = 24$, 57%). Eleven (14%) participants failed the within experiment reliability test and were therefore excluded from the DCE data analysis giving a total of 69 participants included (outpatient rehabilitation $n = 42$; intermediate care $n = 27$). The demographics of the included participants are presented in **Table 3**.

The results of the random effects regression models are presented in **Table 4**. Both the intermediate (transition) care and day rehabilitation groups demonstrated very strong preferences for the transfer of a full electronic

medical record between health professionals caring for an older person (coefficient 0.93, $p \leq 0.001$ and coefficient 0.79, $p \leq 0.001$ respectively). Very strong preferences were also shown by both groups for the medical team determining the duration of rehabilitation therapy (transition care coefficient 0.63, $p \leq 0.001$; rehabilitation coefficient 0.80, $p \leq 0.001$).

Both groups displayed a strong preference for older people to receive information about their treatment and progress via a meeting with senior specialist staff (medical and nursing) with follow-up and a take-home audio recording of the meeting the most preferred level. The intermediate (transition) care recipients demonstrated a stronger preference for this particular attribute level than the rehabilitation group (coefficient 1.03, $p = 0.01$ and coefficient 0.62, $p = 0.01$ respectively). Additionally, the outpatient day rehabilitation group exhibited a very strong preference for shared decision making, with medical staff regarding the post-acute discharge destination (coefficient 0.89, $p \leq 0.001$). The majority of participants ($n = 44$, 64%) displayed non-dominant preferences as shown in **Table 5**, suggesting that most participants were trading

Table 3. Participant characteristics.

Characteristic	Outpatient rehabilitation patients $n = 42$	Residential transition care patients $n = 27$	All participants $n = 69$
Age (mean years, sd)	74.79 (6.63)	80.30 (6.59)	76.94
Cognition (mean MMSE score, sd)	28.17 (1.81)	28.11 (1.58)	28
Post-acute care duration (mean days, sd)	33.88 (16.58)	41.15 (20.78)	37
EQ-5D score (mean, sd)	0.52 (0.24)	0.53 (0.28)	0.52 (0.26)
<i>Gender</i>			
Male	20 (48%)	11 (41%)	31 (45)
Female	22 (52%)	16 (59%)	38 (55)
<i>Has an informal carer</i>			
Yes	28 (67%)	19 (70%)	47 (68)
No	14 (33%)	8 (30%)	22 (32)
<i>Residential Status</i>			
Living alone	10 (24%)	19 (70%)	29 (42)
Living with others	32 (76%)	8 (30%)	40 (58)
<i>Country of Birth</i>			
Australia	32 (76%)	22 (81%)	54 (78)
Other	10 (24%)	5 (19%)	15 (22)
<i>Highest Education</i>			
Primary or secondary	21 (50%)	18 (72%)	39 (58)
Tertiary	21 (50%)	7 (28%)	28 (42)
<i>Reason for post-acute care (%)</i>			
Neurological	24 (57%)	1 (4%)	27 (39)
Orthopaedic	7 (17%)	15 (56%)	24 (35)
Functional decline/falls/mobility	7 (17%)	7 (26%)	14 (20)
Other	4 (10%)	4 (15%)	4 (5)

Table 4. Results of random effects probit regression model (DCE) by therapy group.

Attribute	Outpatient Rehabilitation (n = 42)			Residential Transition Care (n = 27)		
	Coefficient	Standard Error	p Value	Coefficient	Standard Error	p Value
Shared**	0.89	0.24	≤0.001	0.40	0.30	0.19
Total	0.36	0.20	0.08	0.32	0.26	0.22
Written†	0.33	0.19	0.07	0.59	0.23	0.01
Full**††	0.79	0.19	≤0.001	0.93	0.29	≤0.001
Twice	0.18	0.19	0.35	0.01	0.24	0.99
Daily†	0.18	0.18	0.30	0.67	0.28	0.02
Junior	0.19	0.20	0.39	0.28	0.23	0.22
Specialist††	0.62	0.25	0.01	1.03	0.37	0.01
Team**††	0.80	0.19	≤0.001	0.63	0.20	≤0.001
You*†	0.50	0.19	0.01	0.55	0.23	0.02

Number of obs = 189 Number of obs = 122
 Number of groups = 42 Number of groups = 27
 Wald Chi2 (10) = 36.09 Wald Chi2 (10) = 26.21
 Log likelihood = -94.22 Log likelihood = -58.48

*Significant at the 5% level for outpatient rehabilitation group; **Significant at the 1% level for outpatient rehabilitation group; †Significant at the 5% level for residential transition care group; ††Significant at the 1% level for residential transition care group.

Table 5. Dominant preferences for attributes.

Attribute	Participants (n, %)		
	Rehabilitation n = 42	Transition Care n = 27	Total n = 69
Involvement	1 (2)	-	1 (1)
History	5 (12)	5 (19)	10 (14)
Intensity	4 (10)	-	4 (5)
Information	-	3 (11)	3 (4)
Duration	3 (7)	4 (15)	7 (10)
No dominance	29 (69)	15 (56)	44 (64)

between all the attributes rather than making choices based on one or more particular attribute. However, the intermediate (transition) care recipients were more likely than the outpatient day rehabilitation recipients to exhibit dominant preferences ($n = 12$, 44% and $n = 13$, 31% respectively). The attribute most commonly associated with dominance for both groups was the use of an electronic medical record to transfer patients' medical history between the staff caring for them at different sites (rehabilitation: $n = 5$, 12%; transition care: $n = 5$, 19%).

The responses to the attitudinal statements are presented in **Table 6**. The outpatient day rehabilitation recipients were more likely than the intermediate (transition) care recipients to strongly agree that older people should be involved in decisions about their own future care wherever possible ($n = 28$, 67% vs. $n = 12$, 44%). A greater percentage of the day rehabilitation group also strongly agreed that an intensive rehabilitation programme can make a substantial difference to older people's functioning and quality of life ($n = 26$, 62% vs. $n =$

11, 41%). The responses of the rehabilitation group were found to be very similar to those of the intermediate (transition) care group for all of the remaining attitudinal statements.

4. DISCUSSION

This pilot study aimed to examine and compare the preferences of older people receiving either outpatient day rehabilitation or residential intermediate (transition) care following an acute event for alternative configurations of rehabilitation programs. Although the two patient groups differed in terms of their clinical characteristics, the elements of service provision that define quality of health care proved to be very similar for both groups. The high rates of completion and participants' understanding provides support for the practicality and face validity of the DCE approach in an older population. The preferences demonstrated in the DCE results also generally corresponded with the opinions expressed in the attitudinal statements demonstrating a high degree of convergent validity. Both groups prioritised continuity of care and communication as a key feature of high quality post-acute care which is consistent with UK reports on the hospital experiences of older adults with multiple health problems [19].

The only marked difference between groups related to shared decision making, with the outpatient rehabilitation recipients expressing much stronger preferences overall to be involved in decisions about their own future care. A possible explanation for this may be that the rehabilitation group were further along their recovery trajectory and may have felt more confident in participating in de-

Table 6. Dominant preferences for attributes.

	Outpatient Rehabilitation (n = 42)					Transition Care (n = 27)				
	Strongly agree n (%)	Agree n (%)	Neither agree nor disagree n (%)	Disagree n (%)	Strongly disagree n (%)	Strongly agree n (%)	Agree n (%)	Neither agree nor disagree n (%)	Disagree n (%)	Strongly disagree n (%)
Older people should be involved in decisions about their own future care wherever possible	28 (67%)	14 (33%)	-	-	-	12 (44%)	14 (52%)	1 (4%)	-	-
An intensive rehabilitation programme can make a substantial difference to older people's functioning and quality of life	26 (62%)	14 (33%)	2 (5%)	-	-	11 (41%)	14 (52%)	2 (7%)	-	-
The immediate family (rather than the older person) is best placed to make decisions about the older person's future care	5 (12%)	15 (36%)	6 (14%)	16 (38%)	-	4 (15%)	7 (26%)	7 (26%)	7 (26%)	2 (7%)
The development of self confidence is a key ingredient in improving older people's functioning	21 (50%)	20 (48%)	1 (2%)	-	-	11 (41%)	14 (52%)	2 (7%)	-	-
The communication between health care professionals in different settings is poor (e.g. between hospitals and nursing homes or GPs)	7 (17%)	7 (17%)	11 (26%)	14 (33%)	3 (7%)	-	11 (41%)	8 (30%)	8 (30%)	-
The communication between health care professionals and the older person and their family is poor	3 (7%)	4 (10%)	5 (12%)	27 (64%)	3 (7%)	2 (7%)	4 (15%)	2 (7%)	16 (59%)	2 (7%)
The health care services an older person requires should be made available to them regardless of the costs to the health service	12 (29%)	22 (52%)	5 (12%)	3 (7%)	-	10 (37%)	12 (44%)	1 (4%)	3 (11%)	1 (4%)
Currently there aren't enough rehabilitation services available for the older people who need them	7 (17%)	14 (33%)	11 (26%)	10 (24%)	-	6 (22%)	11 (41%)	8 (30%)	2 (7%)	-
Currently there aren't enough nursing home beds for the older people who need them	11 (26%)	19 (45%)	10 (24%)	2 (5%)	-	7 (26%)	11 (41%)	9 (33%)	-	-

cisions regarding their future care. A previous study into autonomy in older rehabilitation patients in an acute care setting demonstrated that, as their recovery progressed; older acute health care recipients began to exert more independence and control and tended to participate more fully in decisions regarding their own health care [20].

Previous studies have suggested that communication with health providers and the provision of information are two key basic principles for defining quality health care, with the ability to motivate patients and positively influence their recovery [21,22]. This includes health professionals spending additional time with patients, giving them an opportunity to speak honestly and the provision of written information which can also be shared with the patient's family [23]. The findings from this study concur with this viewpoint; in general, participants exhibited strong preferences for communication with health providers and the provision of information.

Very strong preferences were also shown in both

groups for the use of electronic medical records, suggesting the importance of communication between health care professionals. An electronic record was not available in South Australia in either hospital or post acute care settings at the time of the study yet. Although both groups had no exposure to the approach, it was felt to be important. However with the Australian government planning to introduce a personally controlled electronic health record system in mid-2012 [24], participants may have had some exposure to this concept via the media. The importance of inter-professional communication was also noted by Westby during focus groups conducted with rehabilitation patients, which revealed that poor communication between health care settings may negatively impact on patient satisfaction, clinical outcomes, and service coordination [25]. Eldar has also identified the interaction between multidisciplinary professionals as a potential influence on quality of care [6].

It is important to note that this study was essentially

exploratory in nature and was necessarily conducted on a very modest research budget with a relatively small sample size. Hence the findings from this study should be interpreted with caution. However, our study has provided important preliminary evidence demonstrating the practicality and validity of the application of DCE methodology to determine older people's preferences regarding what constitutes quality in the delivery of health programs. It is important that further DCE studies are conducted in larger samples of older people to substantiate the findings from this study and to provide further evidence of the practicality and validity of this approach for application with older people.

Given the ageing of the population and the predicted future increase in the demand for health care both in Australia and internationally, involving older people in research which incorporates their views and preferences relating to the optimal configuration of health services is an increasingly important issue [26]. Future research is required into the application of DCEs with larger and more diverse samples of older people in different health and aged care settings to gain a deeper understanding of their preferences for quality care. The potential also exists for the future incorporation of DCEs into an economic evaluation framework, for assessing the cost effectiveness of health care interventions and services targeted for older people.

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REFERENCES

- [1] Brown, C.R. (2007) Where are the patients in the quality of health care? *International Journal for Quality in Health Care*, **19**, 125-126. doi:10.1093/intqhc/mzm009
- [2] Ratcliffe, J., Laver, K., Couzner, L., Cameron, I., Gray, L. and Crotty, M. (2010) Not just about costs: The role of health economics in facilitating decision making in aged care. *Age Ageing*, **39**, 426-429. doi:10.1093/ageing/afq041
- [3] Mainz, J. (2003) Defining and classifying clinical indicators for quality improvement. *International Journal for Quality in Health Care*, **15**, 523-530. doi:10.1093/intqhc/mzg081
- [4] Ryan, M., Major, K. and Skåtun, D. (2005) Using discrete choice experiments to go beyond clinical outcomes when evaluating clinical practice. *Journal of Evaluation in Clinical Practice*, **22**, 328-238. doi:10.1111/j.1365-2753.2005.00539.x
- [5] Brook, R.H., McGlynn, E.A. and Shekelle, P.G. (2000) Defining and measuring quality of care: A perspective from US researchers. *International Journal for Quality in Health Care*, **12**, 281-295. doi:10.1093/intqhc/12.4.281
- [6] Eldar, R. (1999) Quality of care in rehabilitation medicine. *International Journal for Quality in Health Care*, **11**, 73-79. doi:10.1093/intqhc/11.1.73
- [7] Breehaar, B., Visser, A.P.H. and Kleijnen, J.G.V.M. (1990) Perceptions and behaviour among elderly hospital patients: Description and explanation of age differences in satisfaction, knowledge, emotions and behaviour. *Social Science & Medicine*, **31**, 1377-1385. doi:10.1016/0277-9536(90)90076-5
- [8] Ross, C.E. and Mirowsky, J. (1984) Socially-desirable response and acquiescence in a cross-cultural survey of mental health. *Journal of Health and Social Behavior*, **25**, 189-197. doi:10.2307/2136668
- [9] Crow, R., Gage, H., Hampson, S. and Hart, J. (2002) The measurement of satisfaction with healthcare: implications for practice from a systematic review of the literature. *Health Technology Assess*, **6**.
- [10] Lanscar, E. and Louviere, J. (2008) Conducting discrete choice experiments to inform healthcare decision making: A user's guide. *Pharmacoeconomics*, **26**, 661-677. doi:10.2165/00019053-200826080-00004
- [11] Ryan, M. (2004) Discrete choice experiments in health care: NICE should consider using them for patient centred evaluations of technologies. *BMJ*, **328**, 360-361. doi:10.1136/bmj.328.7436.360
- [12] Gerard, K. and Ryan, M. (2008) Discrete choice experiments in a nutshell. In: Ryan, M., Gerard, K. and Amaya-Amaya, M., Eds., *Using Discrete Choice Experiments to Value Health and Health Care*, Springer, Dordrecht.
- [13] Gröndahl, V.A., Karlsson, I., Hall-Lord, M.L., Appelgren, J. and Wild-Larsson, B. (2011) Quality of care from patients' perspective: Impact of the combination of person-related and external objective care conditions. *Journal of Clinical Nursing*, **20**, 2540-2551. doi:10.1111/j.1365-2702.2011.03810.x
- [14] Street, D. and Burgess, L. (2007) The construction of optimal stated choice experiments: Theory and methods. Wiley, Hoboken. doi:10.1002/9780470148563
- [15] Folstein, M.F., Folstein, S.E. and McHugh, P.R. (1975) "Mini Mental State" A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, **12**, 189-198. doi:10.1016/0022-3956(75)90026-6
- [16] Stata Corp. (2009) Stata statistical software: Release 11. College station. StataCorp LP, Texas.
- [17] Ryan, M., Watson, V. and Gerard, K. (2008) Practical issues in conducting a discrete choice experiment. In: Ryan, M., Gerard, K. and Amaya-Amaya, M., Eds., *Using Discrete Choice Experiments to Value Health and Health Care*. Springer, Dordrecht.
- [18] Lanscar, E. and Louviere, J. (2006) Deleting "irrational" responses from discrete choice experiments: A case of investigating or imposing preferences? *Health Economics*, **15**, 797-811. doi:10.1002/hec.1104
- [19] Cornwell, J., Levenson, R., Sonola, L. and Poteliakhoff, E. (2012) Continuity of care for older hospital patients: A call for action. The Kings Fund.
- [20] Jacelon, C.S. (2004) Older adults and autonomy in acute

- care: Increasing patients' independence and control during hospitalization. *Journal of Gerontological Nursing*, **30**, 29-36.
- [21] Lothian, K. and Philp, I. (2001) Maintaining the dignity and autonomy of older people in the healthcare setting. *BMJ*, **332**, 668-670. doi:10.1136/bmj.322.7287.668
- [22] Atwal, A., Tattersall, K., Murphy, S., Davenport, N., Craik, C. and Caldwell, K. (2007) Older adults experiences of rehabilitation in acute health care. *Scandinavian Journal of Caring Science*, **21**, 371-378. doi:10.1111/j.1471-6712.2007.00469.x
- [23] Lui, M.H.L. and Mackenzie, A.E. (1999) Chinese elderly patients' perceptions of their rehabilitation needs following a stroke. *Journal of Advanced Nursing*, **30**, 391-400. doi:10.1046/j.1365-2648.1999.01087.x
- [24] Department of Health and Ageing (2012) E-Health, Australia. <http://www.ehealth.gov.au/internet/ehealth/publishing.nsf/content/home>
- [25] Westby, M.D. and Backman, C.L. (2010) Patient and health professional views on rehabilitation practices and outcomes following total hip and knee arthroplasty for osteoarthritis: A focus group study. *BMC Health Services Research*, **10**.
- [26] McMurdo, M.E.T., Roberts, H., Parker, S., Wyatt, N., May, H., Goodman, C., *et al.* (2011) Improving recruitment of older people to research through good practice. *Age Ageing*, **40**, 65. doi:10.1093/ageing/afr115

A Comparison of the EQ-5D-3L and ICECAP-O in an Older Post-Acute Patient Population Relative to the General Population

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Abstract

Background The measurement and valuation of quality of life forms a major component of economic evaluation in health care and is a major issue in health services research. However, differing approaches exist in the measurement and valuation of quality of life from a health economics perspective. While some instruments such as the EQ-5D-3L focus on health-related quality of life alone, others assess quality of life in broader terms, for example, the newly developed ICECAP-O.

Objective The aim of this study was to utilize two generic preference-based instruments, the EQ-5D-3L and the ICECAP-O, to measure and value the quality of life of older adult patients receiving post-acute care. An additional objective was to compare the values obtained by each instrument with those generated from two community-based general population samples.

Method Data were collected from a clinical patient population of older adults receiving post-acute outpatient

rehabilitation or residential transition care and two Australian general population samples of individuals residing in the general community. The individual responses to the ICECAP-O and EQ-5D-3L instruments were scored using recently developed Australian general population algorithms. Empirical comparisons were made of the resulting patient and general population sample values for the total population and dis-aggregated according to age (65–79 and 80+ years) and gender.

Results A total of 1,260 participants aged 65–99 years ($n = 86$ clinical patient sample, $n = 385$ EQ-5D-3L general population sample, $n = 789$ ICECAP-O general population sample) completed one or both of the EQ-5D-3L and ICECAP-O instruments. As expected, the patient group demonstrated lower quality of life than the general population sample as measured by both quality-of-life instruments. The difference in values between the patient and general population groups was found to be far more pronounced for the EQ-5D-3L than for the ICECAP-O. The ICECAP-O was associated with a mean difference in values of 0.04 (patient group mean 0.753, SD 0.18; general population group mean 0.795, SD 0.17, respectively, $p = 0.033$). In contrast, the EQ-5D-3L was associated with a mean difference in values of 0.19 (patient group mean 0.595, SD 0.20; general population group mean 0.789, SD 0.02, respectively, $p \leq 0.001$).

Conclusions The study findings illustrate the magnitude of the difference in patient and general population values according to the instrument utilized, and highlight the differences in both the theoretical underpinnings and valuation algorithms for the EQ-5D-3L and ICECAP-O instruments. Further empirical work is required in larger samples and alternative patient groups to investigate the generalizability of the findings presented here.

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Key Points for Decision Makers

- The quality of life of older post-acute care patients was significantly lower than that experienced by a general population sample.
- The difference in quality of life was more pronounced when using an instrument based on health (EQ-5D-3L) rather than one focusing on capability (ICECAP-O).
- Further empirical work is warranted in larger and alternative patient samples to further investigate the implications of the application of alternative approaches to the measurement and valuation of quality of life in this context.

1 Introduction

Quality of life is becoming recognized as an important outcome measure of health and social care interventions [1], often being captured alongside traditional clinical outcomes such as mortality or re-admission rates. In this context, it is often health-related quality of life that is measured, rather than quality of life in a broader sense, which may be influenced by a range of factors such as housing, income, and an individual's experiences [1]. Health-related quality of life focuses on the impact that an individual's perceived health status has had on aspects of life such as mobility and activities of daily living [1]. While health status has often been associated with quality of life, it has also been identified as being just one aspect of quality of life [1].

The EQ-5D-3L (3 level version of the EuroQoL 5 dimensional questionnaire) is a generic measure of health status that has been widely used internationally in a variety of patient populations [2]. The instrument consists of five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension contains three levels of increasing severity. The scoring algorithm using Australian general population specific weights allows for the calculation of a single index value representing quality of life ranging from -0.217 to 1 , where 1 represents full health, 0 represents death, and values lower than 0 represent states considered to be worse than death [2, 3]. It is envisaged that the routine incorporation of the EQ-5D-3L will enable patient perspectives to be considered in regard to the measurement and regulation of the performance, safety, and quality of health care providers and services and will also assist patients in making informed choices about their treatment and health care [4].

A recent review article by Lorgelly and colleagues highlighted that, conceptually, quality of life can be viewed in a number of different ways. From a health economics perspective, the quality-adjusted life-year (QALY), with its

narrow focus upon gains in health-related quality of life, may be inadequate in capturing the outcomes that are most important to people in living their lives [5]. The outcomes of many health, aged care, and public health interventions may extend beyond health to encompass quality of life more broadly where this is assumed to encompass the wide range of factors that are important to people in their lives. For example, the provision of independent living accommodation for older people may promote feelings of security while maintaining independence, thereby improving their quality of life. A focus upon QALYs that encapsulate 'health-related' quality-of-life impacts alone would likely under-estimate the relative benefits of this and many other public health interventions when compared with health care interventions [5].

The ICECAP-O capability index (ICEpop CAPability instrument for older people) is a recently developed instrument for the measurement and valuation of quality of life in adults aged 65 years and over that was designed to reflect quality of life in its broadest sense [6, 7]. An individual's quality of life is determined by their capability to achieve the five attributes included in the instrument: attachment, role, enjoyment, security, and control. Each attribute contains four levels, from which participants choose the one that best matches their current situation. The valuation algorithm recently developed using Australian general population values was applied to individual responses to the ICECAP-O instrument. The valuation algorithm generates a single index value ranging from 0 (no capability) to 1 (full capability) [8].

An increasing focus on improving quality of life at older ages [9] has resulted in the wide-spread practice of measuring quality of life from the patients' own perspective using patient-reported outcome measures (PROMs). This approach has a variety of applications, including measuring the outcomes of health and social care interventions. For example, in 2009, the UK National Health Service introduced the routine utilization of the EQ-5D-3L in patients undergoing elective surgical procedures for hip or knee replacements or the repair of hernias or varicose veins, with future plans to include additional diagnoses [4]. PROMs are also utilized in the appraisal of new health care technologies, with their use in clinical trials being recommended by the US Food and Drug Administration. Additionally, PROMs evidence is also required by the UK National Health Service's National Institute for Health and Clinical Excellence [4].

Commonly included as a measure of treatment effectiveness, PROMs typically have two main components. The first is a descriptive system of questions in which patients themselves (as opposed to others, e.g., health professionals) assess their own health and/or health-related quality of life. The second component is a scoring

algorithm to provide summary scores relating to particular dimensions and/or overall quality of life. PROMS may be either specific to a particular condition, such as the Oxford Hip Score [10] and the St George's Respiratory Questionnaire [11], or generic, designed for use across all types of patient populations, such as the SF-36 (Short Form 36 Health Survey) [12] and EQ-5D-3L [2], two of the most commonly used PROMS internationally.

While the 'measurement' of quality of life involves the completion of a PROM, which provides summary scores relating to specific dimensions or overall quality of life, the 'valuation' of quality of life typically requires the use of a specific type of PROM, a preference-based instrument. These preference-based instruments consist of a descriptive system and a valuation algorithm that represents the general population's preferences for the health and/or quality of life states defined by the instrument. In the case of the EQ-5D-3L, the values derived from this algorithm can be incorporated into QALYs, and in the case of the ICECAP-O, potentially QALY-type values for incorporation into economic evaluation [13].

A recent health policy report by the Kings Fund in the UK noted that the process of completing a PROM and the information obtained from it have the potential to influence decision making by patients, clinicians, and health service managers [4]. The approach can assist in the monitoring of disease and treatment progression and may identify problems that may have been overlooked by patients or clinicians [4]. Completion of such instruments may also enhance communication between patients and clinicians, promote shared decision making and clarify the priorities of patients and clinicians in terms of disease effects, treatment options, and possible outcomes [4, 14–16]. Where PROMs are generic and preference based, they may also facilitate resource allocation decision making through the framework of economic evaluation, which enables clinicians and health service managers to assess the efficiency of alternative approaches to the provision of health care in regard to patient outcomes, service delivery, and resource use [4, 17].

Whilst it is undoubtedly useful to measure and value the quality of life of clinical patient groups in this context, it is also beneficial to understand the relationship between the quality of life of patients and the quality of life of the general population. Normative data from the general population can be used as a reference with which to compare the quality of life of patient populations to investigate the impact of ill-health and treatments [18–20]. Such comparisons can assist in the interpretation of patient values by putting them into context in regard to what is considered to be a typical value from the general population [21, 22]. This also provides a benchmark against which patient quality of life can be compared at varying time points

ranging from diagnosis to post-treatment. By examining how the quality of life of specific patient groups compare with the general population, comparisons can also be made between patients experiencing different conditions and treatments, with the needs and health outcomes of the patient groups have the potential to highlight patient groups who need to be prioritized in regard to the allocation of resources and future intervention strategies [18]. In addition to this, consistent reports of limitations by patients relative to the general population in particular domains may indicate potential aspects of recovery that may require further attention in the treatment process.

We sought to directly compare patient and general population values for the EQ-5D-3L and ICECAP-O to assess the magnitude of the differences in values according to whether the focus of the comparison is health status (EQ-5D-3L) or quality of life in its broadest sense (ICECAP-O). Empirical comparisons were made for the total population and dis-aggregated according to age and gender classifications. We hypothesized that because of their health impairment, the older patient sample would exhibit consistently lower values on average for both instruments than older people in the general community. However, to the extent that the EQ-5D-3L and ICECAP-O instruments are based upon different theoretical underpinnings and have different valuation algorithms attached to them, we expected that the magnitude of the difference in values between the older patient sample and older people in the general community may not be consistent for both instruments. Given that the patient sample was individuals recovering from a recent acute illness, it was expected that the difference in values between the patient and general population may be higher in terms of health-related quality of life than capability-based quality of life.

2 Method

Data were collected from three separate study populations: a clinical patient sample of older adults receiving post-acute outpatient rehabilitation or residential transition care ($n = 86$) and two general population samples ($n = 385$ EQ-5D-3L and $n = 789$ ICECAP-O). The data from the three study populations were then pooled to facilitate empirical comparisons between the patient and general population samples.

Participants for the clinical patient sample were recruited from an outpatient rehabilitation clinic at the Repatriation General Hospital and a residential transitional care facility providing post-acute care to adults aged 65 and over following an acute hospital admission. Both facilities were located in Adelaide, South Australia, and participants were recruited between August 2009 and January 2011.

Admission lists were monitored by research staff to identify patients meeting the following inclusion criteria: aged ≥ 65 years; receiving outpatient rehabilitation or residential transition care following an acute hospital admission; Mini-Mental State Examination (MMSE) score of ≥ 24 , indicating absence of cognitive impairment [23]; and absence of communication or comprehension difficulties, e.g., dysphasia or non-English speaking background as determined by the treating health care team.

Eligible patients were approached by research staff within 4 weeks of commencing their post-acute care. Following the provision of informed consent, patients completed a face-to-face, interviewer-administered questionnaire consisting of three sections. Section A contained a series of attitudinal statements about aspects of health care and rehabilitation services for older adults (e.g., communication and involvement in decision making), in which participants, using a Likert-type scale, indicated their level of agreement or disagreement with each statement. Section B was a discrete choice experiment on preferences for alternative configurations of rehabilitation programs, the results of which are reported in a separate paper [24]. Section C included sociodemographic questions such as age, gender, and education level, the ICECAP-O capability index [6] and the EQ-5D-3L health status instrument [2].

The ICECAP-O data from the general population sample were generated from the inclusion of the ICECAP-O in the 2009 Health Omnibus Survey. The survey is conducted annually in South Australia to collect statistics for use in the planning, implementation, and monitoring of health-related projects [25]. Five thousand two hundred households were randomly chosen via a multi-stage systematic area sample. The majority of households selected, 74 %, were located in metropolitan areas, with the remaining 26 % located in regional areas. One person aged 15 years or older was randomly selected from each household to participate in the Health Omnibus Survey. The interviews were conducted as face-to-face interviews in the participant's own home.

The EQ-5D-3L data for the general population were collected via an online panel of survey respondents throughout Australia. Data for this were collected as part of a larger study exploring preferences around EQ-5D-3L and SF-6D health states between February and June 2009. Additionally, data were also collected on sociodemographic characteristics such as age, gender, and marital status, area of residence, country of birth, household income, education, and employment.

Data were analyzed using the statistical software package STATA version 11. Descriptive tests were conducted to summarize participants' responses and sociodemographic characteristics. *T* tests and ANOVA were

performed to analyze associations between ICECAP-O scores and categorical variables. Both the ICECAP-O and EQ-5D-3L instruments were scored using the recently developed Australian general population algorithms pertaining to each instrument [3, 8]. The data were dichotomized as patients or general population and also analyzed according to age (65–79 and 80+ years) and gender.

Approval to conduct the study was obtained from the Southern Adelaide Health Service/Flinders University Human Research Ethics Committee. The Health Omnibus Survey was conducted following approval by the South Australian Department of Health Ethics.

3 Results

The characteristics of the respondents are presented in Table 1. The respondents had a mean age of 73.43 (SD 6.92) years, with the patients being older, on average, than the general population (mean age 77.05, SD 7.38, and mean age 73.16, SD 6.81 years, respectively). The ICECAP-O general population sample was generally older than the EQ-5D-3L general population sample, with mean ages of 75 and 69 years, respectively. Additionally, only 3 % of the EQ-5D-3L general population sample were aged 80 years and over compared with 28 % of the ICECAP-O general population sample. The majority of both patient and general population groups were female (patients: $n = 44$, 51 %; general population: $n = 677$, 58 %). The highest educational attainment achieved for the majority of the patient sample was secondary school or tertiary studies ($n = 56$, 65 %). In comparison, primary school was the highest educational attainment for the majority of the general population group ($n = 643$, 55 %). However, some of these participants may have attended secondary school for a time, but not completed it in its entirety. Patients had been receiving post-acute care for a mean number of 36.10 days (SD 18.33) at the time of interview. The most common diagnoses were neurological ($n = 31$, 36 %) and orthopaedic ($n = 27$, 31 %).

3.1 Capability

The distribution of responses to the ICECAP-O instrument is presented in Table 2. The results were found to be broadly similar across dimensions with the exception of the role and independence dimensions. A smaller proportion of the patient sample reported themselves to be in the highest two categories of the role dimension, indicating that they were able to do either all or many of the things that make them feel valued (patients: $n = 48$, 59 %; general population: $n = 610$, 79 %). In addition, 89 % ($n = 684$) of the general population reported being able to be either

Table 1 Participant characteristics

Variable	Patients (<i>n</i> = 86)	General population ICECAP-O (<i>n</i> = 789)	General population EQ-5D-3L (<i>n</i> = 385)	Total (<i>n</i> = 1,260)
Gender				
Male	42 (49 %)	299 (38 %)	198 (51 %)	539 (43 %)
Female	44 (51 %)	490 (62 %)	187 (49 %)	721 (57 %)
Age (years)				
65–79	53 (62 %)	567 (72 %)	373 (97 %)	993 (79 %)
80 and over	33 (38 %)	222 (28 %)	12 (3 %)	267 (21 %)
Highest qualification				
Primary school	27 (31 %)	278 (35 %)	365 (95 %)	670 (53 %)
Secondary school and/or tertiary	56 (65 %)	499 (63 %)	16 (4 %)	571 (45 %)
Currently studying	–	10 (1 %)	– ^a	10 (1 %)
No education	1 (1 %)	2 (0 %)	–	3 (0 %)
Not answered	2 (2 %)	2 (0 %)	2 (1 %)	

Percentages do not equal 100 because of rounding
^a Data not collected for this sample

completely independent or independent in many things, compared with only 68 % (*n* = 56) of the patient group. High rates of completion were noted for the ICECAP-O, with 95 % (*n* = 82) of patients and 98 % (*n* = 771) of the general population sample completing all of the questions.

Table 3 shows the mean ICECAP-O scores for all participants and for subgroups classified according to age. The general population sample exhibited higher ICECAP-O scores on average than the patient group (general population: mean 0.795, SD 0.17; patients: mean 0.753, SD 0.18), with the difference being statistically significant ($p = 0.033$). When disaggregated for age, the general population group aged 65–79 were found to have higher ICECAP-O scores than patients in the same age group and the differences were statistically significant (general population: mean 0.809, SD 0.16; patients: mean 0.736, SD 0.17, $p = 0.002$). In contrast, the difference in ICECAP-O scores between the general population and patients aged 80 years and over was much smaller and was not found to be statistically significant (general population: mean 0.759, SD 0.19; patients: mean 0.780, SD 0.20, $p = 0.572$).

When analyzed according to gender, no significant difference was found between male patients and male members of the general population in either age group, as shown in Figs. 1 and 2. Although no significant differences were found between female patients and female members of the general population aged 80 years and over, the difference in ICECAP-O scores between female patients aged between 65 and 79 years was highly statistically significant, with the general population having higher scores than the patients (general population: mean 0.811, SD 0.15; patients: mean 0.678, SD 0.16, $p \leq 0.001$).

3.2 Health-Related Quality of Life

The distribution of responses to the EQ-5D-3L instrument are presented in Table 4. While 62 % of the general population sample (*n* = 239) reported no limitations in mobility, only 21 % (*n* = 18) of the post-acute participants reported no difficulty in walking. In regard to self-care, 94 % (*n* = 363) of the general population indicated that they had no problems washing or dressing themselves compared with only 55 % (*n* = 46) of the patient group. The two groups also differed in their ability to perform usual activities. While 70 % (*n* = 271) of the general population sample stated that they had no problems performing their usual activities, this level was reported by only 18 % (*n* = 15) of patients. As with the ICECAP-O, high completion rates were also evident for the EQ-5D, with 98 % (*n* = 84) of the patient sample and 100 % (*n* = 385) of the general population sample who commenced the EQ-5D-3L completing all of the questions in the instrument.

As shown in Table 5, the mean EQ-5D-3L score for the general population group was significantly higher than that of the patient group (general population: mean 0.789, SD 0.02; patients: mean 0.595, SD 0.20, $p \leq 0.001$). This trend continued when the scores were analyzed by age. Members of the general population aged between 65 and 79 years scored significantly higher than the patients in the same age group (general population: mean 0.790, SD 0.19; patients: mean 0.594, SD 0.19, $p \leq 0.001$). Of the participants aged 80 years and over, participants from the general population exhibited higher EQ-5D-3L scores than the patients (general population: mean 0.762, SD 0.14; patients: mean 0.596, SD 0.21, $p = 0.018$).

Table 2 Distribution of responses to the ICECAP-O instrument

	Patients (n = 82)	General population (n = 771)
Attachment		
I can have all of the love and friendship that I want	47 (57 %)	448 (58 %)
I can have some of the love and friendship that I want	25 (30 %)	214 (28 %)
I can have a little of the love and friendship that I want	9 (11 %)	91 (12 %)
I cannot have any of the love and friendship that I want	1 (1 %)	18 (2 %)
Security		
I can think about the future without any concern	31 (38 %)	229 (30 %)
I can think about the future with only a little concern	29 (35 %)	243 (32 %)
I can only think about the future with some concern	16 (20 %)	184 (24 %)
I can only think about the future with a lot of concern	6 (7 %)	115 (15 %)
Role		
I am able to do all of the things that make me feel valued	20 (24 %)	296 (38 %)
I am able to do many of the things that make me feel valued	28 (34 %)	314 (41 %)
I am able to do a few of the things that make me feel valued	24 (29 %)	138 (18 %)
I am unable to do any of the things that make me feel valued	10 (12 %)	23 (3 %)
Enjoyment		
I can have all of the enjoyment and pleasure that I want	27 (33 %)	266 (35 %)
I can have a lot of the enjoyment and pleasure that I want	31 (38 %)	348 (45 %)
I can have a little of the enjoyment and pleasure that I want	21 (26 %)	139 (18 %)
I cannot have any of the enjoyment and pleasure that I want	3 (4 %)	18 (2 %)
Control		
I am able to be completely independent	15 (18 %)	380 (49 %)
I am able to be independent in many things	41 (50 %)	304 (39 %)
I am able to be independent in a few things	22 (27 %)	76 (10 %)
I am unable to be at all independent	4 (5 %)	11 (1 %)

Percentages do not equal 100 because of rounding

Members of the general population aged between 65 and 79 years continued to demonstrate significantly higher EQ-5D-3L scores than the patients when analyzed by gender. As shown in Figs. 3 and 4, male members of the general population group had significantly higher scores than those in the patient group (general population: mean 0.790, SD 0.20; patients: mean 0.631, SD 0.20, $p \leq 0.001$), as did the females (general population: mean 0.790, SD 0.19; patients: mean 0.558, SD 0.18, $p \leq 0.001$). Although appearing similar in magnitude to the differences between the patients and general population samples aged 65–79 years, no significant difference was evident between the patients and general population according to gender in participants aged 80 years and over. However, it is important to note that only 3 % of the general population sample were aged 80 years or over.

With respect to education level, the EQ-5D-3L scores of both the patients and the general population groups differed. In both age groups, members of the general population who nominated primary school as being their highest educational qualification reported higher EQ-5D-3L scores than the patients with the same education level. The difference was more significant in the participants aged

65–79 years (general population: mean 0.793, SD 0.19; patients: mean 0.648, SD 0.14, $p = 0.006$) than those aged 80 years and over (general population: mean 0.744, SD 0.13; patients: mean 0.565, SD 0.25, $p = 0.051$).

4 Discussion

This study has provided a comparison of the quality of life experienced by older adults receiving post-acute rehabilitation or transition care and that of the general population, with quality of life being measured both in terms of health and also in a broader sense. The quality of life reported by the general population samples provided a benchmark against which to compare the quality of life experienced by older post-acute care patients, providing an insight into the impact that a recent acute health problem may have on older adults. The findings presented here will enable comparisons to be made with those obtained in future studies in other patient populations to highlight the differences in quality of life experienced by patients with different diagnoses or receiving alternative treatments. Such comparisons have the potential to highlight patient

Table 3 Mean ICECAP-O scores and tests of association between ICECAP-O scores and key variables by group and age group

Age group	Characteristic	Patients (n = 82)				General population (n = 771)				Significance (p value)
		Mean	Lower 95 % CI	Upper 95 % CI	N	Mean	Lower 95 % CI	Upper 95 % CI	N	
65–79 years (n = 605)	Gender									
	Male	0.794	0.730	0.858	25	0.807	0.783	0.830	217	0.726
	Female**	0.678	0.610	0.746	25	0.811	0.795	0.827	338	≤0.001
	Education									
	Primary school	0.744	0.661	0.827	13	0.817	0.793	0.840	185	0.123
	Secondary school/tertiary*	0.729	0.672	0.787	36	0.805	0.789	0.821	361	0.007
	Currently studying	–	–	–	0	0.839	0.804	0.874	9	–
No education	–	–	–	0	–	–	–	0	–	
Age group total*	0.736	0.688	0.784	50	0.809	0.796	0.823	555	0.002	
80+ years (n = 248)	Gender									
	Male	0.780	0.661	0.899	16	0.764	0.721	0.807	72	0.764
	Female	0.779	0.693	0.866	16	0.757	0.725	0.789	144	0.656
	Education									
	Primary school	0.723	0.597	0.850	12	0.769	0.729	0.808	88	0.445
	Secondary school/tertiary	0.803	0.722	0.883	18	0.753	0.720	0.787	127	0.303
	Currently studying	–	–	–	0	0.680	–	–	1	–
No education	0.910	–	–	1	–	–	–	0	–	
Age group total	0.780	0.710	0.849	32	0.759	0.734	0.785	216	0.572	
All participants (n = 853)	All ages total*	0.753	0.714	0.792	82	0.795	0.783	0.807	771	0.033

* Significant difference between patients and general population at the 5 % level

** Significant difference between patients and general population at the 0.1 % level

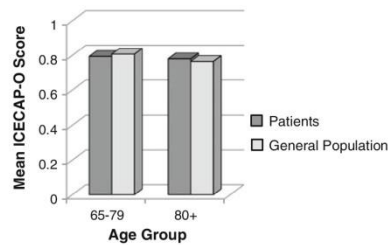


Fig. 1 Mean ICECAP-O scores: males by age group

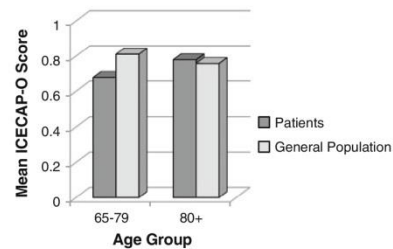


Fig. 2 Mean ICECAP-O scores: females by age group

groups who require increased attention in terms of resource allocation and intervention strategies.

Potentially the most important finding from this study is that the difference in values between the patient and general population samples was found to be far more pronounced for the EQ-5D-3L than the ICECAP-O. This may be due to a number of factors including the nature of the descriptive systems, with the EQ-5D-3L focusing on health status alone and the ICECAP-O focusing on quality of life more broadly. A recent study comparing the ICECAP-O and EQ-5D-3L in a falls prevention clinical setting concluded that the two instruments capture several unique

aspects of benefit and that their simultaneous use may therefore be warranted as each provides complementary information [26]. However, it must also be noted that the EQ-5D-3L and the ICECAP-O are valued using different scales, so a direct comparison may not be meaningful as capability scores were being compared with utilities.

As hypothesized a priori, both capability and health-related quality of life as captured by the ICECAP-O and EQ-5D-3L instruments, respectively, were higher in older members of the general population than the patient sample. These differences were broadly consistent when the data

Table 4 Distribution of responses to the EQ-5D-3L instrument

	Patients (n = 84)	General population (n = 385)	Total (n = 469)
Mobility			
I have no problems walking around	18 (21 %)	239 (62 %)	257 (55 %)
I have some problems walking around	65 (77 %)	146 (38 %)	211 (45 %)
I am confined to bed	1 (1 %)	0	1 (0 %)
Self care			
I have no problems washing or dressing myself	46 (55 %)	363 (94 %)	409 (87 %)
I have some problems washing or dressing myself	35 (42 %)	21 (5 %)	56 (12 %)
I am unable to wash or dress myself	3 (4 %)	1 (0 %)	4 (1 %)
Usual activities			
I have no problems performing my usual activities	15 (18 %)	271 (70 %)	286 (61 %)
I have some problems performing my usual activities	45 (54 %)	109 (28 %)	154 (33 %)
I am unable to perform my usual activities	24 (29 %)	5 (1 %)	29 (6 %)
Pain or discomfort			
I have no pain or discomfort	30 (36 %)	152 (39 %)	182 (39 %)
I have moderate pain or discomfort	45 (54 %)	216 (56 %)	261 (56 %)
I have extreme pain or discomfort	9 (11 %)	17 (4 %)	26 (6 %)
Anxiety or depression			
I am not anxious or depressed	53 (63 %)	278 (72 %)	331 (71 %)
I am moderately anxious or depressed	27 (32 %)	98 (25 %)	125 (27 %)
I am extremely anxious or depressed	4 (5 %)	9 (2 %)	13 (3 %)

Percentages do not equal 100 because of rounding

were disaggregated according to age and gender subgroup classifications. Patients were more likely than the general population to report limitations relating to self-care, mobility, usual activities, role, thinking about the future, and independence, highlighting the areas that may be affected by an acute illness in older adults [27].

The findings of this study are consistent with other studies which have found differences in quality of life between older adult patients and the general population in some but not all domains of the instrument used. Funk and colleagues demonstrated the quality of life experienced by pre-treatment head and neck cancer patients to be significantly lower than that of the general aged-matched population US norms for the mental health dimension of the SF-36 only [28]. In comparison, Lindh and colleagues [29] found older polyneuropathy patients to be more likely to report difficulties in the mobility, usual activity, and pain/discomfort domains of the EQ-5D-3L than members of the general population, with the self-care and anxiety and depression dimensions being largely unaffected. The same patient group was also significantly more likely to score lower on the general health and vitality domains of the SF-36, with male patients also more likely to score lower on

the physical functioning, physical role and bodily pain domains than the general population [29].

As it is a relatively new instrument, a minimally important difference has not yet been identified for the ICECAP-O, highlighting an area for future development. Because of this, the ICECAP-O and EQ-5D-3L instruments could not be compared in regard to their values of minimal important difference. Further to this, the magnitude of the difference in quality of life between the patient and general population also remains difficult to measure. While a minimally important difference of 0.074 has been established for the EQ-5D-3L [30], the value relates to the change in EQ-5D-3L scores within the same sample over time. However, we have compared two samples, patients and a general population sample, at a single time point, rather than a single sample over time. This therefore made it difficult to meaningfully compare the samples based on the minimally important difference value.

It is also important to note that the EQ-5D-3L valuation algorithm produces a wider range of values than the ICECAP-O, with the potential for negative values, which may have contributed to the differences found here. For example, the lowest Australian general population value

△ Adis

Table 5 Mean EQ-5D-3L scores and tests of association between EQ-5D-3L scores and key variables by group and age group

Age group	Characteristic	Patients (n = 84)				General population (n = 385)				Significance (p value)
		Mean	Lower 95 % CI	Upper 95 % CI	N	Mean	Lower 95 % CI	Upper 95 % CI	N	
65–79 years (n = 790)	Gender									
	Male**	0.631	0.550	0.712	26	0.790	0.761	0.819	189	≤0.001
	Female**	0.558	0.486	0.629	26	0.790	0.763	0.817	184	≤0.001
	Education									
	Primary school*	0.648	0.573	0.723	14	0.793	0.773	0.814	355	0.006
	Secondary school/tertiary	0.571	0.505	0.638	37	0.689	0.591	0.787	14	0.069
	Currently studying	–	–	–	0	–	–	–	0	–
No education	–	–	–	0	0.887	0.665	1.109	2	–	
Age group total**	0.594	0.541	0.648	52	0.790	0.770	0.810	373	≤0.001	
80+ years (n = 45)	Gender									
	Male	0.653	0.529	0.778	15	0.761	0.635	0.887	9	0.225
	Female	0.545	0.444	0.647	17	0.764	0.613	0.915	3	0.079
	Education									
	Primary school*	0.565	0.431	0.698	13	0.744	0.661	0.826	10	0.051
	Secondary school/tertiary	0.612	0.516	0.708	17	0.853	0.564	1.142	2	0.130
	Currently studying	–	–	–	0	–	–	–	0	–
No education	–	–	–	1	–	–	–	0	–	
Age group total*	0.596	0.519	0.673	32	0.762	0.671	0.852	12	0.018	
All participants (n = 471)	All ages total**	0.595	0.552	0.638	84	0.789	0.770	0.808	385	≤0.001

* Significant difference between patients and general population at the 5 % level

** Significant difference between patients and general population at the 0.1 % level

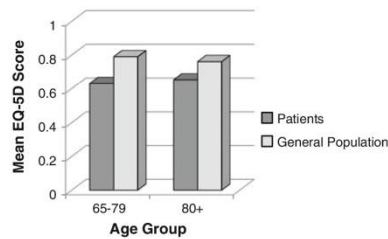


Fig. 3 Mean EQ-5D-3L scores: males by age group

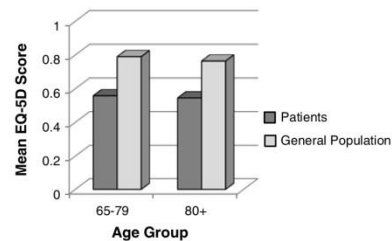


Fig. 4 Mean EQ-5D-3L scores: females by age group

pertaining to the PITS, or most severe health state where the participant is experiencing the lowest level of each domain, for the EQ-5D-3L is -0.217 and the highest value is 1.00, corresponding to full health. In contrast, the ICE-CAP-O has a smaller range of potential values, from 0 (no capability) to 1 (full capability).

The completion rates differed little between the modes of questionnaire administration. However, previous research has suggested participants may be more likely to provide responses that they consider to be socially desirable when participating in face-to-face interviews than

when completing self-administered instruments such as postal or online questionnaires [31]. This is especially so when being questioned about topics considered to be sensitive by the participant, resulting in the under-reporting of behaviors that are considered undesirable, such as smoking, and the over-exaggeration of positive health status and quality of life [31]. Therefore, the general population participants in this study may have been more hesitant to admit to limitations in the interviewer-administered ICE-CAP-O than the online-administered EQ-5D-3L, for example, in areas such as love and friendship. Similarly,

the patient group may have been less likely to admit to limitations in the interviewer-administered EQ-5D-3L than the general population who completed a self-administered questionnaire online, especially in regard to the questions relating to anxiety and depression. Further research is required to more formally assess the impact of mode of administration on individual responses to the ICECAP-O.

It is important to highlight that there were some limitations to this study which were largely associated with its opportunistic sampling approach. Firstly, although a variety of sociodemographic data was collected within each study sample, few of these variables were common to all three samples, meaning limited sociodemographic data was available for inclusion in the data analysis. Further details such as residential status, country of birth, and socio-economic status would enable further examination of the interaction between these factors and quality of life. In addition, the clinical older post-acute patient sample was relatively small. Further work using larger samples of older post-acute patients and samples from other clinical populations would also be beneficial.

Although outside the scope of this study, the measurement and valuation of quality of life longitudinally at multiple time points within the same population groups would also be beneficial. This would allow change over time to be investigated and provide for a wider representation of the quality of life experienced by older patients throughout the patient journey (from initial diagnosis to post-treatment) and assessment of how this compares to that of the general population, aiding in the planning and provision of health and social care services. The purpose of this study, however, was to measure and value the quality of life of patients at a single time point, to obtain a 'snapshot' of the quality of life experienced during the receipt of post-acute care.

While the EQ-5D-3L and ICECAP-O are often used to measure changes in quality of life over time, both instruments have been previously applied to measure quality of life at a single time point only, as was performed in this study. Flynn et al. [7] utilized the ICECAP-O to investigate differences in the quality of life of a sample of the UK general population aged 65 years and over. Additionally, Davis et al. [26] applied and compared both the EQ-5D-3L and the ICECAP-O in a population of older adults attending a Canadian falls prevention outpatient clinic. In regard to future research, it would be beneficial for future studies to include both the EQ-5D-3L and ICECAP-O within the same general population sample. Without this, it is impossible to completely rule out that the differences observed between the EQ-5D-3L and ICECAP-O may reflect underlying differences in the characteristics of the two general population samples from which the mean values for each instrument were generated.

5 Conclusions

This paper has presented descriptive data from the EQ-5D and the ICECAP-O to compare the quality of life of patients and the general population. The findings provide a comparator for future intervention and descriptive studies conducted either in similar samples or in other patient samples and countries. The results illustrate the magnitude of the potential differences in the quality-of-life values pertaining to patient and general population samples according to the instrument utilized for this purpose, and highlight the differences in both the theoretical underpinnings and valuation algorithms for the EQ-5D-3L and ICECAP-O instruments. It is important that further work is conducted to empirically compare individual responses of the EQ-5D-3L and ICECAP-O in larger clinical post-acute samples of older people and alternative patient groups to investigate the generalizability of the findings presented in this study.

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References

1. Brown J, Bowling A, Flynn T. Models of quality of life: a taxonomy, overview and systematic review of the literature. *European Forum on Population Ageing Research*. 2004. http://www.shef.ac.uk/ageingresearch/pdf/qol_review_no_tables.pdf.
2. Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQol Group. *Ann Med*. 2001;33:337–43.
3. Viney R, Norman R, King MT, Cronin P, Street DJ, Knox S, et al. Time trade-off derived EQ-5D weights for Australia. *Value Health*. 2011;14(6):928.
4. Devlin NJ, Appleby J. Getting the most out of PROMs: putting health outcomes at the heart of NHS decision-making: The King's Fund; 2010. <http://www.kingsfund.org.uk/publications>
5. Lorgelly P, Lawson KD, Fenwick EAL, Briggs AH. Outcome measurement in economic evaluations of public health interventions: a role for the Capability Approach? *Int J Environ Res Public Health*. 2010;7:2274–89.
6. Coast J, Peters TJ, Natarajan L, Sproston K, Flynn T. An assessment of the construct validity of the descriptive system for the ICECAP capability measure for older people. *Qual Life Res*. 2008;17(7):967–76.
7. Flynn T, Chan P, Coast J, Peters TJ. Assessing quality of life among British older people using the ICECAP-O capability measure. *Appl Health Econ Health Policy*. 2011;9(5):317–29.
8. Flynn T, Louviere J, Huynh E, Terlich F. What are Australian preferences for quality of life? Results from best-worst scaling

- studies to value the ICECAP instruments. Australian Health Economics Society Meeting, 30 Sept–1 Oct 2010, Sydney, Australia; 2010.
9. Outreville JF. Healthcare expenditure and ageing: a comment. *Appl Health Econ Health Policy*. 2004;3:121–3.
 10. Dawson J, Fitzpatrick R, Carr A, Murray D. Questionnaire on the perceptions of patients about total hip replacement. *J Bone Jt Surg [Br]*. 1996;78:185–90.
 11. Jones PW, Quirk FH, Baveystock CM. The St George's Respiratory Questionnaire. *Respir Med*. 1991;85:25–31.
 12. Ware J, Donald Sherbourne C. The MOS 36-Item Short Form Health Survey (SF-36). I Conceptual framework and item selection. *Med Care*. 1992;30(6):473–83.
 13. Coast J, Flynn TN, Natarajan L, Sproston K, Lewis J, Louviere J, et al. Valuing the ICECAP capability index for older people. *Soc Sci Med*. 2008;67:874–82.
 14. Hahn EA, Cella D, Chassany O, Fairclough DL, Wong GY, Hays RD, et al. Precision of health-related quality of life data compared with other clinical measures. *Mayo Clin Proc*. 2007;82:1244–54.
 15. Greenhalgh J, Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review. *J Eval Clin Pract*. 1999;5:401–16.
 16. Valderas JM, Kotzeva A, Espallargues M, Guyatt G, Ferrans CE, Halyard MY, et al. The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. *Qual Life Res*. 2008;17:179–93.
 17. Cunningham SJ. An introduction to economic evaluation of health care. *J Orthod*. 2001;28:246–50.
 18. March LM, Cross MJ, Lapsley H, Brnabic A, Tribe KL, Bachmeier C, et al. Outcomes after hip or knee replacement surgery for osteoarthritis. A prospective cohort study comparing patients' quality of life before and after surgery with age-related population norms. *Med J Aust*. 1999;171:235–8.
 19. Gralnek IM, Hays RD, Kilbourne A, Naliboff B, Mayer EA. The impact of irritable bowel syndrome on health-related quality of life. *Gastroenterology*. 2000;119:654–60.
 20. Sørensen J, Davidsen M, Gudex C, Pedersen KM, Brønnum-Hansen H. Danish EQ-5D population norms. *Scand J Public Health*. 2009;37:467–74.
 21. Brucker PS, Yost K, Cashy J, Webster K, Cella D. General population and cancer patient norms for the Functional Assessment of Cancer Therapy—General (FACT-G). *Eval Health Prof*. 2005;28:192–211.
 22. Loge JH, Abrahamsen AF, Ekeberg Ø, Kaasa S. Reduced health-related quality of life among Hodgkin's disease survivors: a comparative study with general population norms. *Ann Oncol*. 1999;10:71–7.
 23. Folstein MF, Folstein SE, McHugh PR. "Mini mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975;12:189–98.
 24. Couzner L, Crotty M, Walker R, Ratcliffe J. Examining older patient preferences for quality of care in post-acute transition care and day rehabilitation programs. *Health and Quality of Life Outcomes*. 2013;10:69.
 25. Harrison Research. Health Omnibus Survey. 2010. http://www.harrisonresearch.com.au/health_omnibus.php. Accessed 15 Oct 2012.
 26. Davis JC, Liu-Ambrose T, Richardson CG, Bryan S. A comparison of the ICECAP-O with EQ-5D in a falls prevention clinical setting: are they complements or substitutes? *Qual Life Res*. 2012. doi:10.1007/s11136-012-0225-4.
 27. Sager MA, Rudberg MA, Jalaluddin M, Franke T, Inouye SK, Landefeld CS, et al. Hospital Admission Risk Profile (HARP): identifying older patients at risk for functional decline following acute medical illness and hospitalization. *J Am Geriatr Soc*. 1996;44:251–7.
 28. Funk GF, Hynds Karnell L, Dawson CJ, Means ME, Colwill ML, Gliklich RE, et al. Baseline and post-treatment assessment of the general health-status of head and neck cancer patients compared with United States population norms. *Head Neck*. 1997;19:675–83.
 29. Lindh J, Tondel M, Persson B, Vrethem M. Health-related quality of life in patients with cryptogenic polyneuropathy compared with the general population. *Disabil Rehabil*. 2011;33:617–23.
 30. Walters SJ, Brazier JE. Comparison of the minimally important difference for two health state utility measures: EQ-5D and SF-6D. *Qual Life Res*. 2005;14:1523–32.
 31. Bowling A. Mode of questionnaire administration can have serious effects on data quality. *J Public Health*. 2005;27:281–91.

Measuring and valuing quality of life for public health research: application of the ICECAP-O capability index in the Australian general population

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Abstract

Objectives To assess the applicability of the newly developed ICECAP-O capability index in the measurement and valuation of quality of life in a large community based sample of the Australian general population. With origins in Sen's capability theory, the ICECAP-O may more fully encapsulate the multi-dimensional outcomes of public health policies and interventions than traditional health economic constructs.

Methods 2,937 Australian residents participated in face-to-face interviews. The relationships between ICECAP-O scores according to age groups (<65 or >65 years) and socio-economic status were investigated using descriptive statistics and multivariable linear regression models.

Results Lower income levels and being unemployed or physically unable to work were negatively associated with capability for both age groups. Capability was strongly and positively associated with marriage and cohabitation in the

younger age group, whilst being Australian-born was a positive indicator for the older group.

Conclusions The results provide insights into the assessment of capability in the Australian general population. The ICECAP-O shows promise for application in the measurement and valuation of quality of life in general population surveys, and incorporation into economic evaluations of public health interventions.

Keywords Quality of life · Capability · Health economics · Age groups · Public health

Introduction

The measurement and valuation of quality of life in community based general population samples have become one of the main activities of public health research, informing resource allocation decisions relating to the promotion of population health and well-being (Ravens-Sieberer 2002). Health-related quality of life, most notably the quality adjusted life year (QALY) is increasingly being applied as a measure of health status in general population surveys and in clinical studies of health care interventions (Kurth and Ellert 2002). However, a recent review article by Lorgelly et al. (2010) highlighted that the QALY, with its narrow focus upon health utility gains, may be inadequate in capturing other outcomes which are important to quality of life. The outcomes of many public health interventions may extend beyond health to encompass quality of life more broadly where this is assumed to encompass the broad range of factors that are important to people throughout the course of their life. For example, the provision of independent living accommodation for older people may promote feelings of security whilst maintaining

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independence thereby improving their quality of life. A focus upon QALYs which encapsulate “health related” quality of life impacts alone would likely under-estimate the relative benefits of this and many other public health interventions when compared to health care interventions.

The ICECAP-O index of capability is a new instrument for the measurement and valuation of quality of life designed to be applicable in economic evaluation across sectors including health, social and aged care for clinical and community based interventions. The potential for the instrument to be applied in providing guidance on the effectiveness and cost effectiveness of public health interventions is currently being investigated by the instrument developers in the UK (Coast 2011).

The ICECAP-O has its origins in Sen’s capability theory which suggests that well-being should be measured not according to what individuals actually do (i.e. their functionings) but what they are able to do (i.e. their capabilities) (Sen 1993). The approach is therefore based on a view of living as a combination of various ‘doings and beings’, with quality of life to be assessed in terms of the capability to achieve valuable functionings (Lorgelly et al. 2010). An example of the distinction between functionings and capabilities is to compare two people who are starving, one due to fasting and one because food is unavailable. Both have the same level of functioning (they are both starving). However, one person has the capability to obtain food whilst the other does not. Their capabilities are therefore different; Sen argues that their relative capabilities provide the most useful information for assessing the impact of a policy (Robeyns 2003).

Methods for measuring capabilities in practice remain underdeveloped. However, the recent development of the ICECAP-O instrument has provided a mechanism for the measurement of capability at a population level (Coast et al. 2008a, b). The ICECAP-O incorporates five attributes (attachment, security, role, enjoyment and control); each consisting of four levels (Fig. 1). For each attribute, participants indicate which level they believe most closely corresponds to their life at present. The attributes were developed according to the findings of qualitative interviews with older people focusing on aspects of their lives that they valued and derived the most enjoyment from (Grewal et al. 2006).

The ICECAP-O is also amenable to valuation as it has a preference-based scoring algorithm attached to it ranging from 0 (no capability) to 1 (full capability) (Coast et al. 2008a). This allows a single index value to be calculated for all possible capability states defined by the instrument. It is this capacity for both the *measurement* and *valuation* of quality of life which, in principle, enables the ICECAP-O to be placed in an economic evaluation framework for estimating the cost effectiveness of interventions across

sectors including its potential for application in estimating the effectiveness and cost effectiveness of public health interventions. However, it is important to note that the index values for ICECAP-O do not represent QALY quality–quantity trade-offs (Rowen et al. 2011). In addition, there is no consensus that the ICECAP-O values are cardinal: whilst the ICECAP-O levels allow conceptualisation of the top and bottom states as “full” (1) and “no” (0 capability); since a within (rather than between)-state valuation task was used, it could be argued that the values have interval, not ratio properties (Flynn et al. 2011).

Whilst it was originally developed for use with older adults aged 65 and above, pilot testing has shown that the wording and formatting of the ICECAP-O instrument make it highly appropriate for application with all Australian adults (Flynn et al. 2010a). Indeed, the ICECAP-O is currently being applied with adults of all ages in a variety of clinical, social and aged care settings in several countries including Australia and New Zealand (Coast 2011). However, its application in the context of public health research remains in its infancy. To our knowledge, this is one of the first studies internationally to examine its potential for the measurement and valuation of quality of life in a community general population sample.

This study builds upon the existing work that has been undertaken in the UK to establish the construct validity of the ICECAP-O descriptive system and is complemented by on-going research by Flynn and colleagues to establish an Australian general population-based scoring algorithm for the ICECAP-O (Coast et al. 2008a, b; Flynn et al. 2010a, 2011).

The main objective of the study was to assess the applicability of the ICECAP-O capability index in the measurement and valuation of quality of life in a community based sample of the Australian general population. An important additional objective of the study was to assess the ability of the ICECAP-O in differentiating capability levels within the Australian general population according to a number of key socio-demographic characteristics.

Methods

The Health Omnibus Survey is a face-to-face survey conducted annually in South Australia to obtain social statistics for use in the planning, implementation and monitoring of health-related initiatives. Questions are submitted for inclusion in the survey by government and non-government organisations with an interest in health and quality of life research. The cost of undertaking the survey is shared amongst these organisations, with each paying a fee determined by the number of questions they have submitted (Harrison Research 2010).

Fig. 1 The ICECAP-O index of capability (South Australia, 2009). ICECAP-O ICEpop CAPability index

ABOUT YOUR QUALITY OF LIFE

By placing a tick (✓) in ONE box in EACH group below, please indicate which statement best describes your quality of life at the moment.

<p>1. Love and Friendship</p> <p>I can have all of the love and friendship that I want</p> <p>I can have a lot of the love and friendship that I want</p> <p>I can have a little of the love and friendship that I want</p> <p>I cannot have any of the love and friendship that I want</p>	<input type="checkbox"/> 4 <input type="checkbox"/> 3 <input type="checkbox"/> 2 <input type="checkbox"/> 1	<p>Tick one box only in each section</p>
<p>2. Thinking about the future</p> <p>I can think about the future without any concern</p> <p>I can think about the future with only a little concern</p> <p>I can only think about the future with some concern</p> <p>I can only think about the future with a lot of concern</p>	<input type="checkbox"/> 4 <input type="checkbox"/> 3 <input type="checkbox"/> 2 <input type="checkbox"/> 1	
<p>3. Doing things that make you feel valued</p> <p>I am able to do all of the things that make me feel valued</p> <p>I am able to do many of the things that make me feel valued</p> <p>I am able to do a few of the things that make me feel valued</p> <p>I am unable to do any of the things that make me feel valued</p>	<input type="checkbox"/> 4 <input type="checkbox"/> 3 <input type="checkbox"/> 2 <input type="checkbox"/> 1	
<p>4. Enjoyment and pleasure</p> <p>I can have all of the enjoyment and pleasure that I want</p> <p>I can have a lot of the enjoyment and pleasure that I want</p> <p>I can have a little of the enjoyment and pleasure that I want</p> <p>I cannot have any of the enjoyment and pleasure that I want</p>	<input type="checkbox"/> 4 <input type="checkbox"/> 3 <input type="checkbox"/> 2 <input type="checkbox"/> 1	
<p>5. Independence</p> <p>I am able to be completely independent</p> <p>I am able to be independent in many things</p> <p>I am able to be independent in a few things</p> <p>I am unable to be at all independent</p>	<input type="checkbox"/> 4 <input type="checkbox"/> 3 <input type="checkbox"/> 2 <input type="checkbox"/> 1	

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For the 2009 survey, a multi-stage systematic area sample was conducted which resulted in the selection of 5,200 randomly chosen households. Of these, 74 % were located in metropolitan areas; the remaining 26 % were chosen from regional areas with populations of 1,000 or more. From each of the selected households, one person aged 15 years or older was randomly selected to participate in the Health Omnibus Survey. The survey was conducted as a face-to-face interview in the participant's own home. Households were classified as a non-contact if the interviewer was unable to make contact with the residents after a minimum of six visits to the household.

The survey was conducted following approval by the South Australian Department of Health Ethics Committee and was overseen by a quality control committee. In addition to responses to the ICECAP-O questions, data were collected on socio-demographic variables including age, gender, country of birth, marital status, area of residence, household income, level of education and status and field of employment. Individual responses to the ICECAP-O instrument were converted to a single index score ranging from 0 (no capability) to 1 (full capability) for each individual respondent by applying the existing preference-based scoring algorithm (Fig. 1 above). Descriptive statistical

methods were then employed to analyse the ICECAP-O scores of the participants who completed the instrument by younger and older age groups (dichotomised as <65 years or ≥ 65 years) according to categories of key socio-demographic variables. Categorisation into younger and older age groups enabled a demographic 'snap-shot' description of the quality of life of the South Australian general population as measured by the ICECAP-O. It also facilitates future comparisons of the quality of life of younger and older adults living in the community with the quality of life achieved through the introduction of clinical and public health interventions across a range of sectors.

The socio-economic status of all individual participants was classified according to the Socio-Economic Indexes for Areas (SEIFA), a series of four indexes which rank the geographic area in which the individual resides according to details obtained from the Census of Population and Housing (Pink 2006a). Each geographic area is assigned a score which indicates how disadvantaged that area is in comparison to other areas within Australia, with lower scores indicating higher levels of disadvantage. Levels of disadvantage and advantage are determined according to income, education, employment, occupation, housing (high mortgage, high or low rent, residing in government housing and overcrowding), internet access, car ownership, disability and single parenthood (Pink 2006b). Participants in this study were grouped into quartiles according to the scores assigned to their residential postcode at the time of interview using the SEIFA Index of Relative Socio-economic Advantage and Disadvantage. The quality of life of the participants was then analysed in relation to these socio-economic quartiles.

A series of multivariable ordinary least squares (OLS) linear regression models were also applied to further examine the relationship between ICECAP-O scores and the various socio-demographic variables for younger and older age groups. The regression models included the ICECAP-O score as the dependent variable and a series of dummy variables reflecting socio-demographic characteristics as the independent variables. Ideally, the categorisation of socio-demographic variables and the expected relationships between these variables and quality of life would be based upon prior empirical evidence derived from studies applying other capability and/or preference-based instruments in similar settings (Flynn 2011). However, this was not possible for this study due to the lack of previous empirical research in capability and the application of preference-based instruments in this context. The model selection was therefore informed by variables which had been found to be potentially influential on quality of life in other works such as those reviewed by Brown and colleagues (Brown et al. 2004). The explanatory variables included in the regression model and presented here were:

- Gender
- Country of birth
- Aboriginal and Torres Strait Islander status
- Residential area (regional or metropolitan)
- Living alone
- Employment status
- Highest educational qualification obtained
- Average annual household income
- Socio-economic status.

It was hypothesised that quality of life within both younger and older age groups would be influenced by marital, residential and socio-economic status (with those who were married, living in a metropolitan area or an area of relative socio-economic advantage having higher scores on average) and would be positively influenced by education, employment and income levels.

Results

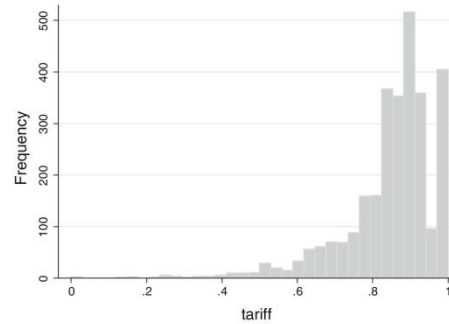
From the 5,200 selected households, 3,007 individuals agreed to participate and provided informed consent. This equates to a response rate of 59.3%. Of the 3,007 participants, 2,937 (98%) were adults aged 18 years or older. The characteristics of the adult participants are described in Table 1. The mean age of participants was 51.6 years (range 18–98 years) and 59.9% ($n = 1,758$) were female. The majority were born in Australia (71.3%; $n = 2,094$), did not identify as being Aboriginal or Torres Strait Islander (98.3%; $n = 2,887$), were married or living in a de facto relationship (57.9%; $n = 1,701$), and did not live alone (69.7%; $n = 2,046$). In relation to employment and education, 53.9% ($n = 1,584$) were employed on a full-time basis and 57.7% ($n = 1,696$) had obtained a tertiary qualification. The greatest proportion of participants resided in a household with an average income ranging from \$20,001 to \$60,000 per annum (29.3%; $n = 862$).

The ICECAP-O demonstrated a high completion rate (99.5%; $n = 2,923$) and the overall mean ICECAP-O score was 0.838 (SE 0.004). The mean ICECAP-O score of participants aged below 65 years (0.841; SE 0.003) was slightly higher than for older participants aged above 65 years (0.831; SE 0.006); these differences were not found to be statistically significant. Figure 2 represents the frequency distribution of scores for the ICECAP-O for all participants who completed the instrument. It can be seen that the capability reported by the participants ranged from no capability (a score of 0) to full capability (a score of 1). Whilst the majority of participants demonstrated high levels of capability, a minority were at the lower end of the scale with 31 participants, having ICECAP scores below 0.40.

Table 1 Participant Characteristics ($n = 2,937$) (South Australia, 2009)

Variable	Sample size
Gender	
Male	1,179
Female	1,758
Age	
18–64 years	2,148
65 years and above	789
Area of residence	
Metropolitan	2,278
Regional	659
Country of birth	
Australia	2,094
Other	836
Aboriginal or Torres Strait Islander status	
Aboriginal and/or Torres Strait Islander	37
Not Aboriginal and/or Torres Strait Islander	2,887
Marital Status	
Married or de facto	1,701
Separated or divorced	393
Widowed	339
Never married	495
Income	
≤\$20,000	511
\$20,001–\$60,000	862
\$60,001–\$100,000	605
≥\$100,001	430
Living alone	
Living alone	891
Not living alone	2,046
Work status	
Work full-time or part-time	1,584
Home duties	226
Unemployed	38
Retired	840
Student	77
Other	38
Not working due to disability or work-related injury	129
Highest qualification	
Currently studying	105
Primary or secondary school	1,127
Tertiary studies	1,696

Table 2 compares the mean ICECAP-O scores across younger ($n = 2,137$) and older ($n = 786$) age groups according to key socio-demographic variables. Younger participants born in a country other than Australia exhibited higher ICECAP-O scores on average than older people born outside of Australia to a statistically significant level

**Fig. 2** Histogram of ICECAP-O scores ($n = 2,923$) (South Australia, 2009). ICECAP-O ICEpop CAPability index

($P < 0.05$). Younger participants residing in areas of higher socio-economic status also had statistically significantly higher ICECAP-O scores than older participants residing in areas of higher socio-economic status ($P \leq 0.05$). There was also a clear differentiation in mean ICECAP-O scores according to average household income levels for both the younger and older age groups, although the magnitude of the differences in mean ICECAP-O scores differentiated by average household income levels was more marked for the younger age group. Older participants with an annual income of \$20,000 or less exhibited higher ICECAP-O scores on average than younger participants in the same category and these differences were found to be highly statistically significant ($P \leq 0.001$).

Tables 3 and 4 document the results of the multivariable regression analyses for the younger and older age groups, respectively. For each age group, the ICECAP-O scores were the dependent variables and the key socio-demographic characteristics were independent variables. Within the younger age group, (Table 3) the socio-demographic characteristics associated with statistically significant variations in overall ICECAP-O scores included marital status (with those participants who were married having higher scores on average compared to those who had never been married, or were separated or divorced), employment status (with those individuals who were not working due to injury or illness having lower scores on average than those in employment) and income (with those in higher income categories having higher scores on average than those in the lowest income category).

Within the older age group (Table 4), the socio-demographic characteristics which were associated with statistically significant variations in overall ICECAP-O scores included country of birth (with those participants who were born in Australia having higher scores on

Table 2 Mean ICECAP-O scores by categories of key variables ($n = 2,923$) (South Australia, 2009)

Socio-demographic variable	Below 65 years ($n = 2,137$)				65 years & above ($n = 786$)				Significance (P value)
	Mean	Lower 95 % CI	Upper 95 % CI	N	Mean	Lower 95 % CI	Upper 95 % CI	N	
Gender									
Male	0.832	0.821	0.843	875	0.821	0.799	0.843	298	0.371
Female	0.845	0.837	0.853	1,262	0.836	0.822	0.850	488	0.290
Area of residence									
Metropolitan	0.842	0.835	0.849	1,682	0.826	0.811	0.840	585	0.055
Regional	0.836	0.821	0.850	455	0.849	0.832	0.865	201	0.234
Country of birth									
Australia	0.842	0.835	0.849	1,614	0.846	0.832	0.860	477	0.628
Other	0.836	0.823	0.850	522	0.810	0.789	0.830	309	0.033*
Aboriginal or Torres Strait Islander status									
Aboriginal and/or Torres Strait Islander	0.841	0.783	0.898	30	0.871	0.775	0.967	6	0.501
Not Aboriginal and/or Torres Strait Islander	0.841	0.834	0.847	2,100	0.831	0.819	0.843	780	0.174
Marital status									
Married/de facto	0.869	0.864	0.875	1,309	0.863	0.852	0.875	391	0.336
Separated/divorced	0.804	0.787	0.820	303	0.804	0.767	0.841	87	0.976
Widowed	0.770	0.714	0.825	52	0.821	0.802	0.841	286	0.079
Never married	0.826	0.810	0.841	470	0.780	0.694	0.866	22	0.265
Lives alone									
Lives alone	0.814	0.801	0.827	501	0.815	0.798	0.832	381	0.903
Lives with others	0.859	0.853	0.865	1,636	0.863	0.853	0.874	405	0.500
Average annual household income									
≤\$20,000	0.753	0.727	0.780	199	0.815	0.796	0.835	310	≤0.001**
\$20,001–\$60,000	0.835	0.824	0.845	603	0.853	0.837	0.869	258	0.064
\$60,001–\$100,000	0.869	0.861	0.878	570	0.896	0.866	0.926	35	0.079
≥\$100,001	0.891	0.882	0.900	404	0.913	0.852	0.974	26	0.449
Employment status									
Working full-time or part-time	0.858	0.852	0.864	1,530	0.875	0.834	0.916	52	0.415
Home duties	0.821	0.789	0.845	192	0.839	0.791	0.886	33	0.512
Unemployed	0.795	0.742	0.848	37	–	–	–	–	–
Retired	0.839	0.810	0.868	150	0.831	0.818	0.843	689	0.610
Student	0.830	0.791	0.869	73	0.850	0.597	1.102	3	0.708
Other	0.805	0.748	0.862	31	0.755	0.352	1.157	6	0.738
Not working: disability or work-related injury	0.711	0.672	0.750	124	0.447	–0.971	1.865	3	0.333
Highest educational qualification									
Currently studying	0.833	0.807	0.859	94	0.792	0.629	0.956	10	0.567
Primary or secondary school	0.816	0.802	0.830	680	0.826	0.809	0.842	444	0.372
Tertiary studies	0.855	0.848	0.861	1,360	0.841	0.824	0.858	332	0.138
Socio-economic quartile^a									
Quartile 1	0.819	0.806	0.833	555	0.830	0.807	0.854	200	0.427
Quartile 2	0.843	0.830	0.857	520	0.837	0.817	0.858	217	0.621
Quartile 3	0.843	0.829	0.856	528	0.827	0.799	0.854	186	0.302

Table 2 continued

Socio-demographic variable	Below 65 years (<i>n</i> = 2,137)				65 years & above (<i>n</i> = 786)				Significance (<i>P</i> value)
	Mean	Lower 95 % CI	Upper 95 % CI	<i>N</i>	Mean	Lower 95 % CI	Upper 95 % CI	<i>N</i>	
Quartile 4	0.857	0.845	0.868	531	0.830	0.805	0.855	183	0.050*

ICECAP-O ICEpop CAPability index, *CI* confidence interval

* Significant difference between age groups at the 5 % level

** Significant difference between age groups at the 0.1 % level

^a Three participants resided in areas that were not allocated SEIFA scores via the Census of Population and Housing and were therefore excluded from this analysis. Quartile 1 = most disadvantaged, quartile 4 = least disadvantaged

Table 3 Results of multivariable regression of ICECAP-O scores on key variables for participants aged below 65 years (*n* = 2,137) (South Australia, 2009)

Variable	Below 65 years			
	Coefficient	Lower 95 % CI	Upper 95 % CI	<i>P</i> value
Female	0.007	-0.004	0.018	0.210
Born in country other than Australia	-0.002	-0.015	0.010	0.701
Aboriginal and/or Torres Strait Islander	0.024	-0.022	0.070	0.311
Residing in regional area	0.006	-0.008	0.020	0.389
Living with others	-0.019	-0.037	0.002	0.030*
Marital status				
Separated or divorced	-0.051	-0.070	-0.032	≤0.001**
Widowed	-0.060	-0.098	-0.023	0.002*
Never married	-0.035	-0.052	-0.018	≤0.001**
Employment status				
Home duties	-0.023	-0.042	-0.003	0.027*
Unemployed	-0.024	-0.065	0.018	0.269
Retired	0.003	-0.020	0.025	0.828
Student	0.020	-0.019	0.060	0.319
Other	-0.022	-0.065	0.022	0.326
Not working: disability or work-related injury	-0.091	-0.117	-0.065	≤0.001**
Highest educational qualification				
Primary or secondary school	0.010	-0.021	0.042	0.522
Tertiary studies	0.019	-0.011	0.050	0.214
Annual household income				
\$20,001-\$60,000	0.046	0.025	0.066	≤0.001**
\$60,001-\$100,000	0.066	0.043	0.089	≤0.001**
≥\$100,001	0.083	0.058	0.108	≤0.001**
Socio-economic quartile ^a				
Quartile 2	0.001	-0.014	0.017	0.847
Quartile 3	-0.005	-0.021	0.010	0.505
Quartile 4	0.001	-0.015	0.018	0.863

ICECAP-O ICEpop CAPability index, *CI* confidence interval

* *P* < 0.05

** *P* < 0.001

^a Three participants resided in areas that were not allocated SEIFA scores via the Census of Population and Housing and were therefore excluded from this analysis. Quartile 1 = most disadvantaged, quartile 4 = least disadvantaged

Table 4 Results of multivariable regressions of ICECAP-O scores on key variables for participants aged 65 years & above ($n = 786$) (South Australia, 2009)

Variable	Coefficient	Lower 95 % CI	Upper 95 % CI	<i>P</i> value
Female	0.017	-0.007	0.042	0.162
Born in country other than Australia	-0.032	-0.055	-0.009	0.007*
Aboriginal and/or Torres Strait Islander	-0.005	-0.148	0.137	0.940
Residing in regional area	0.006	-0.022	0.034	0.666
Living with others	0.000	-0.060	0.060	0.995
Marital status				
Separated or divorced	-0.036	-0.105	0.032	0.301
Widowed	-0.033	-0.093	0.265	0.274
Never married	-0.038	-0.122	0.046	0.374
Employment status				
Home duties	0.038	-0.039	0.116	0.331
Unemployed	-	-	-	-
Retired	-0.002	-0.049	0.044	0.925
Student	-0.003	-0.175	0.169	0.969
Other	-0.012	-0.154	0.130	0.873
Not working: injury or disability	-0.377	-0.575	-0.179	≤0.001**
Highest educational qualification				
Primary or secondary school	0.058	-0.041	0.157	0.250
Tertiary studies	0.060	-0.039	0.159	0.235
Annual household income				
\$20,001-\$60,000	0.020	-0.006	0.046	0.138
\$60,001-\$100,000	0.059	0.003	0.114	0.037*
≥\$100,001	0.091	0.030	0.153	0.004*
Socio-economic quartile ^a				
Quartile 2	0.007	-0.022	0.037	0.635
Quartile 3	0.012	-0.021	0.045	0.478
Quartile 4	-0.014	-0.050	0.023	0.459

ICECAP-O ICEpop CAPability index, CI confidence interval

* $P < 0.05$ ** $P < 0.001$ ^a Three participants resided in areas that were not allocated SEIFA scores via the Census of Population and Housing and were therefore excluded from this analysis. Quartile 1 = most disadvantaged, quartile 4 = least disadvantaged

average compared to those who were born elsewhere), employment (with those individuals who were not working due to injury or illness having lower scores on average than those in employment) and income (with those in higher income categories having higher scores on average than those in the lowest income category). However, the impact of income level upon quality of life was not found to be as pronounced in the older age group as for the younger age group.

Discussion

The findings from this study indicate that although the quality of life of a representative sample of the South

Australian general population as measured and valued by the ICECAP-O capability index was generally high, the ICECAP-O was able to differentiate capability levels according to a number of key socio-demographic characteristics. Lower income levels and being unemployed due to disability or work-related injury were found to be negatively associated with capability for both age groups. Capability was found to be strongly and positively associated with marriage and cohabitation in the younger age group, whilst for the older age group being born in Australia was found to be a positive indicator.

In their assessment of the construct validity of the ICECAP-O descriptive system, Coast et al. (2008a, b) examined the relationship between capability and several participant characteristics in a representative sample of

older people from the general population in the UK. The findings from the UK study and this Australian study are somewhat similar in that no strong relationships between capability and gender or socio-economic status were found. Marital status (specifically being married) was found to be positively associated with capability in both studies. The only clear discrepancy between the study findings arose in relation to age. Whilst the quality of life experienced by participants in the UK study by Coast et al. was strongly influenced by age, the association between age and quality of life in this sample was found to be less pronounced. The reasons for the differences in findings relating to age are unclear but may be attributable to differences in study samples or in unobserved heterogeneity between the groups in Australia and the UK (Flynn et al. 2010b). The study by Coast et al. related to a relatively small sample of individuals ($n = 315$) living in the UK and aged over 65 years only, whilst this study reported on a large sample of individuals living in Australia within a broader age range (18–98 years). Coast et al. also focused more exclusively upon the relationship between age and *individual responses to the ICECAP-O dimension questions*, whereas the primary focus of our analysis was the relationship between socio-demographic variables and quality of life as represented by ICECAP-O scores for younger (<65 years) and older (>65 years) adults.

Previous population level surveys have questioned the sensitivity of traditional QALY-type indicators at the population level (Kurth and Ellert 2002), with capability centred instruments such as the ICECAP-O suggested as a potential alternative for use in economic evaluation (Lorgelly et al. 2010). A comparison of the non-health-specific ICECAP-O with a traditional health-focused QALY instrument such as the EQ-5D would be beneficial, and the authors are currently undertaking such a comparison.

Given that the ICECAP-O was initially developed for use with older adults, the inclusion of study participants below 65 years of age may be viewed as a limitation of this study. However, the findings from this study and our previous pilot testing have demonstrated that the wording and formatting of the ICECAP-O instrument make it highly appropriate for all adults in the Australian general population (Flynn et al. 2010a). At the time of the administration of this study, only the ICECAP-O instrument was publicly available. However, the instrument developers have since produced a capability index for all adults aged above 18 years (the ICECAP-A) which may be more appropriate to use in further studies where younger people are also included. In addition, the existing ICECAP-O scoring algorithm is based upon the preferences of a UK older adult population. However, evaluation exercises are currently being conducted which will generate Australian general population-specific scoring algorithms for the

ICECAP-O and ICECAP-A by Flynn and colleagues. Once these algorithms become publicly available, they will allow for further valuation of quality of life based upon the preferences for alternative ICECAP-O states generated from a representative sample of the Australian population (Flynn et al. 2010a).

This study has provided the first indication of Australian general population quality of life values for the ICECAP-O for younger and older age groups, respectively. This will facilitate comparisons of the quality of life of the general population to that of more specific samples including specific patient groups in rehabilitation medicine and aged care settings. On a wider scale, the application of the ICECAP-O in representative community based samples from the general population of other countries would allow comparisons of the quality of life experiences of the general population at an international level.

In summary, the findings of this study demonstrate the potential for the ICECAP-O capability index in the measurement and valuation of quality of life in population surveys. The outcomes of many public health interventions impact at a population level and may extend beyond health to encompass quality of life more broadly where this is assumed to encompass the broad range of factors that are important to people in living their lives. Further research should investigate the potential for the ICECAP-O to be applied more widely in assessing the quality of life of different population groups and its applicability for the measurement and valuation of the benefits of population level public health interventions within an economic evaluation framework.

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References

- Brown J, Bowling A, Flynn T (2004) Models of quality of life: a taxonomy, overview and systematic review of the literature. European Forum on Population Ageing Research. Cited 13 April 2011. Available from http://www.shef.ac.uk/ageingresearch/pdf/qol_review_no_tables.pdf
- Coast J (2011) In: 2nd ICECAP Users' workshop: introduction. University of Birmingham, February 2011
- Coast J, Peters TJ, Natarajan L, Sproston K, Flynn T (2008a) An assessment of the construct validity of the descriptive system for the ICECAP capability measure for older people. *Qual Life Res* 17:967–976
- Coast J, Flynn TN, Natarajan L, Sproston K, Lewis J, Louviere J, Peters TJ (2008b) Valuing the ICECAP capability index for older people. *Soc Sci Med* 67:874–882

- Flynn T, Louviere J, Huynh E, Terlich F (2010a) What are Australian preferences for quality of life? Results from best-worst scaling studies to value the ICECAP instruments. Paper presented at the Australian Health Economics Society meeting, Sydney, Australia, 30 Sept–1 Oct 2010
- Flynn TN, Louviere J, Peters TJ, Coast J (2010b) Using discrete choice experiments to understand preferences for quality of life. Variance-scale heterogeneity matters. *Soc Sci Med* 70:1957–1965
- Flynn T (2011) Assessing quality of life among British older people using the ICEPOP CAPability (ICECAP-O) measure. *Appl Health Econ Health Policy* 9:317–329
- Flynn TN, Peters TJ, Coast J (2011) Workshop: quantifying response shift or adaptation effects in quality of life by synthesising BWS case 2 and discrete choice data. In: International choice modelling conference, Leeds, UK, June 2011
- Grewal I, Lewis J, Flynn T, Brown J, Bond J, Coast J (2006) Developing attributes for a generic quality of life measure for older people: preferences or capabilities? *Soc Sci Med* 62:1891–1901
- Harrison Research (2010) Health Omnibus Survey. Cited 13 April 2011. Available from http://www.harrisonresearch.com.au/health_omnibus.php.
- Kurth BM, Ellert U (2002) The SF-36 questionnaire and its usefulness in population studies: results of the German Health Interview and Examination Survey 1988. *Soz Präventivmed* 47:266–277
- Lorgelly P, Lawson KD, Fenwick EAL, Briggs AH (2010) Outcome measurement in economic evaluations of public health interventions: a role for the capability approach? *Int J Environ Res Public Health* 7:2274–2289
- Pink B (2006a) Information Paper: an introduction to Socio-Economic Indexes For Areas (SEIFA). Australian Bureau of Statistics, Cat no. 2039.0. Canberra, Australia
- Pink B (2006b) Socio-Economic Indexes for Areas (SEIFA)—technical paper. Australian Bureau of Statistics, Cat no 2039.0.55.001. Canberra, Australia
- Ravens-Sieberer U (2002) Measuring and monitoring quality-of-life in population surveys: still a challenge for public health research. *Soz Präventivmed* 46:201–204
- Robeyns I (2003) Sen's capability approach and gender inequality. Selecting relevant capabilities. *Fem Econ* 9:61–92
- Rowen D, Brazier J, van Hout B (2011) A comparison of methods for converting DCE values onto the full health-dead QALY scale. Health Economics and Decision Science Discussion Paper. University of Sheffield. Available from http://www.shef.ac.uk/polopoly_fs/1.1654951/file/1115.pdf
- Sen A (1993) Capability and well-being. In: Nussbaum M, Sen A (eds) *The quality of life*. Oxford University Press, New York

RESEARCH

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The relationship between quality of life, health and care transition: an empirical comparison in an older post-acute population

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Abstract

Background: The aim of this study was to explore, via empirical comparison, the relationship between quality of life, as measured by the ICECAP-O capability index (a new instrument designed to measure and value quality of life in older people), with both self-reported health status and the quality of care transition in adults aged 65 and over participating in two post acute rehabilitation programs (outpatient day rehabilitation and the Australian National Transition Care residential program).

Methods: The ICECAP-O was administered to patients receiving either outpatient day rehabilitation (n = 53) or residential transition care (n = 29) during a face to face interview. The relationships between the ICECAP-O and other instruments, including the EQ-5D (a self-reported measure of health status) and CTM-3 (a self-reported measure of the quality of care transitions), the type of post-acute care being received and socio-demographic characteristics were examined.

Results: The mean ICECAP-O score for the total sample was 0.81 (SD: 0.15). Patients receiving outpatient day rehabilitation generally reported higher levels of capability, than patients receiving residential transition care (mean 0.82 [SD: 0.15] and 0.79 [SD: 0.164] respectively), however these differences were not statistically significant. The mean EQ-5D score for the total sample was somewhat lower than the ICECAP-O (mean 0.55; SD: 0.27) indicating significant levels of health impairment with the outpatient day rehabilitation group demonstrating slightly higher levels of health status than the transition care group (mean 0.54 [SD: 0.254] and mean 0.49 [SD: 0.30]). The ICECAP-O was found to be positively correlated with both the CTM-3 (Spearman's $r = 0.234$; $p \leq 0.05$) and the EQ-5D (Spearman's $r = 0.437$; $p \leq 0.001$). The relationships between the total EQ-5D and CTM-3 scores and the individual attributes of the ICECAP-O indicate health status and quality of care transition in this patient population to be influential in some, but not all aspects of capability.

Conclusions: The correlations between the ICECAP-O, EQ-5D and CTM-3 instruments illustrate that capability is strongly and positively associated with health-related quality of life and the quality of care transitions. However further research is required to further examine the construct validity of the ICECAP-O and to examine its potential for incorporation into economic evaluation.

Keywords: Aged, Geriatrics, Rehabilitation, Quality of life, Health services for the aged, Health economics

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Background

The life expectancy of Australians is among the highest in the world and is expected to continue to increase, contributing to an ageing population [1]. Currently 13.5% of the total Australian population are aged 65 years and over, a number that is projected to increase to up to 25% by 2056 [2]. This is predicted to result in an increased demand for care and support services and the funding of new technologies, leading to a need for increased resource allocation in a variety of areas including hospitals, pharmaceuticals, medical benefits and private health insurance [3,4].

While the need for the Australian health system to provide services which are cost-effective has been widely acknowledged, ideally this should be undertaken in a way that does not minimise the quality of care provided to recipients. The escalating pressure faced by health systems in relation to the allocation of scarce health care resources highlights the importance of economic evaluations of health and social care interventions in informing such decisions. Quality of life has been recognized as an important outcome of health and social care interventions, and as such is frequently measured in economic evaluations via the calculation of quality adjusted life years (QALYs) which combine health-related quality of life with the period of time spent in each health state. However some interventions may impact on quality of life more broadly than the health-related aspects encapsulated by the QALY. For example, rehabilitation interventions for older people following an acute hospital stay may include education, problem solving, therapy, medical interventions and the provision of aids, e.g. electric wheelchairs and walking aids, in order to promote independent living. Whilst the provision of these interventions may have little or no impact upon health, they may lead to significant improvements in an individual's quality of life [5]. From a health economics perspective, it is therefore important to be able to measure and value quality of life in a way that is suitable for inclusion within an economic evaluation framework, yet which also encompasses the multitude factors that may influence quality of life.

Many countries are expanding the range of post-acute services available to older people partly in response to shortening hospital stays and partly in response to community demand for additional services to reduce the risk of institutionalisation and maintain older people independently in their own homes. The Australian National Transition Care Program was established in 2005 to reduce the length of inappropriate hospital stays and premature admission to residential aged care facilities. The program is targeted at older people at the end of an inpatient hospitalisation who were not eligible for hospital rehabilitation services but who required further care in order to complete their recovery, optimise their level of functioning and make arrangements for long term care

if necessary. The program is time-limited and goal-oriented and can be provided in either an inpatient or community setting. The services provided are determined by individual need and can include low intensity rehabilitation, medication support, case management and nursing and personal care. Prior to commencing Transition Care, patients are required to be medically stable and approved for transition care by an Aged Care Assessment Team [6]. A recent evaluation of the Australian Transition Care program demonstrated transition care provided in the community could reduce both hospital readmissions and transfers to residential care settings [7,8].

This study sought to empirically compare the relationship between quality of life, self-reported health and the quality of care transition in adults aged 65 and over whom were receiving post acute care either by participating in outpatient day rehabilitation or receiving residential Transition Care utilising the newly developed ICECAP-O instrument.

Method

Participants were recruited from an outpatient day rehabilitation unit at the Repatriation General Hospital, a 300 bed acute care hospital in metropolitan Adelaide, South Australia, and City Views a residential transitional care facility providing post-acute rehabilitation type care to adults aged 65 and over who require further recovery time to assess whether they could go home or required residential care admission. These two patient groups were selected as together they are broadly representative of the post-acute population of older people in South Australia. The two groups represent a range of post acute patients' levels of functional independence with the transition care group being functionally more dependent than the outpatient day rehabilitation group [8]. Participants were eligible for inclusion if they were currently receiving post-acute care in the form of either outpatient rehabilitation or the residential Australian National Transition Care Program, were within 3 months of an acute hospital admission, were aged 65 years or over and had a Mini Mental State Examination score of 24 or above [9]. The study sample was obtained sequentially over a 17 month period from August 2009 to January 2011. Admission lists were monitored weekly by research staff for new patients who met the study inclusion criteria. Eligible patients were approached while at either the outpatient day rehabilitation unit or the residential transitional care facility by the same research staff and provided with verbal and written information about the study. All patients who went on to participate in the study provided informed, written consent to do so. The study was approved by the Southern Adelaide Health Service / Flinders University Human Research Ethics Committee.

Data were collected via a face to face interview with individual participants. Participants were asked to complete the ICECAP-O, EQ-5D and CTM-3 instruments. Basic socio-

demographic information was also collected such as age, gender, country of birth, level of education, diagnosis and residential status.

Measures

ICECAP-O index of capability

The ICECAP-O index of capability is a newly developed instrument designed to measure and value quality of life, as defined by an individual's capabilities, for application within economic evaluations of health and social care interventions. The instrument is designed for utilisation with older people (aged 65 years plus) and focuses on quality of life in a broader sense rather than health-related quality of life alone. This means that the ICECAP-O has the potential to inform resource allocation decision making across health, social and aged sectors, [10,11]. In a study to assess the construct validity of the instrument, Coast and colleagues [11] found that individuals' quality of life was influenced by their capability to achieve the attributes included in the ICECAP-O instrument. The instrument is comprised of 5 attributes: attachment, role, enjoyment, security and control. The attributes were developed via qualitative interviews

with older people about what was important to them in terms of their quality of life [10,11]. Each attribute contains five levels from which participants choose the level that best matches their current situation. A preference based scoring algorithm was developed for the instrument using a best-worst scaling discrete choice experiment (DCE) with a representative sample of older people in the United Kingdom [10]. The scoring algorithm can be readily applied to obtain a single index value for all possible combinations of responses ranging from 0 (no capability) to 1 (full capability). This facilitates the potential for the ICECAP-O to be used to measure and value the benefits of health, social and aged care interventions.

EQ-5D

The EQ-5D is a generic measure of health status which is widely applied in the economic evaluation of health care treatments and services. The instrument is comprised of a descriptive system covering five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression, each consisting of 3 levels of increasing severity [12]. The EQ-5D enables the calculation of a single index value indicating quality of life ranging from

Table 1 Characteristics of participants (n = 82)

<i>Characteristic</i>	<i>Outpatient Rehab (n = 53)</i>	<i>Transition Care (n = 29)</i>	<i>Total (n = 82)</i>
Age (mean, SD)	74.87 (7.17)	80.69 (6.27)	76.23 (7.38)
Cognitive score (mean, SD)	27.83 (1.23)	28.17 (1.49)	27.95 (1.78)
Gender: Female (%)	24 (45)	17 (59)	41 (50)
Has a carer (%)	33 (60)	21 (72)	54 (67)
Residential status (%)			
Living alone	14 (26)	21 (72)	35 (43)
Living with others	39 (74)	8 (28)	47 (57)
Country of birth (%)			
Australia	40 (76)	24 (83)	64 (78)
Other	13 (25)	5 (17)	18 (22)
Highest education			
No education	1 (2)	-	1 (1)
Primary or secondary	24 (45)	19 (66)	43 (52)
Tertiary	28 (53)	8 (28)	36 (44)
Post-acute care duration (mean, SD)	33.21 (16.03)	42.59 (21.11)	36.52 (18.42)
Reason for post-acute care (%)			
Neurological	29 (55)	1 (3)	30 (37)
Orthopaedic	8 (15)	18 (62)	26 (32)
Functional decline/falls/mobility	10 (19)	6 (21)	16 (20)
Other	6 (11)	4 (14)	10 (12)
Instrument scores			
ICECAP-O (mean, SD)	0.82 (0.15)	0.79 (0.16)	0.81 (0.15)
EQ-5D (mean, SD)	0.54 (0.25)	0.49 (0.30)	0.52 (0.27)
CTM-3 (mean, SD)*	75.79 (16.78)	63.60 (17.67)	71.48 (17.97)

* Significant difference between sites at between the 1% and 10% levels.

Table 2 Distribution of responses to the ICECAP-O instrument (n = 82)

	Outpatient Rehab (n = 53)	Transition Care (n = 29)	Total (n = 82)
Attachment			
I can have all of the love and friendship that I want	34 (64.2%)	13 (44.8%)	47 (57.3%)
I can have some of the love and friendship that I want	13 (24.5%)	12 (41.8%)	25 (30.5%)
I can have a little of the love and friendship that I want	5 (9.4%)	4 (13.8%)	9 (11.0%)
I cannot have any of the love and friendship that I want	1 (1.9%)	-	1 (1.2%)
Security			
I can think about the future without any concern	17 (32.1%)	14 (48.3%)	31 (37.8%)
I can think about the future with only a little concern	21 (39.6%)	8 (27.6)	29 (35.4%)
I can only think about the future with some concern	9 (17.0%)	7 (24.1%)	16 (19.5%)
I can only think about the future with a lot of concern	6 (11.3%)	-	6 (7.3%)
Role			
I am able to do all of the things that make me feel valued	13 (24.5%)	7 (24.1%)	20 (24.4%)
I am able to do many of the things that make me feel valued	20 (37.4%)	8 (27.6%)	28 (34.2%)
I am able to do a few of the things that make me feel valued	15 (28.3%)	9 (31.0%)	24 (29.3%)
I am unable to do any of the things that make me feel valued	5 (9.43%)	5 (17.2%)	10 (12.2%)
Enjoyment			
I can have all of the enjoyment and pleasure that I want	18 (34.00%)	9 (31.0%)	27 (32.9%)
I can have a lot of the enjoyment and pleasure that I want	22 (41.5%)	9 (31.0%)	31 (37.8%)
I can have a little of the enjoyment and pleasure that I want	12 (22.6%)	9 (31.0%)	21 (25.6%)
I cannot have any of the enjoyment and pleasure that I want	1 (1.9%)	2 (6.9%)	3 (3.7%)
Control			
I am able to be completely independent	13 (24.5%)	2 (6.9%)	15 (18.3%)
I am able to be independent in many things	25 (47.2%)	16 (55.2%)	41 (50.0%)
I am able to be independent in a few things	13 (24.5%)	9 (31.0%)	22 (26.8%)
I am unable to be at all independent	2 (3.8%)	2 (6.9%)	4 (4.9%)

0 (worst imaginable health) to 1 (perfect health) which can be used in economic evaluations [12]. Indeed, the instrument has been widely applied in this context with older adult general populations in the community and older adult patient populations [13-15].

CTM-3

The Care Transition Measure was designed to measure the quality of transitions between health care settings from the older patient's perspective. This can then be used in the evaluation of health service performance [16]. The instrument covers 3 domains: whether the patient understood what they were responsible for in managing their health, the purpose of their medications and whether their preferences and those of their family were taken into consideration. Individual responses to the CTM-3 are used to calculate a score ranging from 0 to 100, with higher scores indicating higher quality transitions [17]. The instrument has been used internationally by organisations involved in health care delivery, quality improvement and research [17].

Basic descriptive tests were used to provide a summary of respondent's characteristics. The data were analysed using SPSS version 17. Spearman's rho was used to examine the association between continuous variables and chi-squared tests, analysis of covariance and T-Tests were performed to assess the associations between categorical variables.

A priori hypotheses were formed about the expected relationships between the ICECAP-O and the other measurement tools and socio-demographic data based upon previous assessments of validity for other measures and evidence of relationships from previously published studies (where available), and the views of the research team members where other evidence was not available.

Health It was anticipated that there would be a strong relationship between health status and capability, supporting previously published studies presented by the developers of the ICECAP-O [11]. It was therefore hypothesised that participants reporting high levels of capability would also experience high levels of self-reported health. The ICECAP-O attributes of control, enjoyment and role were expected to

Table 3 Distribution of mean EQ-5D values across ICECAP-O levels of capabilities (n = 82)

Attribute	Outpatient Rehab (n = 53)	Transition Care (n = 29)	Total (n = 82)
Attachment			
I can have all of the love and friendship that I want	0.568	0.490	0.545
I can have a lot of the love and friendship that I want	0.569	0.498	0.441
I can have a little of the love and friendship that I want	0.398	0.493	0.472
I cannot have any of the love and friendship that I want	0.088	-	0.088
Security			
I can think about the future without any concern	0.565	0.565	0.565
I can think about the future with only a little concern	0.607	0.444	0.562
I can only think about the future with some concern	0.430	0.408	0.420
I can only think about the future with a lot of concern	0.425	-	0.425
Role			
I am able to do all of the things that make me feel valued	0.504	0.748	0.599
I am able to do many of the things that make me feel valued	0.648	0.355	0.564
I am able to do a few of the things that make me feel valued	0.484	0.493	0.487
I am unable to do any of the things that make me feel valued	0.371	0.361	0.366
Enjoyment			
I can have all of the enjoyment and pleasure that I want	0.555	0.721	0.615
I can have a lot of the enjoyment and pleasure that I want	0.623	0.431	0.567
I can have a little of the enjoyment and pleasure that I want	0.394	0.389	0.392
I cannot have any of the enjoyment and pleasure that I want	0.312	0.225	0.254
Control			
I am able to be completely independent	0.595	0.872	0.634
I am able to be independent in many things	0.578	0.549	0.567
I am able to be independent in a few things	0.441	0.379	0.416
I am unable to be at all independent	0.312	0.190	0.230

be associated with health status as they are more closely related to physical health than the remaining 2 domains. It was also hypothesized that each of the EQ-5D domains, would exhibit a strongly associated with capability, but particularly mobility, self-care and usual activities.

Quality of care transitions Previous studies have indicated that there may be a positive relationship between the quality of care transitions and health related quality of life [8,18]. Given the strong relationship between health status and capability previously identified, it was therefore anticipated that there may also be a positive relationship between

the quality of care transitions and capability with those individuals who scored more highly on the CTM-3 exhibiting higher levels of capability according to the ICECAP-O.

Socio-demographic characteristics A relationship was expected between capability and the type of post-acute care being received. It was anticipated that participants receiving outpatient rehabilitation would have higher scores on average than the participants receiving the Australian National Transition Care Program as they had returned to the community to live post-actively while the Transition Care recipients were still requiring institutional care and assistance with activities of daily living.

Table 4 Relationship between the ICECAP-O, EQ-5D and CTM-3 calculated using Spearman's rho (n = 82)

	ICECAP-O
EQ-5D ^a	0.437***
CTM-3	0.234*

^a n = 80 due to incomplete EQ-5D data.
 ** correlation is significant at the 1% level or higher.
 * correlation is significant at between the 1% and 10% levels.

Results

Participant Characteristics

Of the 96 eligible patients approached for participation in the study, 86 (90%) agreed to participate. A total of 4 participants had incomplete ICECAP-O data due to a refusal to answer particular ICECAP-O questions or were unable to fully complete the interview giving a total

Table 5 Tests of association (P values) between the ICECAP-O tariff and other characteristics measured using T-Tests and ANOVA (n = 82)

Characteristic	P Value
Site	0.429
Age	0.614
Gender	0.083
Cognitive status	0.280
Residential status	0.501
Has a carer	0.258
Country of birth	0.316
Education* (n = 80)	0.259
Post-acute care duration	0.826
Reason for post-acute care	0.509
EQ-5D: mobility	0.028*
EQ-5D: self-care	0.007*
EQ-5D: usual activities	≤0.001**
EQ-5D: pain/discomfort	0.995
EQ-5D: anxiety/depression	0.041*
EQ-5D: overall value	≤0.001**
CTM3: hospital staff	0.981
CTM3: managing health	0.173
CTM3: purpose of medications	0.111
CTM-3: overall value	0.161

* n = 80 due to missing education data.
 ** Association is significant at the 1% level or higher.
 * Association is significant at between the 1% and 10% level.

useable response rate of 85% (82/96). Fifty-three of these participants were receiving outpatient rehabilitation, while the remaining 29 were receiving residential transition care. The characteristics of the participants who completed the ICECAP-O instrument are presented in Table 1. The participants had a mean age of 76 years (SD 7.4) and were evenly split in regards to gender (female: 50%, n = 41). At the time of interview, the participants had been receiving post-acute care for a mean duration of 37 days (SD 18.4). Neurological diagnoses were the most common reasons for receiving post-acute care (n = 30, 37%) followed by orthopaedic diagnoses (n = 26, 32%). The majority of participants were not living alone prior to their acute hospital admission (57%, n = 47) and reported having an informal carer (65%, n = 56).

The mean ICECAP-O score for the total sample was 0.81 (SD 0.15). As predicted, the transition care group demonstrated lower levels of capability (mean 0.79, SD 0.16) than the rehabilitation group (mean 0.82, SD 0.15), although not to a statistically significant level. The distribution of responses to the ICECAP-O from participants who answered all five questions is presented in Table 2. The participants reported high levels of attachment

(56%, n = 48) and security (38%, n = 31). Limitations at various levels were evident however in terms of role (78%, n = 64), enjoyment (70%, n = 57) and control (87%, n = 71). A participant was deemed to have a limitation in a particular capability if they selected the second, third or fourth level for that particular question of the ICECAP-O instrument.

Self-Reported Health Status

The participants who completed the ICECAP-O instrument had a mean EQ-5D score of 0.52 (SD 0.27), with the rehabilitation recipients exhibiting higher scores than the transition care recipients (mean 0.54, SD 0.25 and mean 0.49, SD 0.30 respectively) as hypothesised, although not to a statistically significant level (Table 1). It was anticipated a priori that participants reporting high levels of capability via the ICECAP-O would also report high levels of self-rated health as measured by the EQ-5D. The distribution of mean EQ-5D values across the ICECAP-O levels of capabilities is presented in Table 3. This data is based upon participants who answered all five of the questions in the ICECAP-O instrument. A linear increase in EQ-5D scores was accompanied by increases in all of the ICECAP-O domains except attachment and security; however an upward trend was evident for these attributes.

The ICECAP-O was found to be positively associated with the EQ-5D (Spearman's $r = 0.426$; $p \leq 0.001$), as shown in Table 4, indicating that an increase in capability were accompanied by an increase in self-reported health status. This is further supported by the significant associations between the ICECAP-O and EQ-5D scores shown in Table 5 ($p \leq 0.001$), suggesting a relationship between capability and self-reported health. As shown in Table 6, a significant positive association was evident between the ED-5D scores and the ICECAP-O domain of control ($p < 0.05$), indicating that some, but not all, aspects of capability are influenced by self-reported health.

Quality of care transitions

Table 7 presents the distribution of responses to the CTM-3 from participants who completed all five questions of the ICECAP-O instrument. The mean CTM-3 score for the total sample was 71.48 (SD 17.97). The mean score of the rehabilitation patients (mean 75.79, SD 16.78) was higher than that of the transition care recipients (mean 63.60, SD 17.67) to a level that was statistically significant ($p < 0.05$). The CTM-3 was positively correlated with the ICECAP-O (Spearman's $r = 0.217$; $p \leq 0.05$) (Table 4). This suggests that higher quality care transitions are accompanied by higher levels of capability in support of our prior hypothesis. Although no significant relationship was found between the ICECAP-O and CTM-3 scores (Table 5), a significant relationship was

Table 6 Tests of association (P values) between capabilities as measured by the ICECAP-O and other characteristics using chi-squared tests (n = 82)

	<i>Attachment</i>	<i>Security</i>	<i>Role</i>	<i>Enjoyment</i>	<i>Control</i>
Site	0.279	0.119	0.670	0.495	0.251
Age	0.580	0.117	0.660	0.975	0.864
Gender	0.760	0.474	0.799	0.274	0.332
Cognitive status	0.631	0.232	0.106	0.480	0.545
Residential status	0.019*	0.552	0.540	0.232	0.614
Has a carer	0.474	0.890	0.007*	0.525	0.934
Country of birth	0.232	0.111	0.047*	0.105	0.207
Education ^a	0.656	0.916	0.142	0.785	0.196
Post-acute care duration	0.858	0.656	0.623	0.645	0.449
Reason for post-acute care	0.042*	0.633	0.670	0.898	0.875
EQ-5D: mobility	0.335	0.105	0.771	≤0.001**	≤0.001**
EQ-5D: self-care	0.721	0.317	0.018*	0.122	0.003*
EQ-5D: usual activities	0.704	0.668	≤0.001**	0.058	0.004*
EQ-5D: pain/discomfort	0.069	0.073	0.616	0.081	0.140
EQ-5D: anxiety/depression	0.279	0.419	0.364	0.339	0.023*
EQ-5D: overall value ^a	0.741 ^a	0.088 ^a	0.092 ^a	0.058 ^a	0.043 ^a *
CTM3: hospital staff	0.947	0.761	0.459	0.956	0.499
CTM3: managing health	0.020*	0.912	0.097	0.191	0.510
CTM3: purpose of medications	0.810	0.468	0.169	0.125	0.177
CTM-3: overall value	0.139	0.712	0.035*	0.145	0.015*

^a n = 80.

** Association is significant at the 1% level or higher.

* Association is significant at between the 1% and 10% level.

found to exist between the CTM-3 score and the ICECAP-O attributes of role and control, indicating that some, but not all areas of capability are influenced by the quality of care transitions (Table 6).

Socio-demographic characteristics

Tests of association between ICECAP-O scores and socio-demographic characteristics revealed no significant relationships, as shown in Table 5. Despite a priori expectation, no relationship was found to exist between age and any of the ICECAP-O attributes. Of significance however was the relationship between the ICECAP role attribute and country of birth ($p < 0.05$) and whether or not the participant had an informal carer ($p < 0.05$) as shown in Table 6. A relationship was also evident between the ICECAP attachment attribute and residential status ($p < 0.05$) (Table 6). Participants who reported having an informal carer were more likely to experience role limitations.

Discussion

The findings of this empirical comparison suggest the existence of a strong relationship between the concepts of capability, self-reported health and the quality of care transitions when measured in a post-acute setting

(transition care or outpatient rehabilitation) using the ICECAP-O, EQ-5D and CTM-3 instruments. The capability of this population was slightly lower than that reported in other studies utilising the ICECAP-O instrument [10,19]. However this may be attributable to the previous studies being based upon samples of the United Kingdom general population, both of which were younger in age than the current sample. The participants in this study who reported high levels of care transition quality also displayed higher capability levels. The quality of care transitions experienced by the participants was similar to that recorded in other studies of similar populations [8,17]. Higher levels of capability were also evident in the participants exhibiting higher levels of self-reported health. Although participants in this study demonstrated lower levels of self-rated health than in another study of older adults [11], our participants were older and recovering from an acute hospitalisation. The associations between self-reported health and the capability domains suggest health status to be influential in some, but not all aspects of capability, echoing the findings of previous work [11] which also revealed strong, positive relationships between self-reported health and some, but not all capabilities as measured using the ICECAP-O instrument.

Table 7 Distribution of responses to the CTM-3 (n = 82)

	Outpatient Rehab (n = 53)	Transition Care (n = 29)	Total (n = 82)
The hospital staff took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left the hospital			
Strongly disagree	1 (1.9%)	1 (3.4%)	2 (2.4%)
Disagree	8 (15.1)	7 (24.1%)	15 (18.3%)
Agree	26 (49.1%)	12 (41.4%)	38 (46.3%)
Strongly agree	14 (26.4%)	3 (10.3%)	17 (20.7%)
Don't know/not applicable	4 (7.5%)	6 (20.7%)	10 (12.2%)
When I left the hospital I had a good understanding of the things I was responsible for in managing my health			
Strongly disagree	-	2 (6.9%)	2 (2.4%)
Disagree	5 (9.4%)	5 (17.2%)	10 (12.2%)
Agree	22 (41.5%)	15 (51.7%)	37 (45.1%)
Strongly agree	25 (47.2%)	4 (13.8%)	29 (35.4%)
Don't know/not applicable	1 (1.9%)	3 (10.3%)	4 (4.9%)
When I left the hospital I clearly understood the purpose for taking each of my medications			
Strongly disagree	-	2 (6.9%)	2 (2.4%)
Disagree	6 (11.3%)	3 (10.3%)	9 (11.0%)
Agree	20 (37.7%)	13 (44.8%)	33 (40.2%)
Strongly agree	27 (50.9%)	11 (37.9%)	38 (46.3%)
Don't know/not applicable	-	-	-

The absence of a relationship between capability and socio-demographic characteristics is indicative that, in this population, self-reported health and the quality of care transitions were more influential than socio-demographic factors on capability. This is in contrast to the findings of Coast and colleagues [11] who found a strong association between capability and age. However those findings were based upon members of the United Kingdom general population, while this study focused on older Australian sample who recovering from a recent acute illness.

The relatively small sample size is a limitation of this study. We achieved a high consent rate of 93% and the sample contained a diverse range of diagnoses broadly representative of older people attending outpatient rehabilitation and transition care programmes. However, it is important that further research is conducted to verify these preliminary findings in larger clinical samples. In addition, as no Australian alternatives were available at the time the study was conducted, the ICECAP-O and EQ-5D scoring algorithms that were applied were the original algorithms for each instrument which are based

on the values of the UK general population. However, Flynn and colleagues [20] are currently in the process of developing a scoring algorithm for the ICECAP-O instrument based upon the preferences of the Australian general population and an Australian general population scoring algorithm has recently been developed for the EQ-5D [21]. Further studies conducted in Australian patient and general population samples should apply the new Australian general population algorithms pertaining to each instrument.

The data presented here were collected as part of a wider study focusing on the application of a discrete choice experiment to elicit the preferences of patients participating in either outpatient day rehabilitation or receiving residential transition care. Further measurement of capability at multiple time points would be beneficial in establishing the re-test reliability of the ICECAP-O and its sensitivity to change over time. Further research should also be conducted to compare the ICECAP-O with other instruments designed to measure quality of life more broadly amongst older people e.g. the recently

developed OPQOL (Older People's Quality of Life) instrument [22,23]

The use of the ICECAP-O capability index provides an alternative approach for to the measurement and valuation of the quality of life of older people. The ICECAP-O focuses on quality of life more broadly, rather than concentrating on health alone, and has the potential to be applied to aid in the determination of resource allocation decisions across the health, social and aged care sectors. In this study, utilisation of the ICECAP-O has provided insight into the relationship between capability, self-reported health and the quality of care transition in a post-acute population. However future research is required to further examine the construct validity of the ICECAP-O and its potential for application within economic evaluation in larger clinical settings and in alternative settings and populations of older adults.

Competing interests

The authors have no competing interests to declare

Authors' contributions

LC collected the participant data and drafted the manuscript. JR participated in the study design and drafted the manuscript. MC participated in the study design. All authors read and approved the final manuscript.

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References

1. Commission P: *Trends In Aged Care Services: Some Implications*. Canberra, Australia: Commission Research Paper; 2008.
2. Australian Bureau of Statistics: *Population Projections Australia*. Canberra, Australia; 2008. Cat no. 3222.0.
3. Department of Health and Ageing: *Ageing and Aged Care in Australia*. Canberra, Australia; 2008.
4. Australian Government Treasury: *Australia to 2050: Future challenges. In Intergenerational Report*. Canberra, Australia; 2010.
5. Hopman W, Verner J: *Quality of life during and after inpatient stroke rehabilitation*. *Stroke* 2003, **34**:801-805.
6. Department of Health and Ageing: *Transition Care Program: Program Guidelines*. Canberra, Australia: Australian Government Department of Health and Ageing; 2005.
7. Gray LC, Peel NM, Crotty M, Kurlle SE, Giles LC, Cameron ID: *How effective are programs at managing transition from hospital to home? A case study of the Australian transition care program*. *BMC Geriatr* 2012, **12**:6.
8. Flinders Consulting: *National Evaluation of the Transition Care Program: Final Evaluation Report*. Adelaide, Australia: Flinders Consulting; 2008. RFT 206/0506.
9. Folstein M, Folstein S, McHugh P: "Mini Mental State" A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975, **12**:189-198.
10. Coast J, Flynn T, Natarajan L, Sproston K, Lewis J, Louviere J, et al: *Valuing the ICECAP capability index for older people*. *Soc Sci Med* 2008, **67**:874-882.

11. Coast J, Peters TJ, Natarajan L, Sproston K, Flynn T: *An assessment of the construct validity of the descriptive system for the ICECAP capability measure for older people*. *Qual Life Res* 2008, **17**:967-976.
12. Rabin R, de Charro F: *EQ-5D: A measure of health status from the EuroQol Group*. *Ann Med* 2001, **33**:337-343.
13. Brazier J, Walters S, Nicholl J, Kohler B: *Using the SF-36 and EuroQol on an elderly population*. *Qual Life Res* 1996, **5**:195-204.
14. Coast J, Peters T, Richards S, Gunnell D: *Use of the EuroQol among elderly acute care patients*. *Qual Life Res* 1998, **7**:1-10.
15. Holland R, Smith R, Harvey L, Swift L, Lenaghan E: *Assessing quality of life in the elderly: A direct comparison of the EQ-5D and AQL*. *Health Econ* 2004, **13**:793-805.
16. Coleman E, Smith J, Frank J, Eilertsen T, Thiare J, Kramer A: *Development and testing of a measure designed to assess the quality of care transitions*. *Int J Integrated Care* 2002, **2**:1-9.
17. Coleman E, Parry C, Chalmers S, Chugh A, Mahoney E: *The central role of performance measurement in improving the quality of Transitional Care*. *Home Health Care Serv Q* 2007, **26**:93-104.
18. Coleman EA, Smith JD, Frank JC, Min S, Parry C, Kramer AM: *Preparing patients and caregivers to participate in care delivered across settings: The care transitions intervention*. *JAGS* 2004, **52**:1817-1825.
19. Flynn T: *Assessing quality of life among British older people using the ICECAP-O capability measure*. *Appl Health Econ Health Policy* 2011, **9**:317-329.
20. Flynn T, Louviere J, Huynh E, Terlich F: *What are Australian preferences for quality of life? Results from best-worst scaling studies to value the ICECAP instruments*. In *Australian Health Economics Society Meeting*. Sydney, Australia: Australian Health Economics Society Meeting; 2010.
21. Viney R, Norman R, King M, Cronin P, Street D, Knox SA, Ratcliffe J, Brazier J: *Time Trade-Off Derived EQ-5D Weights for Australia*. *Value Health* 2011, **14**:928-936.
22. Bilotta C, Bowling A, Nicolini P, Casè A, Pina G, Rossi SV, et al: *Older People's Quality of Life (OPQOL) scores and adverse health outcomes at a one-year follow-up. A prospective cohort study on older outpatients living in the community in Italy*. *Health Qual Life Outcomes* 2011, **9**:72.
23. Grant RL, Bowling A: *Challenges in comparing the quality of life of older people between ethnic groups, and the implications for national well-being indicators: a secondary analysis of two cross-sectional surveys*. *Health Qual Life Outcomes* 2011, **9**:109.

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