UNIVERSITY
OF TASMANIA

The Trajectory of Decline

A quantitative study to identify variations in the longitudinal functional profile of an Australian nursing home population

by

Suanne Joy Lawrence

BSc (Hons), MPH, MHA, RN

School of Nursing and Midwifery

Faculty of Health Sciences

Submitted in fulfilment of the requirements for the Doctor of Philosophy

University of Tasmania February 2013

Declaration

Statement of Original Authorship

I hereby declare that this thesis is my own work and contains no material which has been accepted for a degree or diploma by the University of Tasmania or any other institution, except by way of background information and duly acknowledged in the thesis, and to the best of my knowledge and belief no material previously published or written by another person except where due acknowledgement is made in the text of the thesis, nor does the thesis contain any material that infringes copyright.

Name: Suanne Joy Lawrence

Signed:

Date:

Statement of Authority

This thesis may be made available for loan and limited copying in accordance with the *"Copyright Act 1968"*.

Name: Suanne Joy Lawrence

Signed:

Date:

Statement of Ethical Conduct

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University.

Name: Suanne Joy Lawrence

Signed:

Date:

Abstract

Population ageing is a public health success story. However, the perceived pressures that the arrival of the 'baby boomer' generation will demand of the health system, coupled with the financial implications of a shrinking tax base, are cause for concern. By 2056 it is estimated that a quarter of Australians will be 65 years and older, double the current proportion. Concurrently demand for residential aged care services will also increase.

In Australia, aged care services are funded by the Australian Government via subsidies paid to service providers, based on the assessed care level required by each eligible client. The level of this subsidy is based on a validated measure of the resident's care needs that is assessed on admission to an aged care facility and then, at a minimum, annually thereafter. Residential aged care is the principal consumer of the aged care budget and it is predicted that costs will increase with the increasing proportion of aged in the population. Approximately 5% of Australians 65 years and older currently live in residential aged care, and the annual recurrent cost of their care is $6.6 billion.

Review of resident care levels has shown that over the past decade the acuity of residents entering aged care facilities has increased while the length of stay of a newly admitted resident has decreased. The increase in resident separations via death will exert further pressure on care services already struggling with staff shortages and increased costs. Such changes highlight an imperative to develop models that will predict the cost basis of care for residents in the increasingly rapid resident turnover environment.

Prediction of care needs and associated costs for an increasing number of elderly can be made based on population change estimates, but this is a coarse measure at best. Models that predict in advance the clinical and resource needs of the elderly described in the literature can potentially be used by policy makers and service providers to bring some certainty in planning future care

and resource demands. One of these is the 'trajectory of decline' model which was articulated by Joanne Lynn in the 1990's. This model, empirically tested in an elderly USA community population in collaboration with June Lunney and colleagues in 2002, revealed five trajectories grouped by their cause of death. The model has been subsequently utilised in a number of policy documents in the UK, USA, EU and Australia and has also been used as a clinical tool for planning end-of-life care in the elderly population. The model predicts that as an elderly person progresses along their illness trajectory the resources required to support them will increase or decrease with the level of care needed. However, the trajectory of decline concept has not been tested in an elderly nursing home population, whose principal mode of separation is death.

This thesis explores if the trajectory of decline, as proposed by Joanne Lynn and empirically tested by June Lunney and colleagues is existent in a nursing home population in Australia; and if there are comparable trajectories to those identified in their research. To replicate the existing empirical studies of this concept in a different population, two critical measures were required: (1) the cause of death to determine trajectory group membership; and (2) a measure of function in a nursing home population. In this study data were collected from the nursing home records of 247 deceased residents utilising the validated Resident Classification Scale (RCS) as the primary measure of function. This provided a total of 990 RCS scores available for analysis. Cause of death data were obtained from the Tasmanian Registrar of Births, Deaths and Marriages.

The degree to which the elderly residents of nursing homes fit the trajectory profiles proposed by Lynn and empirically tested by Lunney and colleagues was examined with a novel statistical analysis using multivariate statistics which allowed the trajectory of each individual to contribute to the analysis. Using this statistic, a predictive model was developed to examine the effect of the variables on the measure of function, the RCS, over the whole admission period as well as the 12 months prior to death. These results inform the

discussion examining the extent to which the trajectory of decline can prospectively predict the decline in functional ability of this elderly population.

The principal findings of this research are that there are four trajectories of functional decline to death in this nursing home population when grouped by their cause of death. More than half the subjects comprised the frailty group with the remainder distributed in similar proportions as found by Lunney and colleagues in the cancer, heart and lung failure and 'other' group which is poorly specified. Using routinely collected data, the functional trajectory of each group can be identified from the point of admission to the nursing home to death and are generally comparable to the trajectories for each group described in the literature. However, in relation to the functional profile, the Frailty Group is statistically different to the other three groups, but the other three groups are not different to each other.

A further finding is that there is poor agreement between what is written on the death certificate and the routine diagnosis made while the resident is still alive which reduces the utility of this concept for the purposes of prospective care planning. Repeating this study prospectively using a standardised medical admission will determine whether the four groups exist in this population or whether two groups, as suggested by this study, would be a better fit.

Acknowledgments

Julie's Pop was 92. He had been a resident at a nursing home for a number of years, sharing a unit and caring for his wife with dementia. Over a 12 month period, Julie's Pop had had a number of hospitalisations for worsening heart failure and associated renal impairment. After his last hospital episode he returned to the nursing home and was living in the 'high care' area. At midnight on Friday his condition worsened. The RN on duty was unable to contact his GP and was advised by the on-call locum service to call the ambulance to take him to hospital. Julie's Mum (as primary carer) was out of town and couldn't be contacted. No beds were available at the private hospital so Julie's Pop was taken to emergency at the public hospital. He was then transferred back to the private hospital at 7am and was dead at 9am.

Thankyou Julie for sharing your experience with me. This research is for the 'Pops' and 'Nan's' that we all love and worry about, and the family and friends left behind to miss them and remember the manner of their passing. Death, in my view, is the book end balancing birth. In between is life.

Thanks to my mother and daughter (pictured above) for their inspiration, as well as my husband Chris without whom I would not have the resources to undertake a PhD. My supervisors Andrew Robinson and Kathy Eagar have given so much of their time and wisdom to bring me through this journey with an end.

Contents

List of tables

List of figures

Glossary of key terms

Aged Care Assessment Team (ACAT)

ACATs help older people and their carers work out what kind of care will best meet their needs when they are no longer able to manage at home without assistance. ACATs provide information on suitable care options and can help arrange access or referral to appropriate residential or community care. ACAT is funded by the AG as well as the State or Territory Government. The ACAT assessment is done by a healthcare professional such as a registered nurse, social worker or occupational therapist.

Aged Care Funding Instrument (ACFI)

The Aged Care Funding Instrument (ACFI) was introduced on 20 March 2008 as the means of allocating Australian Government subsidy to residential aged care providers.

ACCESS Economics

ACCESS Economics (since 2011 Deloitte Access Economics) is an Australian economics advisory practice. This private company provide on contract to government and private sectors, policy, regulatory and strategic advisory, as well as forecasting and modelling.

Australian Government

Australia, also known as the Commonwealth of Australia, is a federation of six states and two territories. With a population of nearly 23 million, it is the 12th largest economy in the world and has the sixth highest per capita income. The system of government is a 'constitutional monarchy' with a federal division of power similar to the US system. The federal government (AG) has constitutional responsibility for trade, currency, defence, postal and communication services, census and statistics, quarantine and taxes. Nominally, the AG has no responsibility for services such as healthcare. However, in the Constitution the AG can make grants subject to States implementing particular policies in their fields of legislative responsibility. Such grants, known as tied grants (since they are tied to a particular purpose),

have been used to give the federal parliament influence over state policy matters such as public hospitals and schools.

Baby Boomer

With the end of World War II in 1945 Australia's servicemen and women returned and family life resumed after an interruption of almost six years of wartime conflict. Nine months later saw the start of a population revolution. As childbirth rates soared - more than four million Australians were born between 1946-1961.People born during this period became known as baby boomers. Combined with an increase in European migration to Australia, the baby boomers changed Australia (and the world) in the second half of the 20th century.

Department of Health and Ageing (DoHA)

The AG Department of Health was first established twenty years after federation and the implementation of the Australian Constitution. to manage public health issues following WW1. Constitutional change over the years has further increased the authority of the AG in national health and welfare administration including the Aged Care Act (1997) after which the name was changed to the Department of Health and Ageing, and the recent health reforms agreed to by the majority of the States for the AG to take responsibility for all aged care services.

General Practitioner (GP)

Is a medical practitioner who treats acute and chronic illnesses and provides preventive care and health education for all ages and all sexes and makes referrals to specialist health care services. This term is common in the UK, and would be equivalent to a family or general physician in north America.

Intergenerational Report (IGR)

Under the Charter of Budget Honesty Act 1998 an Intergenerational Report is required every five years. The reports are prepared by the Australian Department of Treasury and focus on the implications of demographic change for economic growth and assess the financial implications of continuing current

policies and trends over the next four decades. An IGR has been published in 2002. 2007 and 2010.

Medicare Australia

Medicare is one of the programs of the Australian Government Department of Health and Ageing It administers health-related programs including Medicare, the Pharmaceutical Benefits Scheme (PBS), and others. The National Office of Medicare Australia is responsible for policy and program development. Medicare Australia also has many branch offices across Australia, usually located in retail centres. These are responsible for processing payments and claims from members of the public. Medicare is Australia's publicly funded universal health care system, operated by the government authority Medicare Australia. All Australian citizens and permanent residents receive subsidised treatment from medical practitioners, nurse practitioners and allied health professionals who have been issued a Medicare provider number, and can also access fully subsidised treatment in public hospitals. The program was introduced by the Whitlam Labor government in 1975 as Medibank, and was renamed Medicare in 1984.

Medicare and Medicaid USA

Medicaid and Medicare are two governmental programs that provide medical and health-related services to specific groups of people in the United States of America. Although the two programs are very different, they are both managed by the Centers for Medicare and Medicaid Services, a division of the U.S. Department of Health and Human Services. Medicaid is a means-tested health and medical services program for individuals and families with low incomes. The individual States administer this program with some mandatory federal requirements for acute and preventative health services. Medicare is a Federal health insurance program that pays for hospital and medical care. To be eligible for Medicare, an individual must either be at least 65 years old, under 65 and disabled, or any age with End-Stage Renal Disease. In addition, eligibility for Medicare requires that an individual is a U.S. citizen or permanent legal resident for 5 continuous years and is eligible for Social

Security benefits with at least ten years of payments contributed into the system.

National Health Reform

In August 2011, the Council of Australian Governments (COAG) agreed to the National Health Reform Agreement to supersede previous agreement between the federal and State governments. The intent of this new agreement is to deliver major reforms to the organisation, funding and delivery of health and aged care nationally. Through the rhetoric, specific programs of reform have begun to emerge. Aged Care, for example has a broad agenda based on the AG taking full responsibility for aged care in most States, resulting in a nationally consistent and better integrated aged care system. To implement this, a large number of changes will be required. One of the programs aimed at the 'integration' of services is the 'Needs Identification Tool for Aged Care and Carers' which will have a different acronym but provide an assessment process for services that have been provided under the previous split funding system.

Productivity Commission (PC)

The Productivity Commission is the Australian Government's principal review and advisory body on microeconomic policy and regulation. It is an independent statutory authority in the AG Department of Treasury. Examples of work done by the PC are researching the economic implications of ageing in Australia, reviewing the gas access regime, the effects of the disability discrimination act, and the economic effects of removing tariffs on goods from least developed countries. The PC may be asked to do a commissioned study or a public inquiry. In a public inquiry the PC will accept submissions from any member of the public. The guiding principles of the commission are to be independent of government and industry, and open to public participation. Its reports often form the basis of government policy. However, the Treasurer and government are not required to act on Productivity Commission recommendations and may give no response or refuse to act.

Residential Care Scale (RCS)

The RCS is an instrument which assesses a care recipient's care needs. This scale has eight classification levels ranging from low care (RCS 8) to high care (RCS 1), with each level having a specified subsidy level which is paid to the provider for providing the required care to the care recipient. The scale is comprised of four weighted responses to twenty questions or domains of care. The scale range is from zero to 100. The RCS was replaced with the Aged Care Funding Instrument (ACFI) in March 2008.

Residential Aged Care (RAC) refers to care provided to older people, where the care is:

(1) "... personal care or nursing care, or both personal care and nursing care, that is provided to a person in a residential facility in which the person is also provided with accommodation that includes:

(i) appropriate staffing to meet the nursing and personal care needs of the person; and

(ii) meals and cleaning services; and

(iii) furnishings, furniture and equipment for the provision of that care and accommodation" (The Aged Care Act 1997, section.41-4).

Residential Aged Care Facility (RACF) refers to the organisation providing residential aged care. These are still commonly referred to as 'nursing homes' and 'hostels'.

Abbreviations

ACCR	Aged Care Client Record
ACFI	Aged Care Funding Instrument
ACAT	Aged care assessment team
ADL	Activities of daily living
AG	Australian Government
AIHW	Australian Institute of Health and Welfare
A$	Australian dollar (currency)
CACP	Community Aged Care Package
COAG	Council of Australian Governments
DoHA	Department of Health and Ageing
EACH	Extended Aged Care in the Home
GFC	Global Financial Crisis
GP	General Practitioner
IADL	Instrumental Activities of Daily Living
NGO	Non-Government Organisation, e.g. The Salvation Army
NHS	National Health Service (UK)
NH	Nursing Home
NITACC	Needs Identification Tool for Aged Care and Carers
RAC	Residential Aged Care
RACF	Residential Aged Care Facility
RN	Registered Nurse
RCS	Resident Classification Scale
SES	Socio-Economic Status
SIEFA	Socio-Economic Indexes for Areas
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

Papers arising from this research

Lawrence S, Robinson A, Eagar K (2006) "The Trajectory of decline – a report of the literature" Emerging researchers meeting paper, Australian Association of Gerontology, Sydney 2006

Lawrence S, Robinson A, Eagar K (2008) "The trajectory of decline – how did this concept get into aged care policy?" Poster No. C92, American Geriatrics Society Conference, Washington DC 2008

Lawrence S, Robinson A, Eagar K (2009) " Leading cause of death in nursing home residents" Poster, Australian Association of Gerontology Conference, Canberra 2009 (Recipient of conference poster prize)

Lawrence S, Robinson A, Eagar K (2009) "The trajectory of decline - Leading cause of death in nursing home residents" presentation to UTAS Graduate Research Conference, Hobart 2009

Chapter 1 Introduction

1.0   Introduction to the thesis

The elderly have made a clear contribution to the development of society as we now know it. The next generation entering the 65 years and older cohorts are the 'baby boomers' who continue to build and service the national economy. However the perceived burden of this much larger aged cohort, entering the period of their life that will need care and support, is causing concern worldwide. There is growing pressure on society to continue providing quality care to ageing populations while ensuring continued growth and prosperity.

This thesis had its origins in the impact of the death of an elderly grandfather had on a colleague. The story of 'Julie's Pop' is told in the Acknowledgements (on page 6). This elderly man, living in a nursing home, was becoming more unwell due to his acute on chronic renal failure secondary to heart failure. Late one night his condition worsened, and unable to get medical treatment on-site, the nurse on duty called an ambulance to take him to hospital. Due to a bed shortage he was transferred to another hospital, but died within eight hours of leaving the nursing home. There are a number of system failures that can be identified in this story. Decision making, communication and advance care planning based on the patient's preferences about acute hospital care, before further deterioration occurred, may have prevented unnecessary discomfort before death for this elderly man as well as distress to his family (Arendts G and Howard K 2010). However it is difficult to identify the appropriate time to begin discussion about end-of-life care with a patient and family (Zapka J, Carter R *et.al.* 2006; Dy S, Shugarman L *et.al.* 2008).

In recognition of the increasingly levels of end-of-life care occurring in Australian nursing homes, the Australian Government had commissioned researchers at Edith Cowan University to prepare, consistent with the National Palliative Care Strategy - "Guidelines for a Palliative Approach in Residential

Aged Care" (Australian Government Department of Health and Ageing 2004). This evidence based document was introduced with implementation guidelines and targeted staff training in the same period. Coincidently in mid-2005, a group of residential aged care providers in southern Tasmania, recognising the impact on their resources of an increasingly frail elderly population experiencing shorter length of stays, were interested in participating in a research project that explored of the trajectory of decline presented in the Palliative Approach Guidelines as a planning and prediction tool. That project became the study represented in in this thesis.

The Palliative Approach Guidelines draw extensively on the literature to ensure that each guideline has evidence for implementation in the residential aged care setting. With the story of 'Julie's Pop' in mind, the section in the Guidelines 'Recognising when a resident is dying' drew attention. In this section, the text discusses how *there are different illness trajectories for people dying of cancer, organ system failure and dementia* (Australian Government Department of Health and Ageing 2004, p138) so that carers could recognize that there were differences in the symptoms of imminent death for each. The text is accompanied by the following graphic referenced to a paper by Joanne Lynn (Lynn J 2001), which related to her collaborative work with June Lunney establishing the trajectory of decline in US community dwelling elders (Lunney J, Lynn J *et.al.* 2002; Lunney J, Lynn J *et.al.* 2003).

Figure 1.1 Trajectories of decline *from* "Guidelines for a palliative approach in residential aged care" (Australian Government Department of Health and Ageing, 2004, p 139)

FIGURE 4: GENERAL TRAJECTORIES OF FUNCTION AND WELLBEING OVER TIME IN EVENTUALLY FATAL CHRONIC ILLNESSES

A Cancer   B Organ System Failure   C Dementia/Frailty
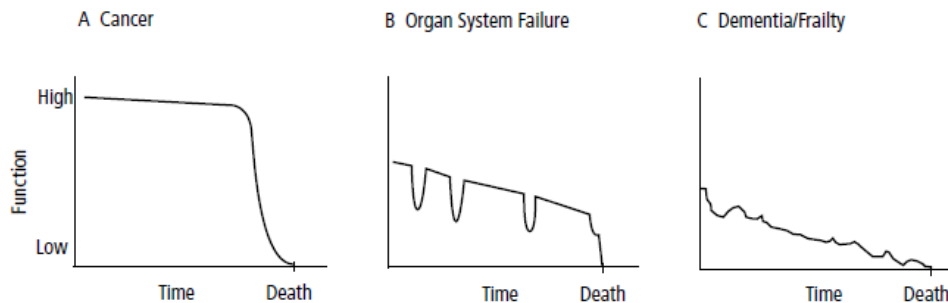
Permission to reproduce this figure received from the Author[13, p. 930]

These graphs, as they appear above or in the referenced paper (Lynn J 2001), do not have any scale on the axes or indication of how 'function' was measured. This led to further reading and ultimately to ask the questions, why were these graphs appearing in a policy document that related to the residential aged care sector. Furthermore, were they applicable to a nursing home cohort when the supporting empirical evidence for the trajectories had been undertaken in a USA community population?

Despite an apparent lack of applicability, the trajectory of decline concept has been generalised to other populations, as is the case with the Palliative Approach Guidelines, to nursing home elders.

The purpose of this research is to determine to what extent the trajectories of decline identified in an USA community cohort aged 65 years and over, exist in a nursing home population in Australia; and whether it is possible to prospectively determine an individual's trajectory in order to determine their resource requirements whilst the nursing home resident is still alive. If the rate of functional decline can be predicted, as suggested by the trajectory authors, then this concept is a potentially powerful tool for resource planning for care providers as well as policy makers at the state and national levels.

1.1   Research questions

1. Can a trajectory of decline be identified in the functional profiles of a residential aged care population?

2. How does the trajectory or trajectories of decline identified in the Australian nursing home context compare to the trajectories of decline identified by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2002) and (Lunney J, Lynn J *et.al.* 2003) in US community living elders?

3. Are there multiple diagnostic groups as identified by Lunney and colleagues in US community living elders amongst a residential aged care population or are they all identified as 'frailty'?

1.2   Aims and rationale for the research

1   To develop a methodology that enables tracking of the resident functional trajectory in residential aged care settings using routine data;

2   To explore the degree to which a population of elderly people resident in residential aged care fits within the multiple trajectory functional profiles as found by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2002) and (Lunney J, Lynn J *et.al.* 2003); and

3   To examine the extent to which the trajectory of decline can prospectively predict care needs in an elderly population.

1.3   Methodology

The research methodology for this thesis is based on two published studies (Lunney J, Lynn J *et.al.* 2002; Lunney J, Lynn J *et.al.* 2003) demonstrating that: (1) a population of elderly people can be classified into groups based on their cause of death; and (2) the subjects' functional profile can be identified (Lunney J, Lynn J *et.al.* 2002; Lunney J, Lynn J *et.al.* 2003). The rationale for this approach is to be able to compare the Lunney results with the findings from this thesis research undertaken in an elderly population in a different setting. Due to the PhD timeframe, and to collect a sufficient sample size, the choice of method was restricted to a retrospective study.

Because there is limited quantitative research in nursing homes reported in the literature, a phased approach to the research was adopted to progressively test the methodology. This is reported in the Methods Chapter. The research was approved by the Tasmania Social Sciences Human Research Ethics Committee (Ethics Ref No:H0009067), and consent to access their deceased resident records and use the collected, de-identified data were obtained from each of the four participating nursing homes.

1.4   Key issues for the thesis

There is concern that with an increasing proportion of elderly in the population there will be a concomitant increase in demand for aged care and health services. This section will define the key issues for this thesis - population ageing; life expectancy; ageing workforce; residential care services and predictions for health service demand by the elderly.

Population growth and the 'baby boomer' effect on population ageing
In 2011, Australia's population was around 22 million. This number is expected to increase to 35.5 million by 2056 if the determinants of population growth - fertility rates, migration, and life expectancy at birth - remain at current predicted levels. The determinant that will have the greatest effect on

future population growth is life expectancy (Australian Bureau of Statistics 2004).

Along with an increased birth rate, Australia, as well as similar economies with increasing standards of living such as the USA, Canada and New Zealand, also welcomed increased migration to meet their rapidly expanding labour needs post WW2. Changes in the size and composition of the population, the rate of change, and the way in which change comes about, are to some extent a product of the prevailing economic, political and social conditions, and societal values of the time. In turn, significant population events can have far reaching effects on social and economic conditions and on people's wellbeing and attitudes. Australia's post-war baby boom is such an event.

Figure 1.2: Age–sex structure of the Australian population, 1976, 1996 and 2016
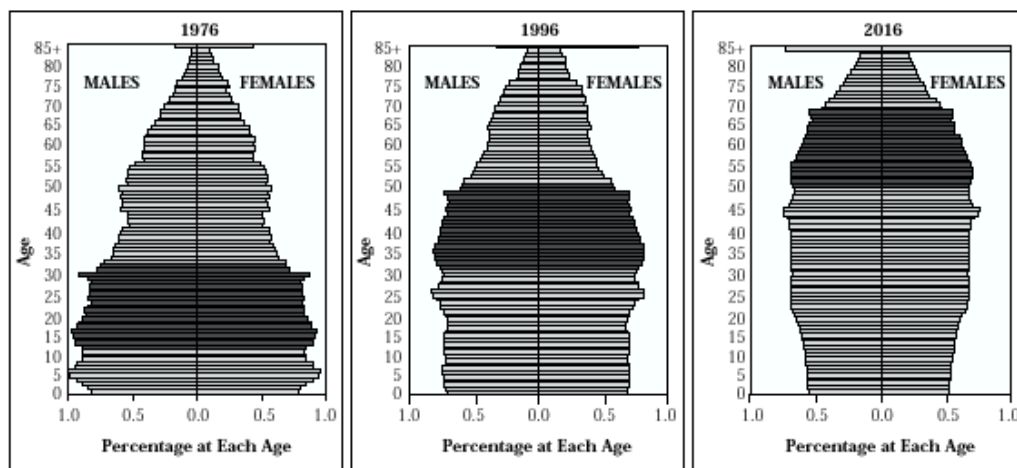
Source: (Jackson N 2001) 1976, 1996: ABS Census of Population and Dwellings; 2016: ABS 2000, Catalogue 3222.0, Series IIa.
Notes: Dark shaded bands = baby boomer

The dark bands in the population pyramids shown in Figure 1.2 above, represent the 'baby boomer' generation. It is the life expectancy of this unusually large cohort that is having such an impressive effect on population proportions. Infant and child health, education, housing and employment are some of the areas of social policy and service provision that have been most

affected as the large cohorts of the initial boom (1946-1965), and its first 'echo' in the early 1970s, have progressed through their life cycle (Australian Bureau of Statistics 2004). The effect of the 'baby boomers' on aged care services was not so long ago discussed as a future event. The reality is that the earliest of this generation are now in their mid-60's, and it would be expected that they will be requiring the care levels used by 80 plus year olds now, sometime in the next 15 years (Payne G, Laporte A *et.al.* 2007; Productivity Commission 2011).

Life expectancy

Life expectancy refers to the average number of additional years a person of a given age and sex can expect to live if the age- and sex-specific death rates observed in a given period continued throughout his/her lifetime. (Australian Institute of Health and Welfare 2006).

Changes to life expectancy are mainly the result of babies surviving their first year of life. In Australia the mortality rate of infants in 1901-1910 was high which kept the life expectancy low (Australian Bureau of Statistics 2000). As the century progressed, the improvements in clean water supply and sewage treatment, better food quality, then immunisation and the availability of antibiotics resulted in more children surviving infancy. Adult life expectancy has also improved for the same reasons combined with targeting of more specific causes of death in a cohort. For example, improved vehicle safety and driver education has reduced fatalities in young adults; and health education aimed at health behaviours such as dietary fat and smoking has reduced the number of deaths from heart disease (Australian Bureau of Statistics 2000). Life expectancy in Australia is one of the highest in the world (Organisation for Economic Co-operation and Development 2011), hence the concern that the growing number of elderly persons with increased need for services to support them as they age, will outstrip Australia's ability to provide services.

Aged care services in Australia

In Australia, 'aged care' refers to a broad spectrum of services, funded by government at all three levels, as well as non-government organisations, the community, family, friends and the individual. Not everyone using an 'aged care' service is old. Some people with severe disability are cared for by the same service and some of these are funded under the same program (Australian Government Department of Health and Ageing 2011).

The setting for this study is in residential aged care. This is an important area for research primarily because of the concern that with an increasing life expectancy, the demand for residential care will increase and the increasing cost to provide this care will become a burden to the government and individual (Access Economics 2010; Australian Government Department of Treasury 2010).

Increased aged care services in the community allow people to stay at home for longer and as a consequence, the acuity of the residents entering residential aged care is increasing (Andrews-Hall S, Howe A *et.al.* 2007). Those who come to residential aged care have needs that cannot be met in the community – the burden of ill-health, personal safety concerns, social isolation (Kendig H, Browning C *et.al.*) and cognitive impairment (Gaugler J, Duval S *et.al.* 2007; Andel R, Hyer K *et.al.* 2007; McCallum J, Simons L *et.al.* 2007).

At 30 June 2010 there were 166,370 residents in mainstream residential care services. This was an increase of 2.5% over the previous year (Australian Institute of Health and Welfare 2011). This means that approximately 5 % of Australians 65 years and older live in a nursing home. The recurrent annual cost for their care is $6.6 billion or 0.05% of Australia's GDP.

Residential aged care (RAC) in Australia is funded by the Australian Government (AG) to provide care to people *whose care needs are such that they can no longer remain in their own homes* (Australian Institute of Health

and Welfare 2011). Cost of care per resident in Tasmania, for example, with a total of 4,243 residents in permanent care places (June 2011), received $196.1m in recurrent funding from the AG in 2010-11 which equates to approximately $46,000 per resident and 72% of this recurrent funding is allocated for high care residents. The determination on whether an individual resident is high or low care and thus what subsidy the care provider receives from the AG is determined by an estimation of their dependency through the use of specific classification tools, the Resident Classification Scale (from 1997-2008) and now the Aged Care Funding Instrument (see Section 1.4.6 over).

Why Tasmania?

Ageing is a significant issue for the State of Tasmania[1]. The aged care 'crisis' will arrive in Tasmania before the rest of Australia (Australian Bureau of Statistics 2010). Tasmania's population is ageing more rapidly than that in other parts of Australia, and the State continues to have a relative shortage of people in the workforce age groups compounded by a relatively low labour force participation rate (Jackson N 2001). The extent to which results from this study undertaken in Tasmania can be generalised to other populations is, as with any research study, of concern. To ensure generalisability, sufficient data were collected in this study to provide a level of confidence that 95% of a similar population will have equivalent results if using the same methodology.

Nursing home or residential aged care?

In Australia, institutionalised aged care is provided by 'residential aged care facilities'. In the course of researching this topic, similar care was found to be provided around the world by long term care, aged care homes, nursing homes, hospices, rest homes, convalescent homes, care home, skilled nursing facility, or the old folk's home. For example, a 'skilled nursing facility' in the USA is a nursing home certified to care for Medicaid recipients. In the UK nursing homes became known as care homes with nursing, and residential homes

---

[1] Tasmania is the island State off the southernmost east coast of mainland Australia.

became known as care homes in 2002 (Age Concern 2007). Canada has long term care and New Zealand has rest homes. The term 'nursing home' seems to be the most consistently used descriptor of care provided in a residential setting by nursing or trained care staff and has been used in this thesis, as well as the term residential aged care, as it is more widely recognised overseas. Australian research also uses nursing home (NH) and residential aged care (RAC) interchangeably.

The Resident Care Scale (RCS)

In Australia, a RCS (Resident Classification Scale) has been done on every permanent resident in an Approved Provider facility from 1997 to 2008. This standardised data are available in the resident record and is used in this study to identify the functional profile of the subjects from their admission to death in the nursing home. It is a measure of the level of care needed by the resident and the facility is paid a subsidy by the AG based on this measure. As well as a measure of the resident's functional ability, the RCS is also a direct measure of the price of providing care.

There is a high inter- and intra-rater reliability for the RCS and strong agreement between the RCS with respect to the Barthel Index (Stepien J, White H *et.al.* 2006). The classification of residents is subject to review by an auditor external to the nursing home (NH) to prevent over claiming by the NH.

The RCS consists of 20 questions, each having a choice of four ratings based on the assessed care needs of the resident. For example, for the item 'Toileting', the lowest numerical score '0' is for someone who is able to use any type of toilet and is independent; whereas the highest score '13.70' applies to the resident who requires staff to carry out all activities – adjusting clothing, positioning the resident to the receptacle or emptying bag or changing pads, and wiping. A complete list of the RCS questions is shown in Table 3.5 (page 124). No routine measures of function are collected from an Australian NH population other than the RCS (and now the ACFI) across all NH and all residents.

Since March 2008, the RCS was replaced by a similar instrument, the Aged Care Funding Instrument (ACFI). Hence data collection was limited to those residents whose admission ended before the ACFI was introduced.

The current policy context

There have been significant changes to government policy in response to concern about the projected increase in aged care service demand in Australia generated by reports by ACCESS Economics and the Intergenerational Report from the Australian Treasury Department. Building on the significant changes of the Aged Care Act (1997), from July 2011, the Australian government has taken sole responsibility for the provision of aged care – residential and community services - to people over 65 years in all states and territories (except Western Australia and Victoria) as part of the National Health Reforms. This recent public policy change signals a significant rearrangement of service provision to the elderly.

In April 2010, the Australian Government Productivity Commission was asked by the Australian Government Treasury to 'develop detailed options to redesign and reform Australia's aged care system' (Productivity Commission 2011,p*xxiii*). The premise for this review was the acknowledgment that the drivers for aged care services – increasing aged population; decreasing workforce and availability of informal carers; increasing aged related chronic disease (including dementia); community concerns for service access and equity – will overwhelm the existing model of care provision, exacerbating the 'delays, discontinuities, constraints and shortages that currently exist' (*ibid*).

Arguably the most important policy shift recommended by this report is that: The Australian Government should adopt separate policy settings (including for subsidies and co-contributions) for the major cost components of aged care, namely care (including personal and health care), everyday living expenses and accommodation.

One of the most critical drivers to government policy now is the finding that the cost of residential aged care has increased 6.6% annually since the introduction of the Aged Care Funding Instrument (ACFI) that replaced the RCS in 2008 and has proved to be more sensitive to the care needs of residents in the highest care levels than the RCS. This thesis has a resonance with the implementation process of this policy because the trajectories of decline evidenced in the aged care setting can inform efficiencies in recognising and resourcing the changing care needs of an increasingly high care resident population.

1.5   Significance of this research

In this thesis, the 'trajectory of decline' concept will be explored as a way of predicting the functional decline to death of residents of nursing homes. The literature supporting this concept claims this predictive tool can assist care providers plan and resource the care needs of their clients (Lynn J 2001; Lunney J, Lynn J *et.al.* 2002; Lunney J, Lynn J *et.al.* 2003; Dy S and Lynn J 2007). For care providers to be able to predict resource demand in their facility; policy makers could prepare budgets based on evidence of predicted demand for aged care services; and the community/politicians could be reassured that our vulnerable elders are being cared for appropriately. However, as the Literature Chapter will show, the policies in place that now use this concept are, in effect, telling the care providers that this is the way to predict care needs yet there is no evidence that these trajectories exist in the nursing home population, or how to actually identify when someone is on such a trajectory.

Lunney and colleagues (Lunney J, Lynn J *et.al.* 2002; Lunney J, Lynn J *et.al.* 2003) have provided evidence of a trajectory of decline in a community living elderly population. Replicating this methodology, this thesis will identify whether there is a comparable evidence base within a residential aged care setting. There is an understanding of decline in a NH population but there is no evidence of the trajectories in a NH population. Having the trajectories will

provide a level of certainty within the general unpredictability of ageing; to inform capacity to allocate resources when it is needed.

1.6   Structure of the thesis

This thesis will follow the format used in quantitative research papers with an Abstract summarising the research, its key findings and a brief conclusion. The Introduction identifies the problem and questions for the research. Key issues will be explained to prepare the reader for the body of the thesis. The Literature Review will provide in detail the policy context of this research as well as previous research on the development of the trajectory concept. Following a restatement of the research questions, the Methodology Chapter contains a review of methodological issues and describes the data collection process and analysis methods. The Results Chapter reports the results of the analysis with progressively more complex statistical models to arrive at the final model that identifies statistical evidence for the trajectories in the research population. The final section in the results compares for generalisability, the findings of this research with Australian national and state residential aged care data routinely analysed by the Australian Institute of Health and Welfare (AIHW). The Discussion Chapter draws together the findings from the Results and discusses how these findings contribute to and improves on previous knowledge of this subject. Limitations of the study and areas for further research are proposed.

Chapter 2   Literature Review

2.0   Introduction

The Literature Review will detail the policy context of this research as well as previous research on the development of the trajectory concept. The key issues identified in the first chapter are continued here in more detail, emphasising the pressures driving change in aged care provision, and why the trajectory of decline is relevant to this sector of care.

The current proportion of the ageing population is a small fraction compared to the numbers representing the 'baby boomer' generation who are now entering the 'aged' cohort. This growing pressure has implications for the already stressed aged care sector who will struggle to provide care into the future. The growing pressure is already evidenced by changes over the past decade in admissions to residential aged care. People entering residential aged care now are older, frailer, more likely to suffer dementia and are having shorter admissions before dying. While there is some evidence that the 'baby boomer' generation will continue to work to older ages than previous generations the majority of the current health workforce are themselves 'baby boomers'. As the current workforce moves into retirement, not only will staffing pressures increase in a sector needing more carers, but this transition also signals a significant loss to the tax base and hence the nation's ability to pay for this expected increase in the care burden.

While an increasing proportion of elderly in the population is the primary driver for aged care services demand into the future, a significant confounder is the effect of government policy. Current government policy seeks to identify, through reviews such as the Productivity Commission report 'Caring for Older Australians' (2011), to 'future proof' the resources of the country against a perceived threat of an overwhelming need for aged care. To identify and predict the patterns of care demand, researchers have proposed trajectories as

an innovative way to plan more efficient and effective care. To answer the question, is there a trajectory of decline in aged care, markers of ageing are summarised as well as models that have been developed that can be used to predict the ageing process and care needs of an ageing population including the trajectory of decline.

This chapter will provide a critical account of trajectory theory and application to aged care. A search of the literature identified three research 'lineages' relating to the use of trajectory in health care. The trajectory theory is first described in the work of Glaser, Strauss and Corbin who presented a graphic representation of the trajectories in 1988. Trajectory theory is strongly linked with the seminal work of Sidney Katz who introduced the well-known 'activities of daily living' (ADL) measure of functional decline. The third literature lineage relates to Joanne Lynn's use of the concept of different trajectories at the end of life to argue for changes in health policy (Lynn J 2001) as well as the empirical research done by Lunney and colleagues (2002 and 2003) which sought to validate the existence of multiple trajectories in the last year of life. While this exploration of the academic literature is interesting, it is the uptake of the trajectory of decline model in aged care policy that generated the question of the applicability of the model to aged care service provision.

2.1   Issues for aged care provision

The mounting pressure on Australia to provide aged care to an increasing number of elderly in an uncertain environment is an issue that has already been introduced in this thesis. This section will further enunciate the important issues for aged care now and into the future. It is argued that the ability to provide services, and the level of demand for aged care services, is not a simple relationship to the proportion of the population being over 65 years. It is important to understand these drivers, or variables, in the determination of the potential for success of a predictive model.

2.1.1   Ageing population. Ageing workforce.

The same population pyramid graphs shown in Figure 1.2 (on page 30) are mirrored by the ageing workforce. The baby-boomers now working and paying taxes (Ranzijn R, Harford J *et.al.* 2002), also comprise the majority of unpaid carers and community volunteers (Merkes M and Wells Y 2003). The baby boomer work force are themselves moving into the age cohort that currently use aged care services. Life expectancy in Australia is one of the highest in the world (Organisation for Economic Co-operation and Development 2011). Hence the concern that the growing number of elderly people with increased needs, will outstrip Australia's ability to provide services. It is estimated that Australia will need a further 67,000 aged care workers in the next 20 years (Price K, Alde P *et.al.* 2004). The baby boomers that will need aged care services are the same people who having powered the economy through the post-war years are now at the threshold of retirement.

However, as an example of the uncertainties with predicting resource use and availability into the future, the retirement plans of baby boomers are not as predictable as once thought (National Seniors Australia Productive Ageing Centre 2012). A qualitative study that compared the retirement intentions between low SES older baby boomers (1946-1955) and high SES older baby boomers (i.e. those closer to retirement age than later baby boomers) found some distinct differences in the expectations and plans for retirement between

the groups (Quine S, Bernard D *et.al.* 2006). While the authors found that the high SES group had plans, and had the resources to plan, the people in the low SES group lacked resources to plan ahead to retirement and indeed were struggling to manage their lives whilst working. This later group were more likely to expect the government to support their income and provide health services as they age. This leads to a concern that this difference between the 'haves' and 'have nots' may well develop a 'two tiered' system of health and social care at least for the ageing baby boomer generation (Skidmore P and Huber J 2003). This socio-economic divide has led to the phrase 'rich boomer, poor boomer' (Hamilton M and Hamilton C 2006). This divide may emerge as an issue in the profile of Australian NHs residents than is currently the case.

Retirement plans are also affected by the state of the economy. It was expected that people in blue collar jobs may have limited choice of whether to retire or not because of the more physical requirements associated with such work vs. the white collar jobs that equate age with valuable experience (Ranzijn R, Patrickson M *et.al.* 2004; Quine S, Bernard D *et.al.* 2006). However the Global Financial Crisis has reduced income from investments that have further discouraged retirement (Humpel N, O'Loughlin K *et.al.* 2010; Snoke M, Kendig H *et.al.* 2011; National Seniors Australia Productive Ageing Centre 2012). Similarly, the retirement plans by doctors and nurses may vary with the individual's physical or economic situation (Health Workforce Australia 2012) however nurses on the whole, do retire earlier than doctors (Schofield D and Beard J 2005).

.

The change in the age distribution of the health work force mirrors that of the population in general. In Figure 2.1 (below), the proportion of GPs aged over 40 years rose from 42% in 1986 to 58% in 2001. In that same period, the proportion of nurses over 40 years rose from 30% to 60%. However, these graphs also illustrate that very few nurses continue working after 60 years, whereas GPs and specialists continue working for longer (Schofield D and Beard J 2005).

Figure 2.1 Age distribution in the health workforce mirrors the age proportions of the general population (Figure 2 from Schofield and Beard (2005, p81)
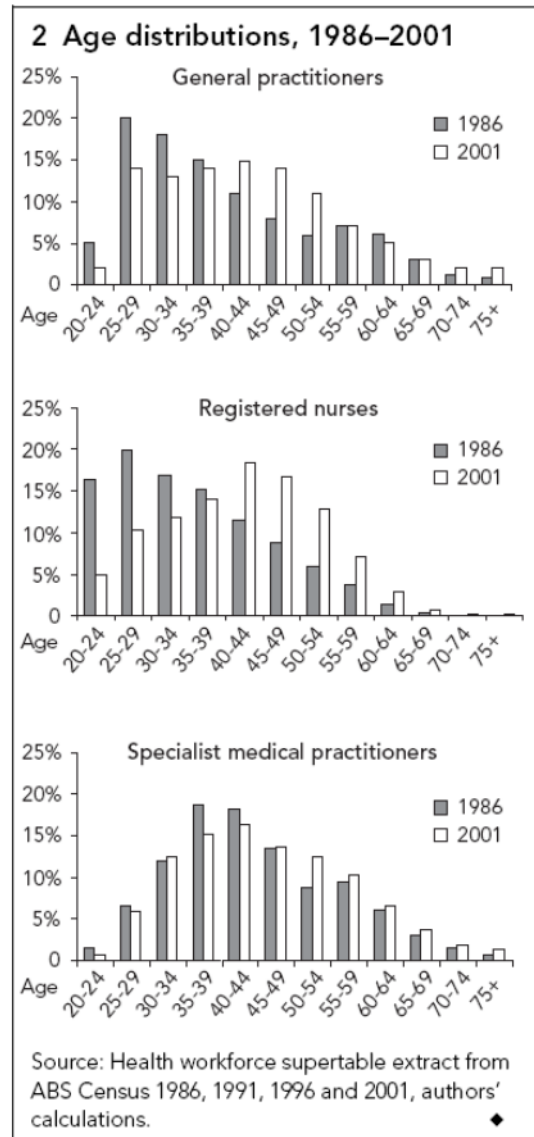
Despite concern about the dwindling nurse workforce, there is limited research about the reasons nurses retire (Blakely J and Ribeiro V 2008). There is an assumption that it is because of rotating rosters and the physicality of nursing work, but what research there are, points to a combination of more complex issues (*ibid*). In Denmark for example, the retirement age for nurses had fallen in the period 1989 to 1999 from 62.3 years (on average) to 61.8 years (Friis K, Ekholm O *et.al.* 2007) for expressed reasons such as lower pay, having a retired partner, poor health and rurality. However the underlying factor for 67% of the retired nurses surveyed, was a change in government policy nearly

20 years earlier that had reduced the pension age to encourage retirement for the benefit of employment rates in younger Danes (Friis K, Ekholm O *et.al.* 2007). By contrast, in Belgium without the early pension incentive, the majority of nurses who wanted to retire before 65 years stated their main reason was for personal health concerns (Boumans N, de Jong A *et.al.* 2008).

The effect of government policy on retirement in general has been recognised by the Australian Government. In Australia there is no fixed age at which people have to retire from work. In 2009, the AG increased the pension eligibility age to 67 years. Though this policy will not take effect until 2017, nor affect anyone born before 1952, the capacity for anyone to live on the government funded pension is diminishing so it is anticipated that these policies, indirectly, will encourage people to stay in the workforce for longer than has previously occurred (Australian Bureau of Statistics 2011). With the additional effects of the GFC on cost of living, retirement funds and superannuation leading to further anxiety about retirement amongst the baby-boomer generation (Humpel N, O'Loughlin K *et.al.* 2010 ; Snoke M, Kendig H *et.al.* 2011).

Australia's health workforce is a part of the suite of priorities in the 2011 National Health Reform Agreement between the state and territories and the AG. One of the Council of Australian Governments (COAG) initiatives was to establish Health Workforce Australia (HWA): *We stimulate and foster change, collaboration and innovation so Australia can deliver a sustainable health workforce that meets the healthcare needs of all Australians*[2]. This and other workforce strategies have been funded in the AG 2011 Federal Budget. Of interest to aged care is the A$302 million fund over four years for the aged care workforce (Australian Government Department of Health and Ageing 2012) supporting programs for nurse practitioners, aged care nurses, dementia care training and indigenous aged care workforce that increase work skills as well

---

[2] http://www.hwa.gov.au/

as improve recruitment and retention for the growing demands in the aged care sector.

The effect of the 'baby boomers' on aged care services was not so long ago discussed as a future event. The reality is that the earliest of this generation are now 67 years old, and it would be expected that they will be requiring the care levels used by 80 plus year olds now, sometime in the next 15 years (Payne G, Laporte A *et.al.* 2007). Furthermore, due to retirement, changing work patterns and shortage of training places, it is forecast that by 2025 in Australia there will be shortage of 2,700 doctors and 110,000 nurses (Health Workforce Australia 2012) which will further exacerbate the current staffing issues for the residential aged care sector (Richardson S and Martin B 2004).

2.1.2   Residential aged care services

In Australia, 'aged care' refers to a broad spectrum of services, funded by government at all three levels (National, State or Territory, and local councils), as well as non-government organisations, the community, family, friends and the individual. Not everyone using an 'aged care' service is old. Some younger people with severe disability are cared for by the same service and these are largely funded under the same program (Australian Institute of Health and Welfare 2011).

The residential component of aged care is funded by the Australian Government (AG) to provide care to people *whose care needs are such that they can no longer remain in their own homes* (Australian Institute of Health and Welfare 2011). The number of residential care place available per person 70 years and over in Australia has declined from 92 places in 1995 to 87 places in 2010. However the AG has replaced residential places with in the home care programs such as 'EACH' (Extended Aged Care at Home) so that their budgeted aim of 113 places per 1000 is nearly on target at 111 places in 2010 (*ibid*). Other policy influences to this trend to non-residential care is the steady reduction in AG funding of low care residential care places since 2004-2005 (*ibid*) and an increase in retirement accommodation with assisted living options

not funded by the AG (Andrews-Hall S, Howe A *et.al.* 2007) increases in transition care; public and private rehabilitation post-acute care services for the elderly has reduced discharges from hospitals directly in to RAC (Flinders Consulting 2008); increased use of respite care services that allows a flexible model of home and RAC services for the elderly and relieves their home carer (Australian Institute of Health and Welfare 2006).

While increased non-residential aged care services allow people to stay at home for longer, the consequence of these policies is that the acuity of the residents entering residential aged care is increasing (Andrews-Hall S, Howe A *et.al.* 2007). Those who come to residential aged care have needs that cannot be met in the community – incontinence, behavioral challenges or personal safety concerns as will be discussed in the following Section 2.1.2. Despite policy drivers and innovations in community based care, the need for residential aged care services will continue.

At present, the greatest proportion of residents in Australian nursing homes are females aged 85 years and over. This reflects the greater proportion of females for this age group in the general population. Similarly the proportion of residents 85 years and over has increased from 50 % in 2000 to 56% in 2010 (Australian Institute of Health and Welfare 2011). The distribution of age and sex of residents is shown in Figure 2.2 (below) sourced from the AIHW.

Figure 2.2 Residential aged care in Australia – age and sex of residents

Figure 3.1: All residents by age and sex, 30 June 2010 (per cent)

Source: Table A2.1.
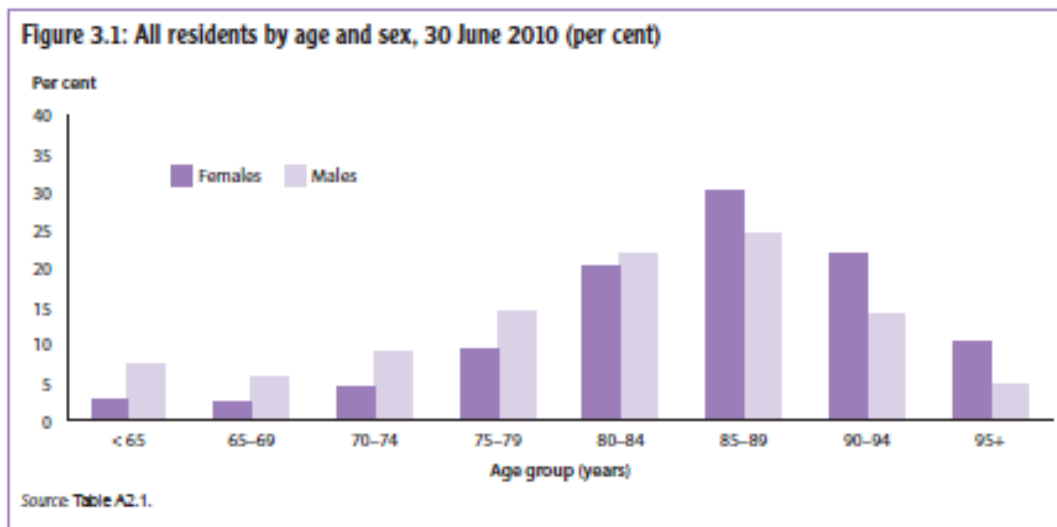
(Australian Institute of Health and Welfare, 2011 p 26)

Only a small proportion of residents are in the 65 years and younger age group with more than half of these being male (7%). Males are in greater proportion to females until the 85 years and older age group.

While the distribution of residents across age and sex generally follows the distribution of the population in each state or territory in Australia, there are some resident differences not related to simple population proportions that are the results of geography and social factors. Of particular interest for Tasmania are the effects of remoteness, country of birth and financial support.

Figure 2.3 Residential aged care in Australia – distribution of places in each state or territory

Figure 2.2: Distribution of residential aged care facilities by state/territory and remoteness, 30 June 2010

Source: Table A1.2.
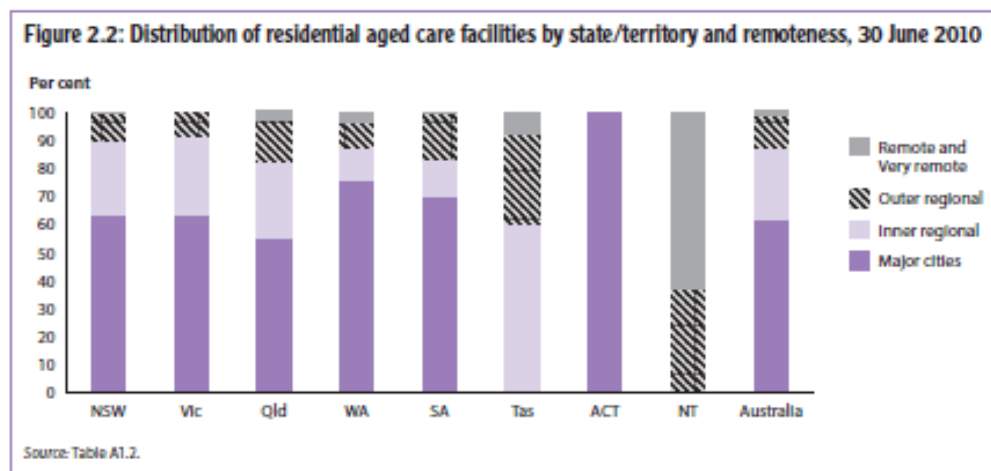
(Australian Institute of Health and Welfare, 2011 p 17)

Tasmania has the highest proportion of remote and very remote as well as outer regional residential care places after the NT (Figure 2.3 above). The majority of Tasmania's facilities are in areas classified under the Australian Standard Geographical Classification (ABS) as 'inner regional' with no areas classified as 'major cities' under this system. Remoteness has a direct effect on the size of facilities with NT having the highest proportion of facilities with 20 or less beds, followed by Tasmania, in contrast to the ACT, which is highly urbanized, with two thirds of facilities being very large (61 and more beds) (Australian Institute of Health and Welfare 2011).

The country of birth of over a quarter of Australian nursing home residents is not Australia. In contrast, only 16% of Tasmanian nursing home residents are born overseas most commonly the UK, Ireland and northern Europe. Tasmania also had the highest proportion of residents stating English as their preferred language (97.6%) compared to the Australia overall (90.3%) (Australian Institute of Health and Welfare 2011).

Not-for-profit and private organisations are the primary providers of residential aged care services across Australia with the State of Victoria having a significant proportion of services provided by local government compared to

other states and territories. The AG provided around 70% of the funding for RAC in 2009-10 with other income to facilities from residents, voluntary work, and local government. The amount of funding that the AG pays for residential care has increased from over $5.6 billion in 2006-07 to nearly $8 billion in 2010-11 and the cost per resident varies by remoteness and level of care required (Figure 2.4) (Australian Institute of Health and Welfare 2011).

Figure 2.4 Number of permanent residents in Australian nursing homes as at June 2011, by state and territory, by level of care with AG annual funding for 2010-11 (A$m)
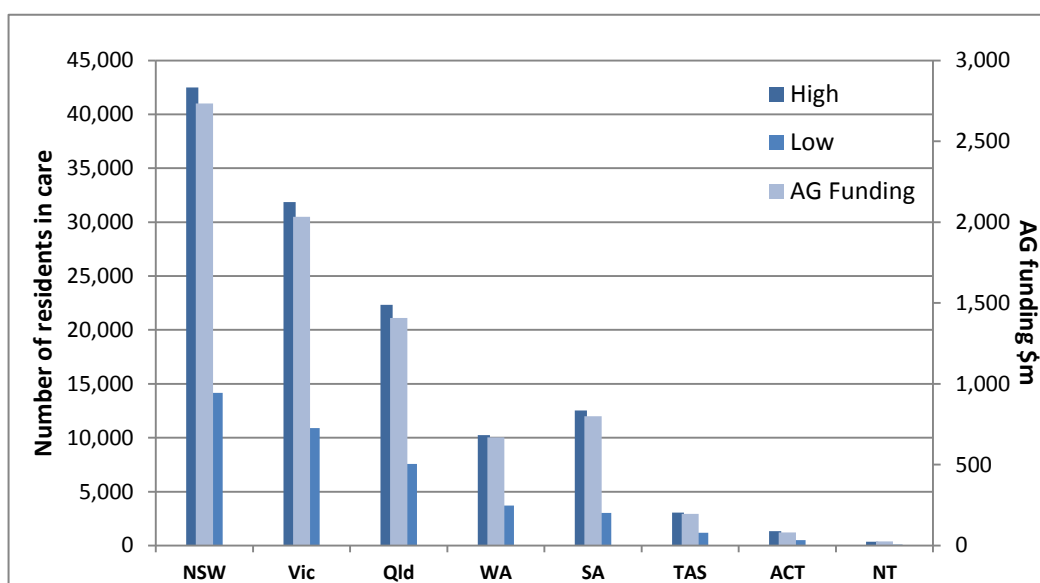
Data source: Australian Government Department of Health and Ageing, 2011 Table 20, p38 and Table 22, p41
.

Cost of care per resident in 2010-11 can be estimated from the DoHA data used to create Figure 2.4 (above). For example Tasmania with a total of 4,243 (72% high care) residents in permanent care places (June 2011), received A$196m in recurrent funding from the AG in 2010-11 which equates to approximately A$46,000 per resident with nearly three quarter of this subsidy being for highest levels of NH care. The determination on whether an individual resident is high or low care and thus what subsidy the care provider receives from the AG, is determined by their Residential Care Scale (RCS) score, a standardized assessment of dependency for every nursing home resident in Australia. The RCS was replaced by the Aged Care Funding Instrument (ACFI) in March

2008. Thus, through the RCS and now the ACFI, dependency is directly equated to the price paid for of residential aged care.

2.1.3   Current trends in nursing home usage in Australia

The Australian Institute of Health and Welfare (AIHW) identifies and reports trends in service usage across Australia's health system including aged care. Trends are an important tool in the prediction of future resource needs as well as motivating adjustment to policies, for example that will effect payments and subsidies to providers and consumers of these services. One of the ways to control cost of residential aged care is to limit the number of places available, (Gibson D 1998, p35). However, with ongoing pressure from the community and service providers, the proportion of places available is now fixed at 1.1% of the population over 65 years (Australian Institute of Health and Welfare 2011).

Over the past decade, there has been an increase in the number of permanent and respite residents in residential aged care due to the ageing of the population and the corresponding increase in the number of residential places. Of note is the increase in the number and proportion of residents aged 85 years and over. (Australian Institute of Health and Welfare 2011, p66).

Over the past decade there has been a 23% increase in the number of permanent residents in aged care and nearly 90% of this increase was for residents 85 years and over. This trend suggests a 'compression of morbidity' effect (a concept that is discussed later in this Chapter). The proportion of residents entering a nursing home that were 80[3] years and over has continued to increase by nearly 10% every decade (Australian Institute of Health and Welfare, 2011). The concomitant increase in this age cohort in the general Australian population was 42% ((Data source: ABS 3101.0 (1999) and ABS

---

[3] Age cohort reporting is inconsistent between DoHA , ABS and AIHW reports and over time. For this comparison, data for 80+ was available in both not 85+.

3101.0 (2011)). As confirmed by other research (Andrews-Hall S, Howe A *et.al.* 2007) Australians in the 80+ age group are living at home for longer before requiring the level of care provided by NH. Dependency levels of NH residents have increased since the late 1960's however the trend varied in response to government targeting policies (Gargett S 2010). Hence just using population is not a sufficient predictor of demand for aged care services.

Earlier reports by the AIHW indicated that length of stay in RAC increased over the decade 1999-2010 from 131 weeks to 145 weeks (Australian Institute of Health and Welfare, 2011). However, in this reporting, the AIHW had not taken into account a significant policy change 'Ageing in Place' in 1997 (Australian Government Department of Health and Ageing 2002; Andrews-Hall S, Howe A *et.al.* 2007) whereby a resident reclassified from low care to high care in the same facility was not counted as a separation as had happened in the past which may have led to an overestimation of length of stay in RAC (Andrews-Hall S, Howe A *et.al.* 2007). The most recent report by the AIHW of RAC statistics found that resident turnover, which includes all separation, has been relatively constant over the past decade (Australian Institute of Health and Welfare 2012). Death accounts for 90% of the separations from Australian nursing homes and approximately 2% of permanent residents were transferred to hospital (Australian Institute of Health and Welfare 2011, p 42).

2.1.4   Who needs nursing home care?

With increasing acuity, decreasing length of stay and the primary mode of separation being death, the person needing nursing home care today is arguably 'sick enough to die' (Dy S and Lynn J 2007, p511). The facilities funded by the AG to provide services to people close to the end of their lives are defined by the following statement:

The Australian Government funds aged care facilities to provide residential aged care to older Australians whose care needs are such that they can no longer remain in their own homes. Facilities provide suitable accommodation and related services (such as laundry, meals and cleaning), as well as personal

care services (such as assistance with activities of daily living). Nursing care and equipment are provided to residents requiring such assistance.
(Australian Institute of Health and Welfare 2011, p2)

Age is the most obvious risk factor for admission to NH (Andel R, Hyer K *et.al.* 2007; Tomiak M, Berthelot J *et.al.* 2000). In Australia (June 2010) 56% of NH residents were 85 years and over. Only 4% were under 65 years old. (Australian Institute of Health and Welfare 2011). This compares to the overall Australian population of 1.8% being 85 years and older; and approximately 70% being 65 years and younger for the same period (Australian Bureau of Statistics 2010). Related to age but also a risk factor in itself, 70% of NH residents are women and male residents were younger than female residents. Two factors that increase the chances of a female being admitted to a NH sooner than a male is that women are more likely to be living alone and without a spouse (McCann M, Donnelly M *et.al.* 2012). On admission to NH 65% of females and only 26% of males reported their marital status as widowed. Furthermore, prior to admission, males are more likely to have been living with family than females who were more likely to have been living alone (Australian Institute of Health and Welfare 2011, p37). Admission to NH was higher in younger age groups for indigenous Australians by more than 3 times in the 60-64 age groups, but not in the older age groups compared with non-indigenous Australians (Australian Institute of Health and Welfare 2011, p49). In 2001-2002, almost 60% of admissions into permanent NH care were from the acute sector, with only 36% of permanent care admissions coming from the community (Australian Institute of Health and Welfare 2008, p 51).

Other risk factors for nursing home placement are the burden of ill-health, personal safety concerns, social isolation (Kendig H, Browning C *et.al.* ; Crisp D, Windsor T *et.al.* 2012); physical decline (Latham K 2011) and cognitive impairment (Gaugler J, Duval S *et.al.* 2007). Gender specific risk factors are marital status, living situation, housing and car availability, and incontinence (Luppa M, Luck T *et.al.* 2009). Another significant trend for risk of nursing

home admission in Australia is the increasing numbers of the elderly suffering dementia (McCallum J, Simons L *et.al.* 2007). The current estimate of the number of Australians suffering from dementia is nearly 300,000 and this number is expected to triple by 2050 with the increasing proportion of elderly in the population (Australian Institute of Health and Welfare 2012, p*ix*). This will put an increasing burden on aged care and particularly residential aged care services with over half of residents already having a diagnosis of dementia (Australian Institute of Health and Welfare 2012, p15) and nearly 90% of residents with dementia classified as needing high care (Australian Institute of Health and Welfare 2012, p42). Approximately a sixth of the annual recurrent expenditure for RAC in Australia is for residents suffering from dementia (Australian Institute of Health and Welfare 2012).

2.1.5   Dementia and Frailty

One of the consequences of increased life expectancy and not dying of heart disease or cancer is the increased risk of dementia and frailty. Research is beginning to emerge on the trajectory of dementia and there is increasing understanding of the markers of progress of these disorders (Section 2.6.2).

Dementia

Life expectancy is reduced in the elderly with dementia, the incidence and prevalence of which increases with age (Hall P, Schroder C *et.al.* 2002; Jagger C, Matthews R *et.al.* 2009; Brodaty H, Seeher K *et.al.* 2012; Tinetti M, McAvay G *et.al.* 2012) and is estimated to effect a third of Australians 85 years and older (Australian Institute of Health and Welfare 2012). Dementia was the strongest predictor of mortality compared with other life-shortening diseases in the elderly (Tschanz J, Corcoran C *et.al.* 2004) and the burden on the health system is already substantial (Moschetti K, Cummings P *et.al.* 2012). Reporting of dementia will increase as awareness and treatment options for the disease increases (Brodaty H, Breteler M *et.al.* 2011).

Mitchell and Teno argue that for too long dementia has been under recognized as a terminal illness and that a better understanding of the clinical trajectory of

end-stage dementia is a critical step toward improving the care of patients with this condition' (Mitchell S, Teno J *et.al.* 2009). A further finding of their study of nursing home residents with advanced dementia, is that life expectancy was reduced to the same extent as other end-of-life conditions and that the patients in the study died of conditions caused by dementia and not other fatal events such as a myocardial infarction (Mitchell S, Teno J *et.al.* 2009, p1535).

Figure 2.5 Proportion of NH residents with diagnosed dementia or mental illness in 2010

Figure 5.2: Diagnosed dementia and mental illness for permanent aged care residents with an ACFI appraisal, 30 June 2010

No recorded dementia or other mental illness 23.0%

Dementia 52.0%

Mental illness, no dementia 25%

Source: Table A4.10.
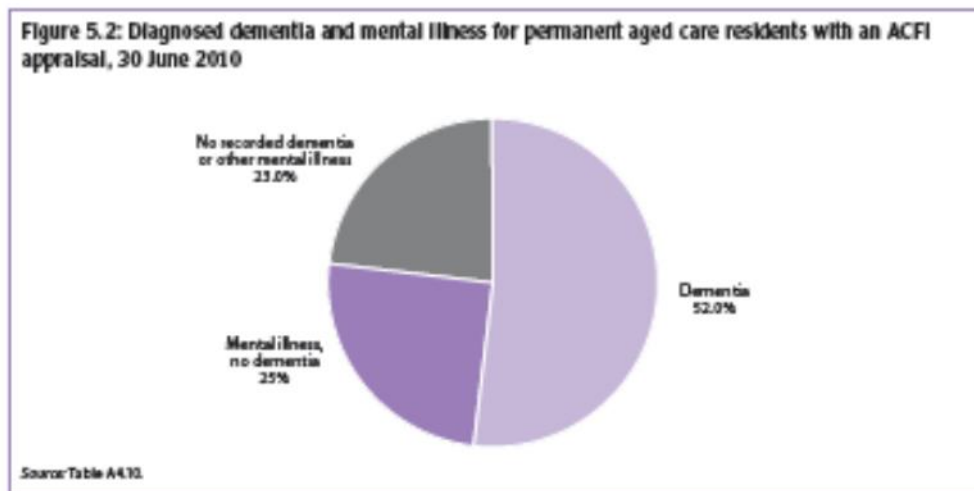
(AIHW 2011, p64)

More than half of NH residents in 2010, shown in Figure 2.5 above, had a diagnosis of dementia and another quarter of residents had a mental illness other than dementia (Australian Institute of Health and Welfare 2011) and only a quarter of the residents having neither.

The findings of the studies described above, confirm the growing concern that with an increasingly aged population, NH will have more admissions of the oldest-old needing dementia specific, high needs care.

Frailty

Lynn simply defines frailty as a fatal chronic condition in which all of the body's systems have little reserve and small upsets cause cascading health problems (Lynn J and Adamson D 2003, p5). Community services are usually familiar with the concept of frailty (Rochat S, Cumming R *et.al.* 2010). They

know these are people who are only just coping at home, not sick, not well, but managing until they have a fall or get the flu. Frailty is associated with mortality and admission to nursing home (Rockwood K, Mitniski A *et.al.* 2006). Interventions for the frail elderly still living in the community may prevent unnecessary admission to hospital (Gill T, Baker D *et.al.* 2002; Hjaltadottir I, Hallberg I *et.al.* 2011; Weaver F, Hickey E *et.al.* 2007; Rosenberg T 2012).

Identifying frailty is difficult in studies of population level cause of death data because of the focus on a single underlying cause of death (Figure 2.6 below). This leads to an underestimation of the extent of co-existing disease contributing to the burden of illness leading to death (Tinetti M, McAvay G *et.al.* 2012). With age, the principle causes of death changes proportionally (AIHW Mortality FAQ 2012[4]). As the graphs below show (Figure 2.6), cancer as the predominant cause of death in older Australians declines while deaths from cardiovascular causes increase with age, the trend being more obvious in females.

Figure 2.6 Major causes of death in older age groups for Australians in 2005
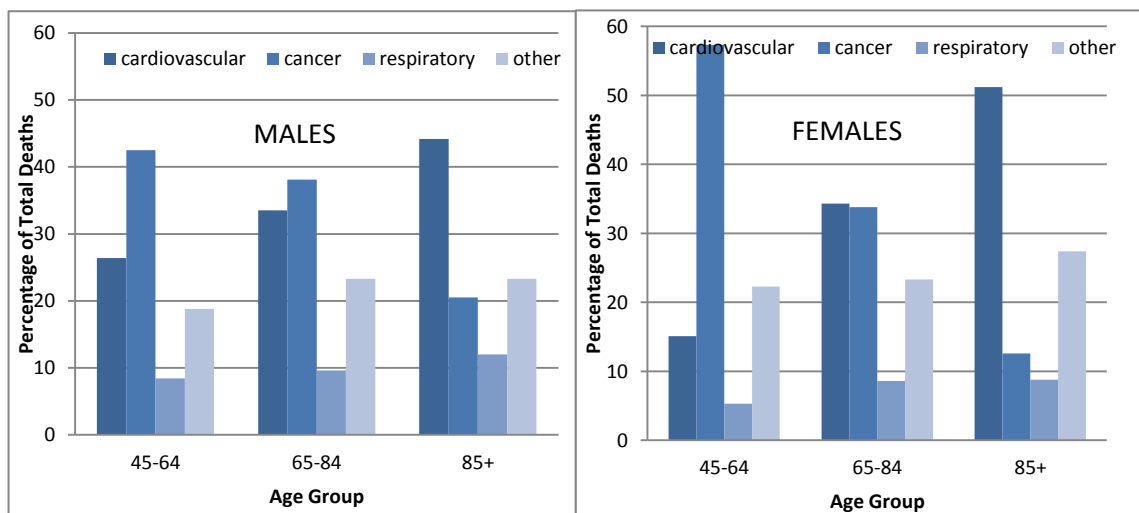
Data for graphs from the AIHW National Mortality Database 2005

---

[4] http://www.aihw.gov.au/deaths-faq/

The correct identification of frailty is important because *frailty is highly predictive of adverse health outcomes* (Weiss C 2011). The frailty trajectory can be identified by measures associated with frailty – declines in physical function, weight loss, anorexia and fatigue – that have no identifiable or reversible cause (Stevenson J, Abernethy A *et.al.* 2004). However, the definition of 'frailty status' varies leading to different estimates of the prevalence and difficulty in comparing research studies (Collard R, Boter H *et.al.* 2012).

The trajectory of frailty has been identified in elderly populations living in the community and nursing home. Kenneth Covinsky describes the functional trajectory of patients enrolled in a community support program *as slowly progressive functional deterioration, with only a slight acceleration in the trajectory of functional loss as death approaches* (Covinsky K, Eng C *et.al.* 2003). In a comparison study of three measures of frailty in an elderly nursing home population identified only a weak association with age but correlated moderately well with a disability measure. By all three frailty measures compared in this study, frailty was significantly associated with increased risk of mortality, disability and cognitive decline (Rockwood K, Abeysundera M *et.al.* 2007). However there is some contention in the applicability of frailty scores in everyday clinical practice (Pijpers E, Ferreira I *et.al.* 2012).

The research by Lunney classified frailty from death certificate as well as physician claim data in an elderly population (Lunney J, Lynn J *et.al.* 2002). The functional trajectory of frailty was identified in subsequent research where any subject with a nursing home admission was classified as being frail (Lunney J, Lynn J *et.al.* 2003). As suggested by Lunney, this single frailty trajectory with characteristically low levels of functional ability compared to the other trajectories of decline may comprise multiple trajectories as shown in Figure 2.7 (below). The trajectory of decline for frailty is described by Lunney as 'bimodal' whereby the trajectory of prolonged , diminishing capacity ends with a short period of rapid decline precipitated by a critical event such as a

stroke, infection or an acute exacerbation of an underlying chronic disease (Lunney *in* Cowen P and Moorhead S 2006, p 315).

Figure 2.7 From Lunney (Cowen and Moorehead, *eds*, p315): Possible trajectories of dying for frail elders
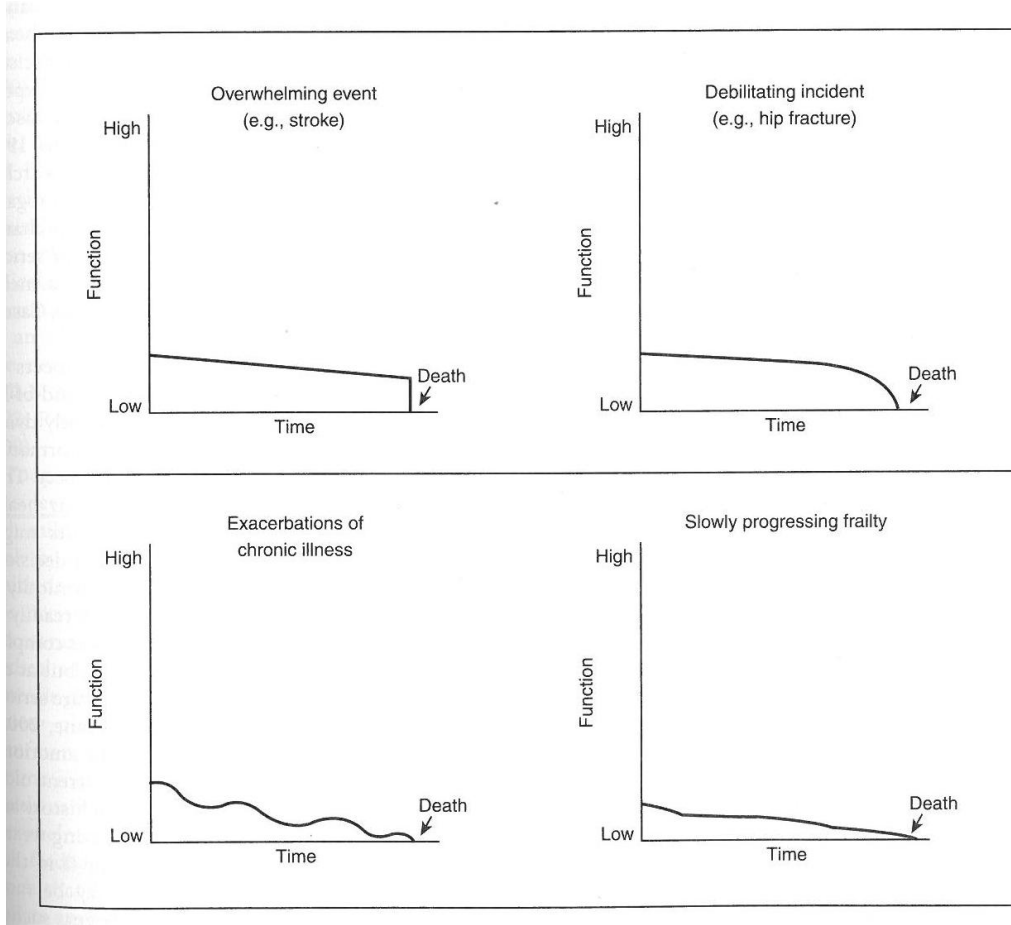
The relationship between frailty and dementia in nursing home residents is not clear in the literature and despite Lunney (Lunney J, Lynn J *et.al.* 2002; Lunney J, Lynn J *et.al.* 2003) included dementia in the frailty group, future studies are needed to further distinguish differences in order to target interventions for treatment and alleviation of symptoms specific to each.

This section has given an overview of the most common health conditions that residents of Australian nursing homes live with. Due to the increasing life expectancy of Australia's elderly and the increased proportion of elderly baby boomers, new admissions to NH can be expected to have higher care needs, particularly for dementia specific care and frailty, than ever before.

2.1.6   End-of–life care in the nursing home

Given the changing resident profile – increasing levels of frailty and dementia, decreasing length of stay with the principal mode of separation being death (Australian Institute of Health and Welfare 2011) - it could be argued that end of life care is 'core business' for nursing homes and hence expected that there would be considerable research done to ensure quality care for this population. A systematic review of US literature found only 43 articles published over seven years and this research was found to be focussed on 'poor' care rather than ways to improve the care at the end of life (Oliver D, Porock D *et.al.* 2004). Similarly, the Australian researcher Margaret O'Connor argues that despite being a common occurrence in residential aged care, discourses reveal that little is known about how dying actually happens despite the 'literature of concern' regarding end of life care in nursing homes (O'Connor M 2009).

The consequence of this lack of knowledge of death in a nursing home population may result in an inability to recognize the needs of the dying in that environment. As Partington (2006) notes it is *this group of people (those who are found to 'slip away') who are most prevalent (42%) in care homes, to whom 'palliative care' may not be given due to a lack of recognition of their impending death and the needs associated with it* (Partington L 2006, p51).

In response to concern raised by Palliative Care Australia regarding a lack of access to palliative care services in Australian NHs (Palliative Care Australia 2012, pp71-72) and in recognition of the growing need for palliative care in NH , the AG commissioned the evidence-based 'Guidelines for a palliative Approach to Residential Aged Care' (Australian Government Department of Health and Ageing 2004, p2). In these Guidelines, as mentioned in the Introduction, there is reference to the 'trajectories of decline' (Lynn 2001) as a way of *determining when the terminal phase has commenced* (Australian Government Department of Health and Ageing 2004, p138). The defining aspect of these trajectories of decline as described by Lynn (2005 pS16), is that *most people follow some fairly stereotyped courses … most common three*

trajectories of care needs over time. The basis of the theory is that there are different trajectories for different causes of death that can be used to plan care appropriate to the changing needs of the resident.

This section has described a number of changes in the profile of the Australian NH resident in the past decade since the introduction of standardised reporting and funding mechanisms. In Australia, the profiles of residents in NHs now reflects a higher dependency with increasing numbers of residents with dementia. This change highlights an imperative to accurately target the allocation of resources in the residential aged care sector, which due to the baby boomers, will be sandwiched between a decline in the health workforce and increasing demand for services. The targeting of resources is determined by government policy (Productivity Commission 2011). Hence the next section of this thesis will explore how the current policy context is set to significantly change Australia's aged care sector. This is important because research on the trajectory of decline in residential aged care, the most costly sector within aged care, has the potential to influence these new policy directions now.

2.2   The current Australian aged care policy context

There have been significant changes to government policy in response to
concern about the projected increase in aged care service demand in Australia
as described in the previous section. In this time of significant policy change,
this thesis will provide evidence for guiding policy direction. From July 2011,
the Australian government has taken sole responsibility for the provision of
aged care – residential and community services - to people over 65 years in all
states and territories (except Western Australia and Victoria) as part of the
National Health Reforms. Before this change, community services were
managed and funded through state and local service agencies. This significant
public policy change signals a rearrangement of current service provision to the
elderly and will lead to standardised data reporting for community aged care as
occurs now in residential aged care. This could allow the trajectory of service
use by an elder to be tracked from home care through to NH care.

What is public policy

Public policy, as a term, is difficult to define (Bridgman P and Davis G 2004).
It is *an authorative statement by government of its intentions*; it relies on
'hypotheses about cause and effect'; and is 'structured around objectives'
(Bridgman and Davis 2007, p5). Ambiguity arises from the setting in which the
policy is placed – a ministerial announcement compared to a department level
policy that is not altered by the political cycle (Bridgman and Davis 2007, p6).
An oft quoted authority on policy, Hal Colebatch, says that *the essential thing
about policy is not the aspirations, but the effect they have on the action: policy
is, in Schaeffer's (1965) words, 'a structured commitment of important
resources'* (Colebatch H 2004, p17).

How organisations such as the Australian Government and the Department of
Health and Ageing decide on and implement policy *could* be described as a
linear process or a cyclical one (Bridgman and Davis 2007, p26). However,
even these authors suggest that their proposed policy cycle is a guide rather
than a theory. The reality being more complex (Bridgeman and Davis 2007,

p23). The implementation of the National Health Reforms is a real time example of these complexities.

2.2.1   National Health Reform and aged care policy changes

This thesis has a resonance with the implementation process of this policy in aged care because the AG, through the National Health Reforms, now has the responsibility of ensuring efficient and effective care is delivered to a growing number of elderly across the entire spectrum of aged care services. In August 2011, the Council of Australian Governments (COAG) agreed to the National Health Reform Agreement to supersede any previous agreement between the Federal and State governments. The intent of this new agreement is to deliver major reforms to the organisation, funding and delivery of health and aged care nationally. Through the rhetoric, specific programs of reform have begun to emerge. Aged Care, for example has a broad agenda based on the AG taking full responsibility for aged care in most States, resulting in a nationally consistent and better integrated aged care system[5]. To implement this, a large number of changes will be required. One of the programs aimed at the 'integration' of services is the 'Needs Identification Tool for Aged Care and Carers' (NITACC) which will have a different acronym but provide an assessment process for services that have been provided under the previous split funding system. Identifying the trajectory of decline in an Australian NH population using existing, routinely collected data offers policy makers and care providers a measure of certainty, and a model that could potentially be extended to the first interaction of the elderly person with the aged care sector.

To place this thesis into the current context of the Australian policy scene, a selection of strategic public documents are reviewed to gain a sense of the future of the Australian aged care sector and how this study fits into this future. After all it is the wish of any researcher to be relevant. Over the past 12 months (2011-12) as part of the National Health Reform agenda, there are three

---

[5] http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/nhra-justreleased

documents in particular that shed light on the current policy context driving change for aged care in Australia.

2.2.2   The Productivity Commission Inquiry Report-Aged Care, June 2011

The most 'visible' policy action, to which the subsequent documents all refer, has been the Australian Productivity Commission into aged care. In April 2010, the Productivity Commission was asked by the Australian Treasury to *develop detailed options to redesign and reform Australia's aged care system* (Productivity Commission 2011, p*xxiii*). The fundamental reason for this review was the acknowledgment that the drivers for aged care services – increasing aged population; decreasing workforce and availability of informal carers; increasing aged related chronic disease (including dementia); community concerns for service access and equity – will overwhelm the existing model of care provision, exacerbating the *delays, discontinuities, constraints and shortages that currently exist (ibid)*.

Emphasising the AG's responsibility for aged care, the document reminds us that the role of government is to ensure that through management of the service provider market; these vulnerable consumers (the elderly) continue to have equitable access to the care services they need. Arguably the most important policy shift recommended by this report is that:

The Australian Government should adopt separate policy settings (including for subsidies and co-contributions) for the major cost components of aged care, namely care (including personal and health care), everyday living expenses and accommodation (Productivity Commission 2011, pxxviii).

This recommendation requires the current aged care model to be 'unpacked' into separate costing components of accommodation, health and personal care and everyday living expenses to provide more flexibility and transparency for provider, carer, consumer and government in any care setting. Flexibility would also come from freeing providers from the *current highly regulated, risk-averse regime* (Productivity Commission 2011, p*xxix*) while maintaining a

regulatory system to oversight *safety and quality, protecting the vulnerable and addressing market failures* (*ibid*).

The Commission proposes a number of reforms that will support these aims, such as a single 'Australian Seniors Gateway Agency' encompassing all the information, assessment and co-ordination services currently undertaken by the Commonwealth, State, non-government organisations and private providers (Productivity Commission 2011, p*xxix*). This proposal led to the Department of Health and Ageing tender for a new assessment tool - NITACC - for implementation at the 'Gateway' (see Section 2.2.4 below).

The Australian Government responded to the Report in April 2012. Not all the recommendations were adopted and during the press release the Prime Minister noted that the actual increase to aged care funding was 'modest', the new programs being funded within the current budget (Stephen Lunn, The Australian, April 21, 2012). The current federal government is in a minority position and hence unlikely to implement reforms that may result in a voter 'backlash' for example the recommendation to fund an elderly person's aged care by borrowing against their home (Productivity Commission 2011, p*xxxviii*).

2.2.3   Review of the Aged Care Funding Instrument

The Aged Care Funding Instrument or ACFI, replaced the Residential Classification Scale (RCS) in March 2008. The RCS had been in use since the implementation of the 1997 Aged Care Act (October 1997). In November 2009 the then Minister for Ageing requested DoHA to review the ACFIs impact on aged care residential services (Australian Government Department of Health and Ageing 2011). These classification tools, the ACFI and RCS, determine the level of subsidy paid by the Commonwealth toward the care of a permanent resident in a nursing home. While the RCS and ACFI have been developed to do the same job, from this review it appears that the ACFI is more sensitive to the care needs of the resident in the highest care categories than the RCS. The impact of this is evident in the annual funding to RAC to care for residents

with the highest and most complex care needs, increased over 13% since the introduction of the new funding tool (Australian Government Department of Health and Ageing 2011, p6).

2.2.4 Commonwealth of Australia Senate: Community Affairs Legislation Committee Estimates

The government response and concern for the unexpected increase in aged care cost from the ACFI review and the progress of the reforms in the aged care sector is revealed by evidence given to the Senate Estimates Committee, published by the Committee Hansard dated 15th February 2012. This Committee comprises Senators who are from the upper house of the Australian Parliament. These Senators can call for reports from anyone they choose, in this précis, the highest level of bureaucracy in the AG Department of Health and Ageing (DoHA).

In response to a question regarding evaluation of costs associated with implementation of the ACFI, Ms Carolyn Smith (First Assistant Secretary, Ageing and Aged Care Division, DoHA) states that "residential aged care expenditure growth is growing faster than anticipated and faster than historical trends" and that the actual variation "equates to $1.9 billion over the 4 years" (Proof Committee Hansard 2012, pp55-58).

Embedded in the discussion paraphrased above is a very strong driver for government driven policy change – cost. In the current economic climate there is a strong will on both sides of government, to manage costs and keep budgets from 'blowing out' as described by Senator Siewert (Proof Committee Hansard 2012, p57).

2.2.5 Needs Identification Tool for Aged Care and Carers (NITACC)

The *'New Front End for Aged Care'* (Productivity Commission 2011)
In response to its responsibilities under the National Health Reform Agreement, the AG, being the level of government responsible for the national

aged care system, has tendered for a consultant to 'assist in the development and validation of an Assessment Framework and the Needs Identification Tool for Aged Care and Carers' (RFT DoHA/047/1112). As part of the overall plan for the AG to develop a new health and hospitals system, governance will devolve to Local Hospital Networks and Medicare Locals that are part of the National Health Reforms. Work has already begun to develop and build these models across the country. The function of the 'new front end for aged care' the 'Australian Seniors Gateway Agency', will include contact and screening, information provision, needs identification assessment, comprehensive/complex assessment, service linking, review and referral. The intention is to overcome the current gaps, duplication, inequities and involvement of different levels of government and NGOs. The NITACC will be a *single integrated needs assessment tool that considers the needs of both care recipients and carers together* (Australian Government Department of Health and Ageing 2012 pB4)

2.2.6   The relationship between policy and care.

The Australian Government has a policy of controlling the number of nursing home beds being commissioned. In the past when more beds per population were available, the beds were filled (Gibson 1998, p37). The policy to increase options for home care has meant less demand for residential care (Productivity Commission 2011, p33). Alternatively, the reduced availability of beds means that people are forced to accept the home care option. Government policy and payment schemes has a significant effect on the services elderly people have access to and are referred to by their doctor (Frijters D, Mor V *et.al.* 1997).

The connection between policy making, research and care need is contested (Walshe K and Rundall T 2001; Mor V, Gruneir A *et.al.* 2011). The health system looks at care needs from two perspectives. The medical perspective of disease treatment and the perspective of functional support. Both are cost drivers and should be measured together. The contrast between the two perspectives, and the resulting confusion for policy makers, is demonstrated by two recently published, policy informing documents. The first, as an example

of the medical perspective, is from an expert panel of geriatricians convened by the American Geriatrics Society. This group has published a pair of documents in the society's journal that are tools for the clinical management of 'older adults with multiple chronic conditions' (American Geriatrics Society Expert Panel on the Care of Older Adults with 2012). Both documents are excellent reviews of evidence based practice and acknowledge the complexities of managing care for these individuals that goes beyond the evidence based best practice for a single disease (Boyd C 2012). But the group minimally acknowledges the role of funding ('reimbursement structure' *ibid* p9) on care practice. In contrast, arguably the most significant, current policy informing document in Australia is the Productivity Commission Report - Caring for Older Australians (Productivity Commission 2011) that mentions geriatric assessment units, but not geriatricians, and medical care thus:

The Australian Medical Association argued that GPs are reluctant to provide services because GPs:… are the primary medical care providers for older people living in the community and form long term relationships with their patients and their families. They play a crucial role in managing and coordinating care for an older person. However current Medicare benefit arrangements do not reflect the time it takes to provide care to older people with chronic long term conditions and do not cover the costs of delivering medical care outside of the doctor's surgery. As a result, home visits no longer feature in general practitioner care as much as they once did… Adequate incentives must be developed, and access to nursing and allied health services must be improved, to support the medical workforce to provide medical care to older Australians living at home and in aged care facilities. (sub. 330, p. 1)

Hence, there is an understanding in the Productivity Commission Report, sourced from submissions received form the medical profession (above), that to optimise medical care of the NH resident, GPs need to be paid for their services. In contrast, the AGS guidelines describe best clinical practice without ant supporting policy to reimburse or provide incentive to providing this best practice.

There is a desire in Government to embed policy more firmly in care needs. The Residential Care Scale (RCS) and now the Aged Care Funding Instrument (ACFI) is an enactment of this control. Access to aged care in Australia is not restricted to ability to pay (Gibson 1998, p40). An alternative method of ensuring services are used appropriately is "targeting on the basis of dependency" (Gibson 1998, p41). In 1987 a program of assessment by 'aged care assessment teams' was implemented nationally to determine eligibility for services funded by the Commonwealth which proved to reduce demand for aged care services and the dependency levels of people entering nursing homes increased (*ibid* p42). At the same time service providers were required to assess their clients' dependency using the Residential Classification Instrument (replaced in 1997 with the RCS). This instrument identified higher dependency needs and the financial compensation to the service was also increased, hence encouraging service providers with an incentive to admit higher dependency clients than before these changes were introduced (*ibid* p42).

The Productivity Commission Report (2011) calls for reform of policy to meet the growing need for aged care and to segregate accommodation services from care provision. The NITACC embodies this drive; the Senators are talking about it; and the fact that the Department does not understand (or won't articulate) why costs are exceeding predicted trends despite the data provided to them by the nursing homes in the ACFI shows that the processes driving aged care policy in Australia are indeed facing a significant change that has already started. The focus of the PCs report is aged care services, drivers of demand and strategies for managing costs and currently unmet demand into the future.

To identify and predict the patterns of care demand, researchers have proposed trajectories as an innovative way to plan more efficient and effective care. Determining whether there are trajectories of decline are in nursing home is the key focus of this thesis and this is especially important because 70% of funding is directed to the residential component of Australia's age care sector. In order

to understand the potential use for trajectories the next section of the literature review will be a critical account of trajectory theory and how it originated.

2.3   The genesis of the trajectory of decline theory

To address the uncertainty presented by the issues for aged care provision -
increasing older population; reduction in health workforce; reducing tax base;
increasing acuity of residents and shorter stays in nursing homes; increasing
costs; political concern and bureaucratic uncertainty – models that account for
these variables have been articulated in the research literature. However one
model in particular – the trajectory of decline – has appeared in a number of
aged care policy documents worldwide (Table 2.1 on page 83). This section is
a review of the literature pertaining to 'trajectory' - the development of the
theory, identification of functional change and prediction of decline to death,
and the literature from which the 'trajectory of decline', as articulated by
Joanne Lynn, arose.

A 'trajectory' is defined as (1) the curve that a body (as a planet or comet in its
orbit or a rocket) describes in space or (2) a path, progression, or line of
development resembling a physical trajectory (Merriam-Webster.com). To
describe a trajectory mathematically, there must be at least two points of
measurement to draw the line of the trajectory. The graphs described by Joanne
Lynn (Figure 1.1 on page 27) have no scale and hence only conceptualise the
change and rate of change in function over time for the trajectory groups.
Starting with references cited by the Lynn research, the literature review
extended into an exploration of literature that traversed the social science,
medical, nursing and actuarial landscapes. In effect using a 'family tree' to
track the academic lineage of the research, three threads were identified that
define the 'trajectory of decline' model for this thesis. Each thread of research
could be followed to a source that used the term in similar ways but there was
no cross–referencing to the other research 'lineages' until 2002.

2.3.1   Literature search strategy

To place the 'trajectory of decline' in health research literature an initial search
of the electronic databases of Pubmed, PsychInfo and Sociological Abstracts
from January 1960 was undertaken. Keywords used in the search included:

trajectory, decline, death, function, chronic disease, aged, palliative care, end of life, nursing homes, hospice, hostel, aged care and residential aged care. The search was limited to English language and people older than 65 years. Results of each database search were downloaded to a citation manager program (Endnote vX4, Thomson-Reuters) to exclude duplicates and to manage the documents. Results of this search (to October 2007) were presented at the American geriatrics Society Conference in 2008 (Lawrence et.al. 2008, Poster C92). A further hand search included research literature and policy documents referred to by any of the references found through the electronic search. Google was used as a first step to locate portals that opened into the 'grey' literature such as parliamentary reports, government policies, commentary and submissions by aged care providers or clinical guidelines from local health authorities. It was also helpful to make use of the electronic database add-ons to locate papers that had cited research of interest as well as reading comments posted online in response to publications. While not meeting the 'peer-reviewed' quality of published papers, these comments provide interesting insights into the immediate issues researchers and clinicians are dealing with rather than waiting for research delayed by the publishing process.

The oldest referenced lineage is that of the qualitative researchers Barney Glaser and Anselm Strauss dating to the 1960's. The next lineage reviewed includes the work of Sidney Katz who introduced the now well-known concept of ADLs. The third body of work reviewed is by Joanne Lynn and the literature that has followed on the work of Lynn to use the trajectories of decline in policy and research. The temporal lineage of these research groups are described in this section, linked to concurrent policy and contexts of use.

2.3.2 The 'work of death' trajectory: the Glaser/Strauss/Corbin thread

The social scientists, Glaser and Strauss identify the journey people take from death, as something that will happen in the future, to death being imminent as the "dying trajectory" and argued that to study dying requires consideration of the period before the actual death because, *dying takes time* (Glaser B and

Strauss A 1968, p1). The impetus for the work of Glaser and Strauss was their observation that in the early 1960's more than half of all deaths in the US occurred in hospitals and even more in nursing homes. They considered this to be a point of difference between economically advanced nations and less developed countries where, in the absence of institution based medical support, people are more likely to die at home.

It is safe to predict that the shift in delegation of responsibility from family to hospitals, nursing homes, and other institutions yet to be invented will bring about an increasing examination of what happens as patients lie dying in those institutions – what happens to everyone implicated in the dying.

<div align="right">(Glaser and Strauss 1968, px)</div>

Hence care becomes part of the hospital staff technical "work", organized to occur over time, whether or not death comes slowly or swiftly. In their monograph "A Time for Dying"[6] Glaser and Strauss focus on this concept of dying as a temporal process. It is here that the authors introduce the concept of a "dying trajectory" – being the individual's course of dying:

The dying trajectory of each patient has at least two outstanding properties. First, it takes place over time: it has duration. Specific trajectories can vary greatly in duration. Second, a trajectory has shape: it can be graphed. It plunges straight down; it moves slowly but steadily downward; it vacillates slowly, moving slightly up and down before diving downward radically; it moves slowly down at first, then hits a long plateau, then plunges abruptly to death (Glaser B and Strauss A 1968, p5)

Glaser and Strauss argue that these trajectories are perceived – their dimensions depend on when the perceiver initially defines someone as dying and on his expectations of how that dying will proceed (Glaser B and Strauss A 1968, p6). The difference between the perceived course of death and the actual

---

[6] This book is the third of a series of four published over 1965 to 1967 this last being the eponymous *The Discovery of Grounded Theory*.

is a subtle argument because the trajectory will then be based on the experience of the perceiver. That is, the health professional with experience of death as part of their work will predict, from that experience, the probable trajectory of death for someone with a particular diagnosis. The family member who has never known anyone to die will not have any experience to create a perception of a trajectory.

This view, that the trajectory exists only in the experience of the person, would be the difference between the Glaser and Strauss thread and other researchers that attempt to measure, from a set point and then either retrospectively or prospectively, to attempt to define the trajectory of the person through a concrete measure such as their health care costs (Lunney *et.al.*2002) or declining physical function (Covinsky K, Eng C *et.al.* 2003).

In a later monograph Glaser and Strauss reiterate the difference between the course of the illness and the illness trajectory (Strauss A, Corbin J *et.al.* 1984). Here they state that health professionals use the term *course of an illness* to describe the phases and symptoms of an illness over time. Whereas, *illness trajectory*, that is stated as *a term coined by the authors* covers not only the physiological changes of the illness but also the organization of work and impact of that work on those involved in the course of the trajectory. For example, health professionals talk about managing a chronic illness in terms of the 'work' that is done by them that will shape the illness trajectory. Not however, an ability to completely control the trajectory (*ibid* p64).

In 1988 Corbin and Strauss (Corbin J and Strauss A 1988) continue the development of the trajectory in regard to chronic disease and management at home by the *couple.* In this monograph the authors may be referring to a same sex couple living with HIV-AIDS in a period of the US where this was not openly discussed. This idea that the trajectory of health work extends beyond the patient and the health professional directly involved in care has been used recently by deRouck and Leys (De Rouck and Leys 2012). These researchers

found that parents with a baby in neonatal intensive care (NICU) will seek internet information at identifiable points along the trajectory of the baby's stay in NICU.

The illness trajectory work of Glaser and Strauss, and later co-researchers, is further developed with their work on chronic illness as published in the monographs "Chronic illness and the quality of life' (Strauss A, Corbin J *et.al.* 1984) and "Unending work and care" (Corbin J and Strauss A 1988). Also writing in the 1980's, the nursing theorists, Weiner and Dodd further focused the illness trajectory on cancer only (Penrod J and Liu C 2006). The Glaser and Strauss thread continues in these later publications to further the difference between the course of an illness and trajectory. They expand the nomenclature with the *trajectory projection* being the decision made by the physician (sic) about the course of the illness based on their expert knowledge of the diagnosis, symptoms and the individual's response/s to therapy (Corbin J and Strauss A 1988, p32). Based on this knowledge, the physician then determines a *trajectory scheme* that may also be affected by the organizations ability to provide the required care or care options (*ibid* p35). The *trajectory projection* is also shaped by controlling information imparted by the person, health profession, or family either amongst themselves or externally. So the act of conceiving the illness trajectory may be affected by the audience. For example a conversation of their partner to an acquaintance may be brief and positive "oh yes she'll be fine" to a more detailed and frank discussion between the health professional and the person with the illness (*ibid* p46).

However all parties can shape the trajectory. Glaser and Strauss writing in the 1960s comment that information can be withheld by the physician in order to manipulate the patient's anxiety response. Later, Corbin and Strauss argue, the shape of an illness trajectory is not *contingent upon physiological fate alone* (Corbin J and Strauss A 1988, p42). Despite arguing that the *ultimate shape of a trajectory cannot be known until the end of a person's life ... nevertheless, theoretically we can look back on the evolution of anyone's trajectory, noting*

its shape up to the present moment. (*ibid* p43) So, in this 1988 monograph, the following trajectories appear for the first time, as *theoretical* graphical representation of the trajectory only. There is no empirical evidence in this publication, qualitative or quantitative, to support these trajectory shapes.

The first figure (Figure 2.8 below) represents the ongoing effects of a relatively minor chronic illness, sinusitis. The dips represent the periods where the person requires treatment.

Figure 2.8 From Corbin and Strauss 1988 p 43: The sinusitis trajectory

Figure 1. Sinusitis Trajectory.
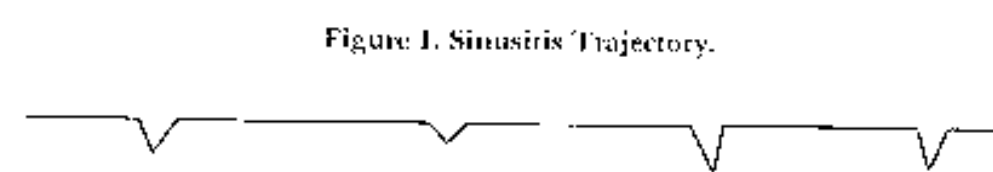
The following three figures (Figure 2.9) are representations of the trajectories for cardiac disease, stroke and cancer. It is confusing that these authors base the trajectory on the variation in the amount of work for the person or carers, and not the physiological variation in the illness. Surely if the y-axis was for care work, then the periods of exacerbation should be represented as 'ups' not downward slopes. Corbin and Strauss, while stating that these trajectories *reflect an even course in terms of the "work" involved in managing the illness's and work's impact on the person's life* (Corbin and Straus 1988, p43) they do not link this to the variation in the person's ability to care for themselves, that is physical function or daily care activities. They emphasis the physiological or emotional recovery or decline due to the illness only. Furthermore it is not clear why the trajectory for stroke trends up while the cardiac trends down. The x-axis is time; there is no definition of the y-axis. There is mention of *deterioration* and *comeback* (*ibid* p46) and that these phases are dependent on physical and emotional changes over the course of the illness.

Figure 2.9 From Corbin and Strauss 1988 p44: Trajectories of work for cancer, stroke and cardiac disease

Figure 2. Cardiac Disease Trajectory.
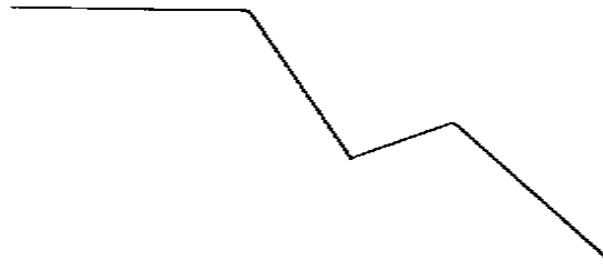
Figure 3. Stroke Trajectory.

Figure 4. Cancer Trajectory.

These are the first graphic representations of the trajectory theory in the literature and are referred to in the 1997 US Institute of Medicine review of end-of-life care (Field M and Cassel C 1997, p 28) but not referred to in the work by Lynn, the author of the trajectory graphs shown in Figure 1.1 (on page 27) until 2002.

The theorists, Glaser and Strauss use the trajectory concept to describe changes in work done either by the patient or care staff as a temporal relationship. Later, as will be described in Section 2.5.4, Joanne Lynn uses this concept to describe the temporal relationship between the patient's function and time to death. In the next section the literature that links the work of the theorists,

Glaser and Strauss with Lynn's graphs is reviewed. This work focusses on human functional ability, how it is measured and how it changes over time.

2.3.3   The functional decline/rehabilitation trajectory: the Katz, Branch and Crimmin's thread

In 1963 Sidney Katz published work describing the development and application of the Index of Independence in Activities of Daily Living (IADL) − a standardized measure of function for the elderly and chronically ill (Katz S, Ford A *et.al.* 1963). Katz notes that the changes in function (as measured by the IADL) were sequential, for example, going to the toilet independently could only follow if the person was able to transfer (from bed and chair) independently. This early paper focused on recovery of function. Katz hypothesized that *just as there is an orderly pattern of development, there is an ordered regression as part of the natural process of aging (ibid* p918*).*

The connection between ADLs and predicting care needs appears in the paper of Branch and Ku (1989) who identify activities of daily living (ADL) scores and hospitalizations as the most useful predictors of need for long term care, based on a 10 year longitudinal study of 1625 community dwelling elderly people. Such information, as emphasized in the paper, *can be used as the basis for actuarial estimates for long-term care policies* and insurance, public, private or self-funded. After all, according to these authors:
An additional concern when insuring people is estimating differential risks based on their characteristics at the time of enrollment. Understanding these risks reduces the potential for "adverse selection", that is, disproportionate enrollment by those most likely to need the services (Branch L and Ku L 1989, p372). These authors present their research as a tool for insurers to identify high risk clients.

Referencing the research of Branch and Katz, Bortz (1990) published a retrospective review of the hospital records of 97 patients of a geriatric service (acute setting) to identify the *trajectory of dying*, based on their functional status. Bortz identifies the need to *characterize life not just by its duration but by quality* (Bortz W 1990, p146). He also refutes the notion that the elderly cost too much in the acute setting, arguing that cost of hospital care has a direct

relationship to functional status and <u>younger</u> age. That is, *older and dysfunctional patients had lower dying bills than those who were younger and more vital* (Bortz W 1990, p147). However he also acknowledges that this may be due to rationing, implicit or explicit, of high cost services such as ICU to these patients. Bortz reviewed the records of all his patients that had died in the preceding 12 months for demographics, diagnoses, medicine use, evidence of advanced directives, length of stay and functional status based on his own three point score based on what was in the record (that is, not necessarily measured at the time of the patient's life) or his memory. The results found, that similar to the study done with community elders (Branch L, Katz S *et.al.* 1984), functionality is maintained into the last year of life, and rationing health care on the basis of age is inappropriate. There is no reference in this paper to the Glaser and Strauss trajectory, and the term trajectory is used in regard to quality of life.

.

The work of Branch, but not Bortz, is extensively referred to in a paper by Crimmins and Saito (1993) that is itself cited 145 times (Google Scholar October 2012). The paper, titled "Getting Better and Getting Worse; transitions in functional status among older Americans" publishes the results of a two year study done in 1986 of 3,169 community living elders aged 70 and older. Crimmins and Saito measured 21 indicators of ability to care for themselves independently – in the home and outside the home. They use the term transition in relation to a major finding of their research, that older individuals can both lose and regain the ability to perform specific functions (Crimmins E and Saito Y 1993) . Also, as described by Bortz (1990), while age is related to the likelihood that functioning will deteriorate, the decline is worse when the person has poor general health and a significant physical impairment, such as stroke (Crimmins and Saito, 1993).

Functional transitions and *transitory fluctuations* in physical function in relation to hospitalizations are reported in a paper by Mor (Mor V, Wilcox V *et.al.* 1994). This research supported the finding by Crimmins and Saito, that

functional status in the elderly is not simply downhill, and also found that there is a link between functional decline and hospital use, especially in the period immediately prior to death. The term, *trajectory of decline* is used in a paper by Zarit (Zarit S, Johansson B *et.al.* 1995) that reported the results of a four year (three measurement intervals) longitudinal study of initially 324, 84 – 90 year old people. This study combined measures of physical function (personal care and instrumental care, such as using a washing machine) with measures of cognitive function (Figure 2.10). The authors state that this hadn't been done before.
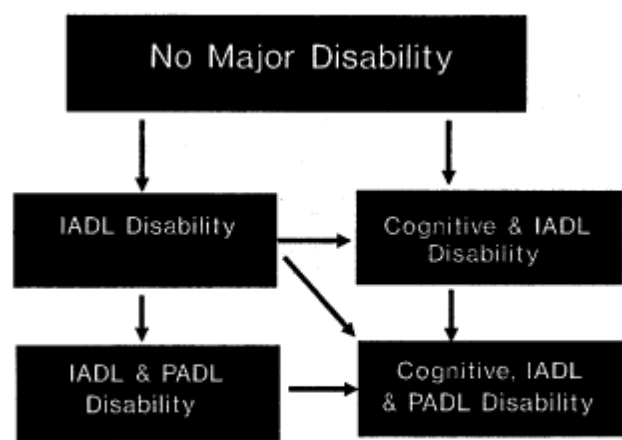
Figure 2.10 From Zarit *et.al.*1995, p9: Development of disability in the elderly

Figure 1. **Patterns of decline in cognition and activities of daily living.**
NOTE: Improvement would be indicated by movement in the opposite direction.

Zarit describes that over time, the measured changes in functioning declined considerably in that over each measured two year interval, one half of participants who had no significant disability had declined or died. Also while decline was the main trend, a small number improved in functioning between intervals, supporting the findings of previous authors. What is important about these studies is that they have identified the risk of using simple, population based studies of disability. For example Zarit found that while there was a high incidence of disability there was, at the same time, a low prevalence of disability. That is while participant disability increased, they also died. The paper by Crimmins and Saito (Crimmins E and Saito Y 1993) also found, that disability in women increased compared to men, but looking deeper than population level, that this is due to women living longer and hence also more likely to enter institutional care than men. These findings have important

implications for costing the future care of the elderly. As Payne notes, *the role of age, morbidity, and death in health care expenditures … is not a uniform picture* (Payne G, Laporte A *et.al.* 2007, p 248) because while people may live to beyond ninety and the cost of their death is less than for a younger cohorts, their overall use of health services is also extended (Payne G, Laporte A *et.al.* 2007).

This body of literature also uses the terms 'transitions' and 'trajectory'. However, while there are similarities with the Glaser and Strauss monographs, there is no reference to any author between the threads from either literature. Arguably the most important point to emerge from the literature reviewed in this section is that functional decline does not have a simple relationship with age or time. In the section to follow, Joanne Lynn argues the same point in relation to the functional decline experienced by a dying person and has drawn three representative trajectories of functional decline to death.

2.3.4   The Lynn thread

The first paper reviewed for this thesis was the Joanne Lynn reference given for the graphs shown in Figure 1.1 (Lynn J 2001, p930). Using this paper as a starting point, any subsequent citing papers and preceding papers cited by Lynn were identified and included in this section of the literature review. In seeing where the trajectories have come from and where they have been used in subsequent literature will assist in understanding how they can be applied.

The 2001 reference to the Lynn trajectory graphs is a single case study/policy discussion paper of a young man (aged 47 years) with advanced cancer (Lynn 2001). Lynn discusses the needs of this man, his family and their interactions with care services. It is an example of policy determining the care that the man receives and how he tailors his needs to what is available and what he can afford. Lynn uses the trajectories to illustrate the difference in functional support requirements of people dying of chronic disease – not just cancer – and how hospice services could support these different ways of dying. Actually what Lynn describes here (*ibid* p930-31) is the difference in funding (in the US

health system) of each trajectory group. In essence the cancer group are covered by hospice services/payments; the organ failure group are 'generally covered by health insurance' and will get a mix of aggressive and palliative treatments based on what insurance they have and what they can afford if not covered by insurance. The third group, dementia or frailty, have long-term expenses that are *borne privately or, for the poor and those impoverished by long survival with dependency, by Medicaid* (*ibid* p 931).

The USA Institute of Medicine discussion monograph – "Approaching Death – Improving care at the end of life" (Field M and Cassel C 1997) uses the trajectory of dying concept to emphasis the uncertainties for clinicians in determining life expectancy and discussing it with the patient and family. The graphs used to illustrate the concept are not themselves referenced. However, in a personal communication with Dr Lynn it was confirmed that she did prepare these graphs for the IoM report and that this document should be used as the first reference for the trajectory of decline graphs. As shown in Figure 2.11 (below) from the IOM report, there are only three trajectories depicted – 'sudden' death from an unexpected cause (accident or massive heart attack); steady decline from a progressive disease with a terminal phase (cancer, neurodegenerative diseases, cystic fibrosis, complex congenital malformations) and; advanced illness marked by slow decline with periodic crises and 'sudden' death (chronic disease). Frailty group is not discussed in this report.

Figure 2.11 "Prototypical death trajectories" from Field and Cassel (IoM 1997, p29)
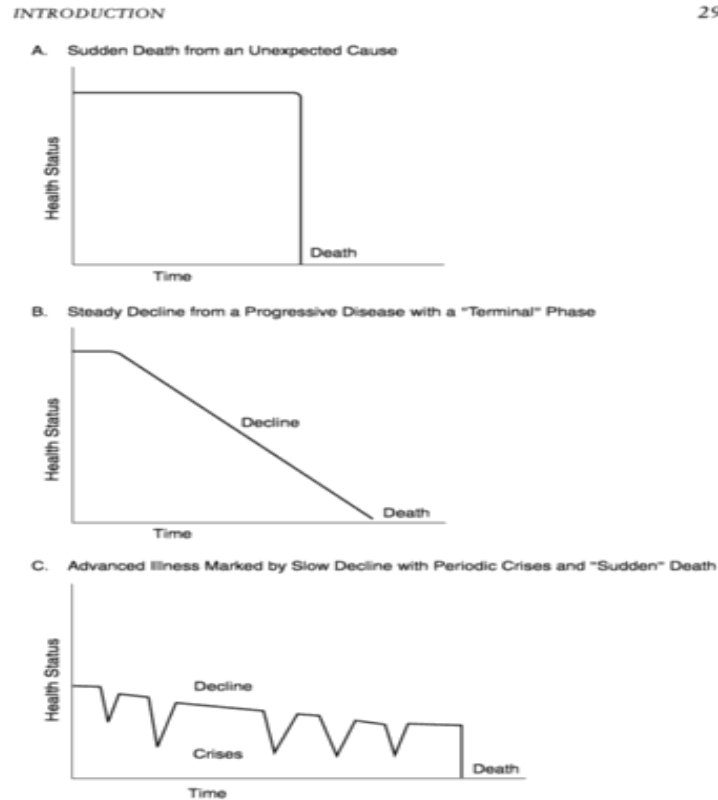
FIGURE 1.1   Prototypical death trajectories.

Clearly there is a strong similarity between these graphs attributed to Lynn and those from the Corbin and Strauss monograph shown in Figure 2.9 on page 66. It is not until 2002 in the collaborative empirical research paper by Lunney (Lunney J, Lynn J *et.al.* 2002) that Glaser and Strauss are referenced. Even so, it is actually the earlier Glaser and Strauss (1968) monograph that proposes the trajectories that is referenced first, not the monograph that shows the Corbin and Strauss diagrams in 1988.

Subsequent to the 2001 discussion paper by Lynn are a number of policy documents that are listed in Table 2.1 (on page 83). The limited number of

research papers that provide evidence for the trajectories of decline are discussed in the next section. Other publications that use the trajectory of decline graphs are all discussion papers that can be broadly classified as (1) end-of-life care policy informing; and (2) clinical interventions.

2.4   Use of the 'trajectory of decline' in health policy and practice guidelines

The trajectories of decline graphs and concepts are used in policy documents and practice guidelines around the world (Table 2.1). The graphs are used to illustrate that there are different pathways of functional decline preceding death with the proposition that knowing that an individual was 'on' a particular trajectory would improve the quality of care of that person in the period preceding their death (Lynn and Adamson 2003). This is also relevant to planning care under the palliative approach philosophy (Lunney *et.al.*2002; Murray *et.al.* 2002; Lunney *et.al.*2003; Lynn and Adamson 2003; Kristjanson L, Walton J *et.al.* 2005).

Table 2.1 Policy documents that include the 'trajectory of decline' graphs

Organisation	Year	Title	Trajectory Illustration/discussion	Context
USA Institute of Medicine	1997	Approaching Death – improving care at the end of life	p29	The differences in patient experiences as they approach death
World Health Organization (Europe)	2004	Palliative Care - the solid facts	p13	Uncertainty of prognosis for people living with serious chronic illnesses
Australian Government Department of Health and Ageing	2004	Guidelines for a Palliative Approach in Residential Aged Care	p139	Recognising when a resident (of an aged care facility) is dying
Tasmanian Department of Health and Human Services	2004	Palliative Care in Tasmania: current situation and future directions	p8	Using the trajectories of chronic illness to identify need and planning for palliative care
World Health Organization (Europe)	2004	Better Palliative Care for Older People	p15	Planning and resourcing care for the dying
Gold Standards Framework Programme	2005	Prognostic Indicator Guidance v2.25	p1	Recognising need for palliative care according to different diagnoses
NHS National End of Life Care Programme	2010	End of life care for heart failure	pp 6,21,23	The diagrams describe the points of the trajectory where care changes should be made/discussed.

As discussed in the previous section, trajectories commenced their existence as a useful concept but now, through their continued publication in policy documents and clinical literature, appear as fact despite the reality that the empirical evidence supporting the existence of these trajectories is limited (Section 2.3). Furthermore, there is no research to support their use beyond the context of the USA health care system in which they are based. However this limitation has not stopped policy makers in the EU, UK and Australia from reproducing the trajectory illustrations in aged care documents as fact and to be used (operationalised) by care providers in planning services for clients.

The trajectory of decline has been used in policy, as well as clinical practice guidelines specifically in end-of-life care and chronic disease management in various clinical settings. These will be described in more detail in the following sections.

2.4.1   End-of-life care practice guidelines that use the trajectories of decline.

This section identifies a group of publications that have used evidence of the trajectories of decline to propose policy change in particular for end-of-life care.

Figure 2.12 From Lynn and Adamson 2003: Three trajectories of decline over time

High
Function
Mostly cancer
Time
Death
Low
Short period of evident decline

Chronic, consistent with usual role
Healthy
Chronic, progressive, eventually fatal illness

High
Function
Mostly heart and lung failure
Time
Death
Low
Long-term limitations with intermittent serious episodes

High
Function
Mostly frailty and dementia
Low
Prolonged dwindling
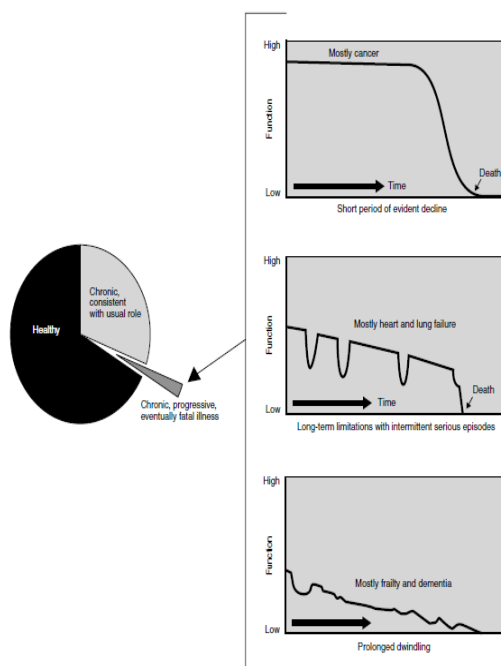
Figure 3. Chronic Illness in the Elderly Typically Follows Three Trajectories

This graphic of the trajectories of decline (Figure 2.12) is used by Lisa Shugarman (Shugarman L, Lorenz K *et.al.* 2004) in a paper discussing policy changes that could lead to improvements in end-of-life care in the USA by identifying and targeting the different needs of the proportion of people with chronic, eventually fatal disease trajectories before they die.

The same graph is referred to in a RAND Health (RAND Health 2006) publication that cites Lynn (2004) and Lynn and Adamson (Lynn J and Adamson D 2003). This publication calls for reform of the US health system to better meet the needs of people at the end of life.

As a response to the US Institute of Medicine report "Crossing the Quality Chasm" Joanne Lynn extended the trajectory concept beyond the period describing the end-of-life to describe a framework for efficient and effective health care resourcing for the entire population. This "Bridges to Health"

Model (Lynn J, Straube B *et.al.* 2007) segments the population into eight groups based on their likely health care needs. Starting with people in good health; maternal/infants; people with an acute illness; with stable chronic conditions; serious but stable disability; then the three trajectories of decline to death for short but fatal decline (cancer); exacerbations of organ failure; and the long, dwindling course (frailty and dementia). The care needs identified in this paper range from the 'healthy' person who works and keeps appointments with a primary physician, to 'frailty, with or without dementia' person requires extensive personal care. Each segment has different priorities and needs based on population estimates. However since publication (in 2007) this concept has had only limited citation.

The "Bridges to Health" is a concept paper. Over a decade before, Joanne Lynn was part of an extensive study conducted in the US to develop the 'SUPPORT' model[7]. Using this model, it was argued, clinicians are able to bring certainty into their discussions with their patients who have a potentially fatal disease to avoid what otherwise might be free-floating conjecture about a person's life span. (Lynn J, Teno J *et.al.* 1995, p256).

Five years later these same authors write (SUPPORT) was ineffective in changing communication, decision making, and treatment patterns despite evidence that counselling and information were delivered as planned (Lynn J, DeVries K et.al. 2000). They identify a number of obstacles to the model, one of which being the lack of reimbursement to the hospital to provide a peaceful death. Furthermore, patient choice was limited to the services available. Some of the hospitals had little or no home care or hospice option and their rate of in-hospital deaths were higher than those hospitals with a network of homecare services that supported families so that they could continue working. Hence the authors argue that rather than change being demanded by the individual, care

---

[7] SUPPORT being an acronym = study to understand prognoses and preferences for outcomes and risks of treatment.

needs to be organised at a system level to best meet the needs of the majority. They suggest by identifying a 'usual course of care' based on evidence based practice that serves most people best with room for customising is a more realistic model for system level improvement in care for those who can articulate their needs equally with those who can't.

In a recent example of the promotion of trajectory of decline for use in a clinical setting, the NHS (UK) has used the trajectory concept throughout the current National End of Life Care Programme (2010). To add to the confusion, this more recent policy publication has referenced Goodlin (Goodlin S 2009) using her graphic representation of the recommended care for heart failure (Figure 2.13 below). There is no reference to Joanne Lynn or any other functional decline thread research in this article despite the obvious similarities.

Figure 2.13 From Goodlin 2009: Conceptualisation of heart failure care
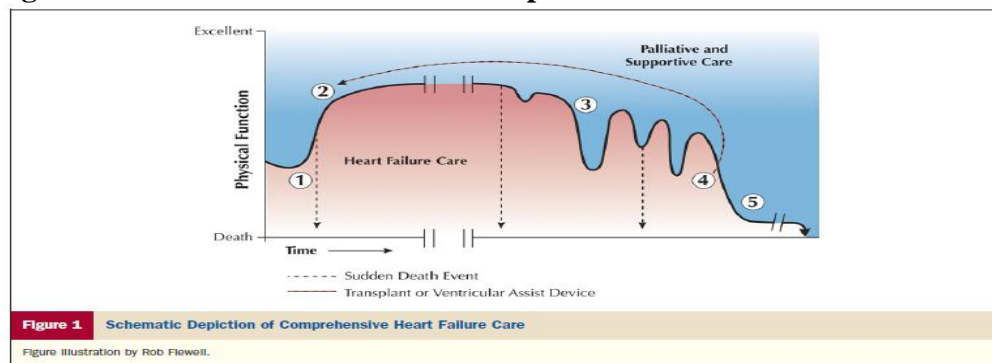
2.4.2   Proposed use of the trajectories of decline in chronic disease management

In a discussion paper published by RAND Health Joanne Lynn and David Adamson review the changing demographic of American's health and the growing pressure on health services of chronic disease. The graphic shown in Figure 2.12 (on page 85) is used to illustrate the care needs of those elderly people *sick enough to die* (Lynn J and Adamson D 2003). Writing for the College of Physicians (UK) Felicity Murtagh used the trajectory of decline graphs to illustrate variance in the illness trajectories according to the patient's

diagnosis (Murtagh F, Preston M *et.al.* 2004). The heart failure trajectory is described by Goldstein and Lynn (Goldstein N and Lynn J 2006) in regard to planning care and policy change (Figure 2.14 below).

Figure 2.14 from Goldstein and Lynn (2006 p12): Typical trajectory of disease for patients with cancer and heart failure
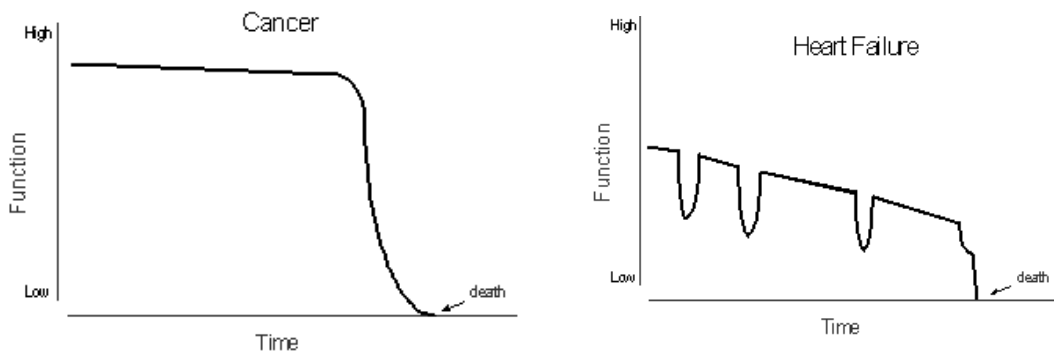
Freedman used the trajectories of decline in developing a framework for identifying the effect of interventions on late life disablement (Figure 2.15 below).

Figure 2.15 From Freedman et.al. 2006 (p496): Illustration of three prototypical trajectories of the disablement process
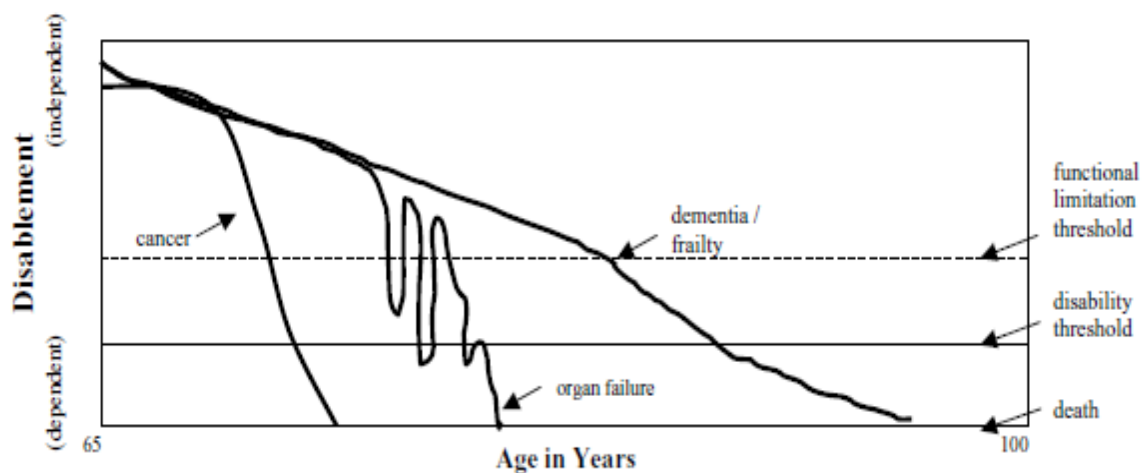
This paper reviews the literature for interventions to avoid the rapid decline phase of the three trajectories by either avoiding onset of pathology leading to

disability; slowing the progression of disease; and strategies to restore function and autonomy. This is similar to the disablement process described by Verbrugge in Section 2.6.2 (on page 100).

Three studies have identified different trajectories of functional limitation for community living elders suffering from dementia.

Figure 2.16 From (Nikolova R, Demers L *et.al.* 2009, p30): Differences in functional limitation related to severity of cognitive decline over time
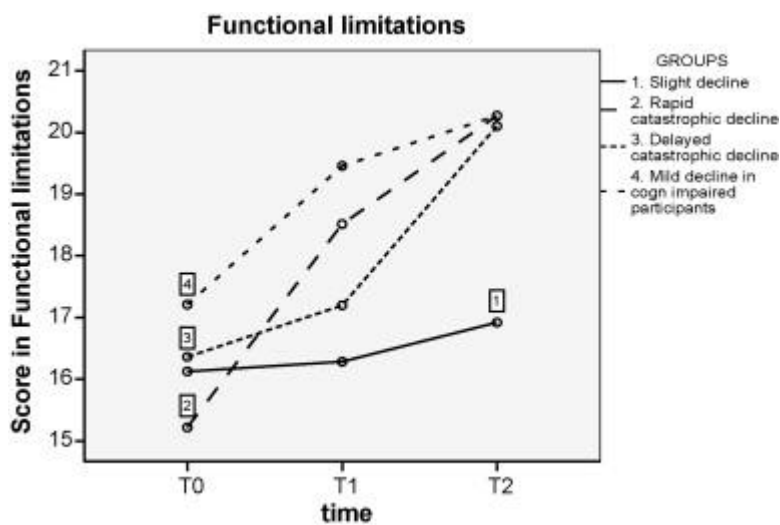
The study by Nikolova (Figure 2.16 above) identified four cognitive trajectories associated with functional limitation whereas Dodge (Dodge H, Du Y *et.al.* 2006 and McConnell (McConnell E, Branch L *et.al.* 2003) identified three trajectories of functional decline in people with dementia. These studies were done in community living elders and the oldest subjects were in the trajectories with the most marked decline.

Figure 2.17 From Murray *et.al.* 2005: Typical illness trajectories for people with progressive chronic illness. Adapted from Lynn and Adamson 2003
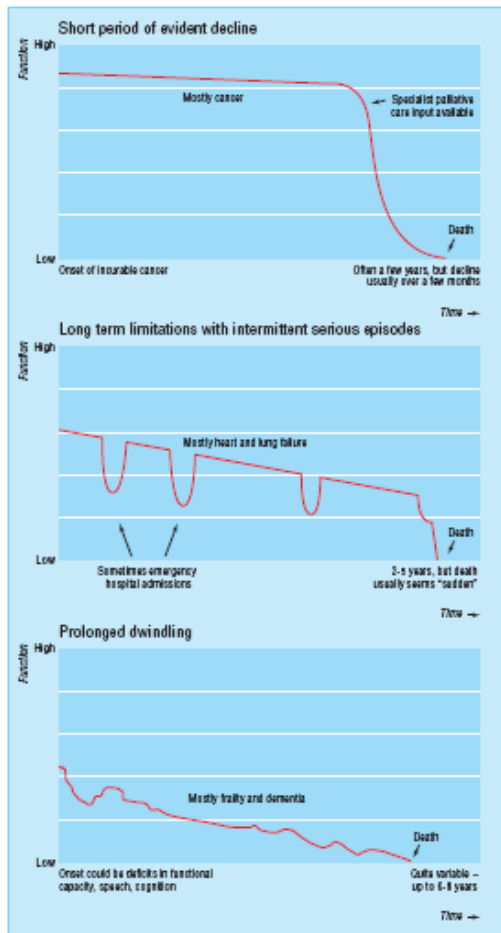
Fig 1 Typical illness trajectories for people with progressive chronic illness. Adapted from Lynn and Adamson, 2003.' With permission from RAND Corporation, Santa Monica, California, USA.

Murray in the UK has used the trajectory of decline to describe the service use of patients dying with cancer in comparison to other disease conditions (Murray SA, Boyd K *et.al.* 2002; Murray S, Kendall M *et.al.* 2005). The graph depicted in this paper (Figure 2.17) has been 'adapted' from another publication by Joanne Lynn in 2003 (Lynn J and Adamson D 2003).

What emerges from this review of the use of the trajectory of decline model in the literature following the first publication of the graphs by Joanne Lynn in 2001, is that the trajectory of decline model has a broad application and appeal not just in aged care. For example in response to the article published by Murray (2005) in the BMJ an intensivist in NZ wrote:

Finally, I have been searching for a graphical way to convey the concept that since critical illness often leads to death and prediction of individual outcome in intensive care.

Stephen Streat, *in* BMJ 'Rapid Responses' to Murray *et.al.* BMJ April 2005.

These figures, attributed to Joanne Lynn have appeared in the Australian Government 'Guidelines for a Palliative Approach in Residential Aged Care' (2004, p139) shown in Figure 1.1 (on page 27) as well as other, more recent,

policy documents in the UK, EU and US (listed in Table 2.1 on page 83). However, it appears that although this concept arose in the earlier Glaser and Strauss literature this thread is unrelated in that there is no cross referencing between the threads until 2002. While this could be an interesting academic exercise, it becomes an effort to understand where this trajectory concept resonates (if it can be demonstrated empirically). As described by Stephen Streat above, for a clinician this concept makes sense. What was found in the course of the literature review process, and what made the review difficult at times, is that the threads for the trajectory of decline theory appear in particular literature lineages and their related publishing modalities. Glaser and Strauss for example did not publish in the BMJ or JAMA. They use monographs – that are completely invisible outside the sphere of the university library – being discovered through reading about them in the first reference to Glaser and Strauss (1968) by June Lunney in 2002. However, policy makers are not interested in academic arguments about literature lineages.

2.5   Empirical evidence of the 'trajectory of decline'

There are only two papers that report empirical evidence of the <u>multiple</u> trajectories of decline in an elderly population as articulated by Joanne Lynn and two that identify additional differences between the trajectory of cancer and renal failure for all patients not just the elderly. In Figure 1.1 attributed to Joanne Lynn, there are only three trajectories described – cancer; organ system failure; and dementia/frailty (DoHA 2004). The first research paper, that classified deceased elders based on their Medicare claim data, introduces two hitherto undescribed trajectories – sudden and 'other' (Lunney J, Lynn J *et.al.* 2002). The graphic representation of four of the trajectories from this paper is reproduced in Figure 2.18 below. There is no graph for the 'other' group. The cause of death was determined from the physician code on the Medicare claim, a classification method that is comparable to cause of death information from the death certificate (Hogan C, Lunney J *et.al.* 2001).

Figure 2.18 From Lunney, Lynn and Hogan (2002 p1109) "Proposed trajectories of dying"
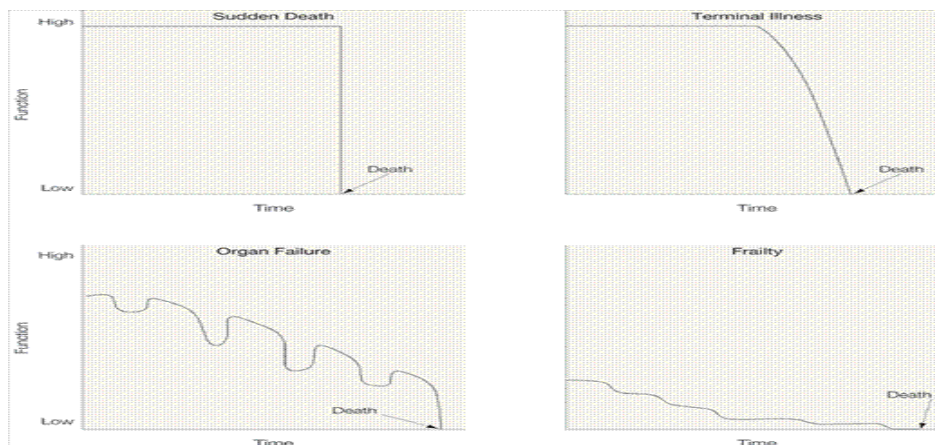
Having established that an elderly population could be classified by cause of death and that there were some differences in demographics and care expenditure before death between the groups, the second study sought to determine if the groups differed by their slope of functional decline. In this paper deceased elders were classified into their diagnostic group primarily by

death certificate data. The measure of function (determined via interview of participant or carer) for participants in each trajectory grouping over the 12 months before death was clustered by month of interview to give a mean value of function. As shown in Figure 2.18 below, the mean function declined in all groups. The frailty group in particular had the highest ADL dependence before death (Lunney J, Lynn J *et.al.* 2003).

Figure 2.19 From Lunney, Lynn et.al. (2003 p2390): "Dependent activities of daily living (ADLs) for each month cohort, by trajectory group"
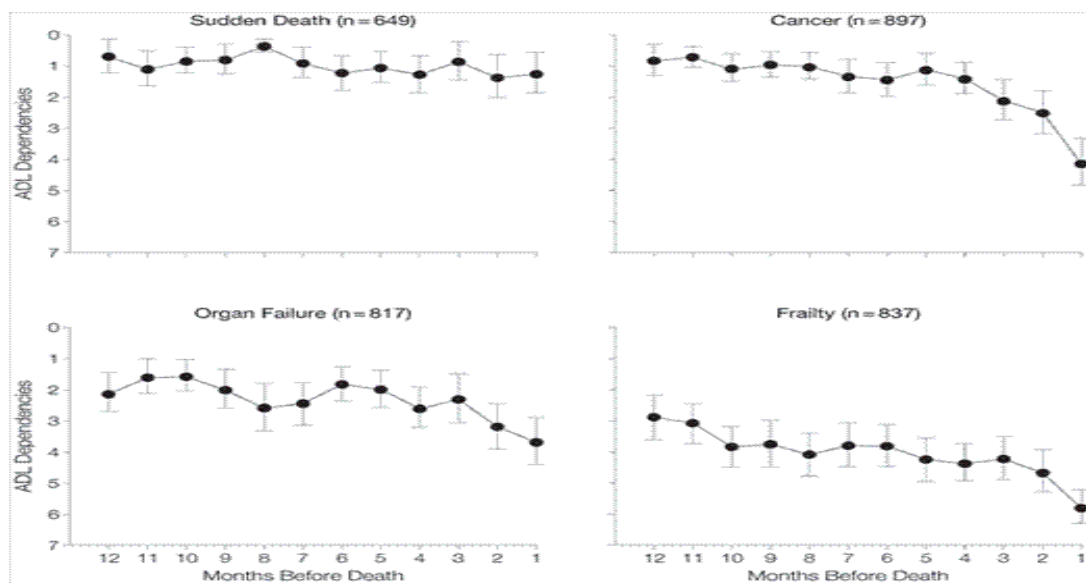
Unlike the 2002 study where a participant was classified into the frailty group if they had a Medicare claim for Alzheimer's disease, dementia, delirium, Parkinson's disease, stroke, pneumonia, dehydration, hip fracture, incontinence, syncope, or leg cellulitis[8], the 2003 methodology placed any subject with a nursing home admission into the 'frailty' trajectory. This was important because hospital deaths from cancer declined from 1980 with an increasing number of people dying at home by 1998 (38%), and 17% occurring

---

[8] Classification based on analysis from the large USA HMO Kaiser Permanente (Haan et.al 1997)

in nursing homes (Flory J, Young-Xu Y *et.al.* 2004). Hence it is arguable that 17% of cancer deaths were excluded from the cancer trajectory group involved in this research because they were classified as being on the 'frailty trajectory' in a nursing home. The implication of this potential misclassification is that residents of nursing homes are being identified as having conditions related to frailty only and thus may be excluded from interventions targeting diseases that could directly lead to their death, such as cancer.

Comparing differences in the pattern of functional decline between people dying of cancer and other leading causes of death in adults (30 years and older) Joan Teno used a retrospective interview method with the next of kin. The measure of physical function was an estimate of the dying person's difficulties with ADLs and mobility. As with the other studies, the measure of function for the subjects was grouped by month to give a mean score. The trajectories for each identified disease group are shown in Figure 2.20 below.

Figure 2.20 From Teno, Weitzen, Fennell and Mor (2001 p461) "Age-adjusted activities of daily living (ADLs) scores by month before death"
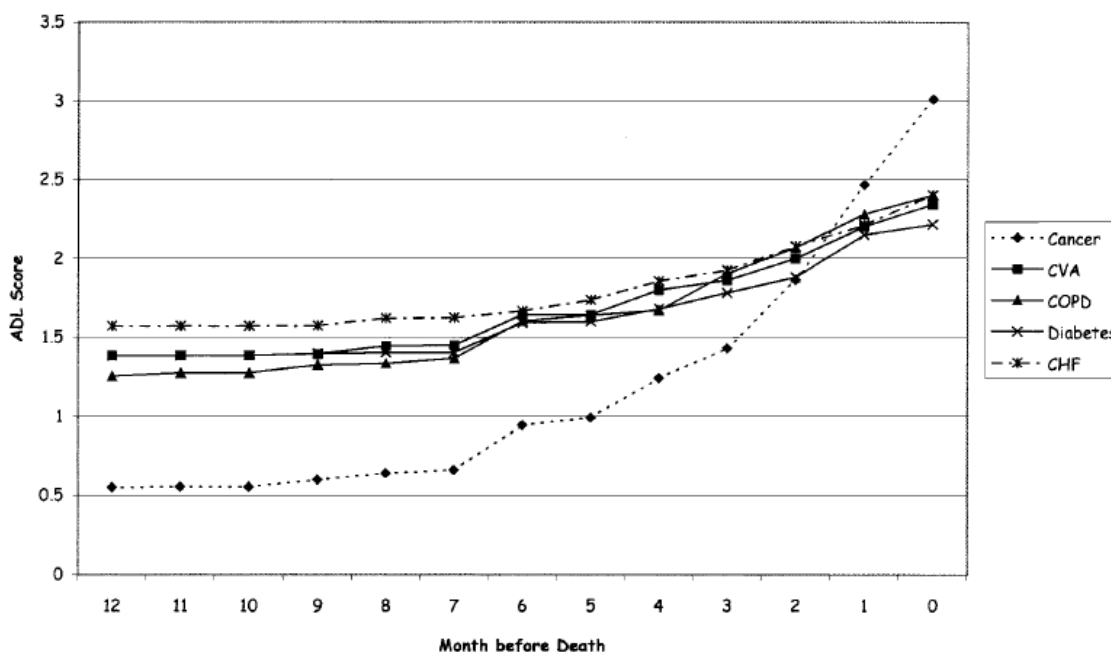
These graphs do not try to emulate the Lynn concept by reversing the y-axis to demonstrate a 'decline' in function. A worsening ADL score indicates

increasing care needs. This study does show a difference between the cancer trajectory and other diseases. There are a few studies in the research literature that have identified an association between ADL loss and diagnosis in the elderly. In these studies of community living elders 80 years and older, the diagnosis group with diseases such as cancer and heart disease had no or minimal ADL loss. In comparison the group with health conditions associated with frailty such as stroke, cognitive impairment and fracture did have significant ADL loss (Bootsma-van der Wiel A, de Craen A *et.al.* 2005; Cesari M, Onder G *et.al.* 2006; Takayama M, Hirose N *et.al.* 2007; Ferrer A, Formiga F *et.al.* 2008; Wu H, Flaherty J *et.al.* 2012). However, these were cross-sectional cohort studies and hence only reported an association between functional loss and diagnosis not a trajectory of functional decline.

Building on the empirical research of Lunney and colleagues described above, a sixth trajectory of decline has subsequently been identified for renal failure (Murtagh F, Addington-Hall J *et.al.* 2011). However the population for this study was not restricted to an elderly cohort. The age range was 51 to 95 years, being selected from hospital patients with end stage renal failure. The graph shown in Figure 2.21 below used mean data grouped by month of measurement. The same analysis method used by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2003).

**Figure 2.21 From Murtagh, Addington-Hall and Higginson (2011 p4)
"Trajectory of mean Karnofsky Performance Scale (KPS) score over the
last year of life for those who die (N=46).**
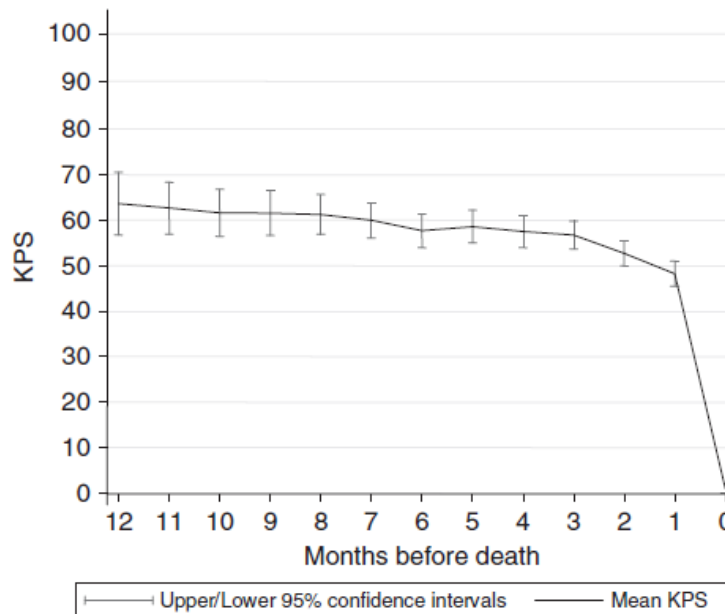
There does appear to be a modest decline from mean scores in the mid-60's to
low 50's with no significant difference from 12 months to the month before
death. However the dramatic downward slope is due to the Karnofsky Scale
being zero for death.

The trajectory of decline graphs have been taken up by policy makers
worldwide for use in a broad range of populations including nursing home
residents. The two empirical papers by Lunney and colleagues (Lunney J, Lynn
J *et.al.* 2002; Lunney J, Lynn J *et.al.* 2003) identify the trajectory of decline in
community living US elders. Yet there is no evidence that the trajectories of
decline exist in the NH population with specific, expensive and growing care
needs. In the next section, the markers of ageing and the conceptual models
used to describe the ageing process are reviewed in order to identify what
options there are available to profile the functional changes in a nursing home
population and map their trajectory.

2.6   The ageing process

This section will define ageing from the point of recognising the effect of life expectancy on ageing, specific markers of the ageing process and models from research literature on ageing that describe a framework for the ageing process. This is relevant to this thesis because the 'trajectory of decline' is also a model of the ageing process. However, the trajectory of decline focusses on the period preceding death rather than the longer continuum of ageing that most of the ageing models describe. The trajectory of decline may articulate with the end phase of some of these models.

2.6.1   Life expectancy

The most important determinant of ageing is life expectancy (Australian Bureau of Statistics 2004). In 2011, Australia's population was around 22 million. This number is expected to increase to 35.5 million by 2056 if the determinants of life expectancy - fertility rates, migration, and life expectancy at birth - remain at current predicted levels.

Life expectancy is a definition derived from a demographic determinant:
Life expectancy refers to the average number of additional years a person of a given age and sex can expect to live if the age- and sex-specific death rates observed in a given period continued throughout his/her lifetime.
(Australian Institute of Health and Welfare 2006).

It is important to note that life expectancy does not mean that people will die at that age (Australian Bureau of Statistics 2004). Life expectancy is calculated from life tables. The life table depicts the mortality experience of a hypothetical group of newborn babies throughout their entire lifetime. It is based on the assumption that this group is subject to the age-specific mortality rates of the reference period. All components of a life table are based on the mortality rate and hence are dependent on a valid method of population (births and deaths) data collection (Australian Bureau of Statistics 2004).

Changes to life expectancy are mainly the result of babies surviving their first year of life. In Australia the mortality rate of infants in 1901-1910 was high which kept the life expectancy low (Australian Institute of Health and Welfare 2006). As the century progressed, the improvements in clean water supply and sewage treatment, better food quality, then immunisation and the availability of antibiotics resulted in more children surviving infancy. Adult life expectancy also improved with the same factors plus more specific targeting of cause of death in a cohort. For example, improved vehicle safety and driver education has reduced fatalities in young adults; and health education aimed at health behaviours such as dietary fat and smoking has reduced the number of deaths from heart disease including in the elderly (Australian Institute of Health and Welfare 2006). In the same way public health programs have targeted smoking or vehicle safety based on knowledge of the causes of premature death, understanding the specific determinants of ageing will lead to programs that may prolong life or at least ensure the ageing population is offered targeted health promotion or health maintenance programs.

2.6.2   Models used in the study of the ageing process

A search of the literature has identified a number of models, other than the trajectory of decline, used to define the ageing process and are included in the literature review to increase understanding of 'trajectory' and modelling .While the models included in this section are not directly used in this research of the trajectories of decline, it is important to be aware of alternative models articulated in the literature, their theory and resulting conjecture. Also, the trajectory of decline focusses on the end stages of the ageing process, that period preceding death. Thus the trajectory of decline will articulate with these models that describe a framework for understanding the ageing process.

Disability and dependency

In the aged care literature and policy, the word 'dependency' is used interchangeably with 'disability'. For practical purposes, argues Gibson, they are one and the same. However, Fried warns, disability should not be used

interchangeably with the terms frailty and comorbidity because they require different care and research strategies (Fried L, Ferrucci L *et.al.* 2004). The classic measures of disability, the ADL and IADL, are in fact measures of dependency in that the measure is the level of assistance needed by the person to shop or bathe (Covinsky K, Hilton J *et.al.* 2006). Dependency, as measured by the functional status, is the most important predictor of the cost of nursing home care (Williams B, Fries B *et.al.* 1994).

Another area in ageing where dependency is overtly or covertly created in the aged is financially with expectations of leaving the workforce and the provision of the aged care pension; and from the perspective of the carer, often a woman, who by taking on the 'burden' of care for an elder, also becomes financially vulnerable (Gibson 1998, p201).

There is a risk when focussing on the negative – *burden* of ageing, *tsunami* of aged, *cost* of *dependency*, to name a few phrases – of forgetting that approximately one-third of people over 60 years are 'successful agers' particularly in regard to an absence of disability (Jeste D, Depp C *et.al.* 2010). As well, pessimism may limit debate on good aged care vs cost (Coorey M 2004).

Life course approach to modelling the trajectory of a person's life.
The basis of this concept arose in the early twentieth century when the importance of a person's early life, even in utero, affects adult characteristics – biological, psychological, social risk factors as well as age-related disease, functional decline and disability (Leinonen R, Heikkinen E *et.al.* 2001). At a recent symposium published in the Journal of Gerontology, Alwin described the current state of this concept:

A body of work referred to as the "life course" framework (also known as "life course theory," the "life course paradigm," and the "life course perspective") has been increasingly used to motivate and justify the examination of the relationships among variables in social and behavioral science, particularly in the study of population health and aging. Yet, there is very little agreement on

what some of these concepts mean, and there is hardly any agreement on what the "life course" is (Alwin D 2012).

International Classification of Functioning, Activities and Participation (ICF)

The ICF is the international standard to describe and measure health and disability[9] (WHO 2001). This tool is linked to the ICD10. There seems to be only limited implementation of this standard in research of disability in the elderly (Guralnik J and Ferrucci L 2009).

The Disablement Process

In the model proposed by Verbrugge and Jette (1994) the 'Disablement Process' (diagram shown in Figure 2.22 was drawn by Avlund 2003 based on the concept of Verbrugge and Jette 1994), identifies domains of measurable change in ageing.

Figure 2.22 From (Avlund K 2003 p316): The Disablement Process
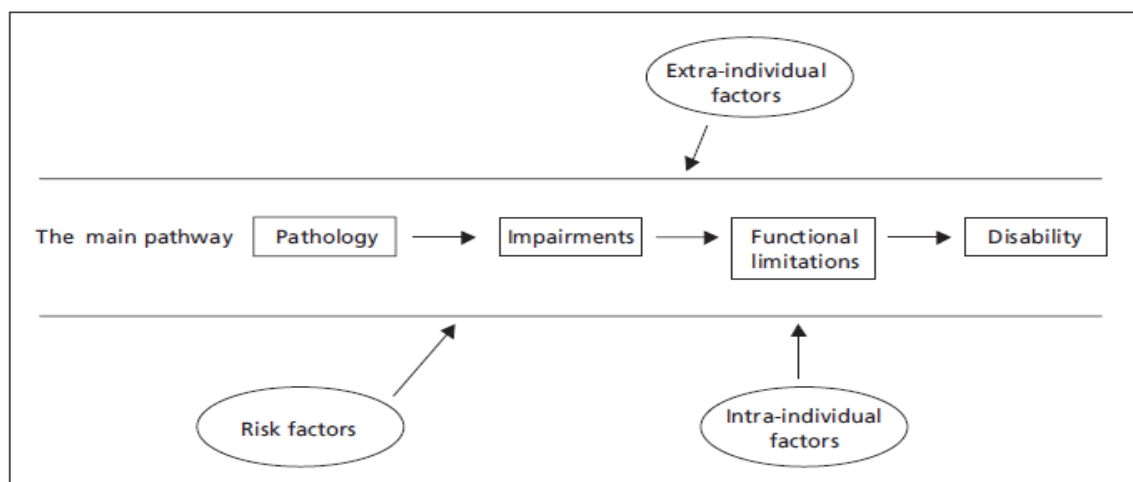
'Pathology' in this model, refers to physiological abnormalities that can be detected and measured or medically labelled such as a stroke. 'Impairments' are dysfunctions that can be evaluated using clinical examination, such as a

---

[9] (http://www.who.int/classifications/icf/en/ accessed 21/03/2012)

peak flow measure. 'Functional limitations' are restrictions on the person's ability to undertake basic daily physical and mental tasks matched to age group regardless of the context of the function. This contrasts to 'Disability' which measures a person's ability to undertake a specific task. Most common measures of this domain are activities of daily living (ADL) which are either physical – bathing, walking or eating for example; or instrumental activities that a person needs to be able to do to manage living in society – banking, catching a bus or taking medications. The strength of this seemingly simple concept is that the disablement process can turn into a series of feedback loops whereby someone with arthritis may stop walking, develop social isolation and spiral into increasing weakness and frailty (Verbrugge L and Jette A 1994).

'Successful' Ageing

Using a British dataset of community living participants, Bowling and Iliffe (Bowling A and Iliffe S 2006) tested five models of 'successful ageing' they had derived from the literature. They found that the lay based model predicted quality of life better than the other more one-dimensional measures (Figure 2.23).

Figure 2.23 Five Successful Ageing models from Bowling and Iliffe (2006, p609)

Box 1. Construction of models of successful ageing, based on the literature [22]
Biomedical model: Comprised summing of variables, recoded as 1 good/best versus 0 rest, number of diagnosed, chronic medical conditions (score: none), activities of daily living (ADL) (no/little difficulty score: <10), no psychiatric morbidity [General Health Questionnaire-12 (GHQ-12): 5+]
Broader biomedical model: Comprised summing of the above plus number of different social activities engaged in during past month (3+), as an index of social engagement
Social functioning model: Comprised summing of number of different social activities engaged in during past month (as above 3+), frequency of social contacts score (1–8), helped/supported in all 5 areas of life asked about
Psychological resources model: Comprised summing of self-efficacy score (best <11), best optimism score (<6), plus single GHQ items (3, 6, 8, 10, 11) on sense of purpose: playing useful part; coping: facing up to problems, overcoming difficulties; self-esteem: feels has self-confidence and has self-worth
Lay model: Comprised summing of the above (minus separate GHQ items as they were already included in GHQ score in biomedical models and singularity would be violated by their inclusion) plus gross annual income (>£7,280) and perceived social capital [rating of area facilities (e.g. transport, closeness to shops, services), area problems (e.g. crime, vandalism, graffiti, speed and volume of traffic, air quality), somewhere nice to go for a walk, feels safe walking alone during the day or night]

A later review Jeste (Jeste D, Depp C *et.al.* 2010) identified ten different domains of successful ageing in the quantified research literature the most common being disability/physical function, cognition and then life satisfaction

measures. These authors concede that there is no agreed definition of what comprises 'successful ageing'.

The compression of morbidity

The concept of 'compression of morbidity' has been contentious since its introduction by James Fries, Professor of Medicine at Stanford University in an article in the New England Journal of Medicine in (Fries J 1980). This theory has been contentious (Crimmins E and Beltran-Sanchez H 2010) despite supporting empirical evidence (Vita A, Terry R *et.al.* 1998).

Life expectancy, as introduced in the previous chapter, is high in Australia. However it must be remembered that as with population predictions, the determinant 'life expectancy' is hypothetical. Debate about these hypothetical trends uses the following arguments:

'compression of morbidity'=the argument that due to improvements, current and future, in health care that morbidity will be 'compressed' into an increasingly shorter period toward the end of life; or,

'expansion of morbidity'=whereby increasing years of life will be associated with increasing periods of morbidity; or,

'dynamic equilibrium'=is somewhere in between. While prevalence of disease (level of morbidity in the population) may increase due to increased survival, due to healthcare, the severity and impact of diseases is reduced (Crimmins E and Beltran-Sanchez H 2010; Australian Institute of Health and Welfare 2006).

An example of the use of this concept in predicting demand for health care services by an ageing population is described by Caley and Sidhu (Caley M and Sidhu K 2010) who demonstrated the effect of three different modelling approaches on estimating future costs. The most cost effective model relied on investment of the health system in preventative health measures to ensure a healthy population that live into old age with fewer illnesses – the 'compression of morbidity'. However, as Bruen postulates, the compression of

morbidity has been in place for heart disease, stroke and cancer for example, but there is no sign of delay in the onset of dementia (Bruen W 2005).

2.6.3   Indicators of ageing

As explained in the Methodology Chapter, the research for this thesis will emulate the methodology described by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2002; Lunney J, Lynn J *et.al.* 2003) to identify the same trajectories of decline in a nursing home population. Hence the measure that will be used to identify the trajectory is the Resident Classification Scale, a tool validated for this population with a high level of care need. This section will explore what is known about ageing and other options that could be used in a study of trajectories of ageing. Rather than the result of the failure of a specific body system or gene it is now believed that constitutes 'ageing' is an *extremely complex multifactorial process* (Weinert B and Timiras P 2003).

The literature that identifies factors that can be measured longitudinally (as trajectories) can be grouped into seven subheadings, domains or indicators of the ageing process. The following is a summary of this literature:

Physiological Indicators

Physiological indicators – characteristics of the disease process and consequences of multiple co-morbidities or frailty are a good measure of trajectory if no reversible causes are present (Stevenson J, Abernethy A *et.al.* 2004):

- Peak flow rate is a strong predictor of total mortality in the elderly, independent of smoking, respiratory disease, cardiovascular risk factors, socio-economic status, cognition, functional independence and self-assessed health (Cook N, Evans D *et.al.* 1991);
- Slow gait speed and physical inactivity are strong predictors for development of disability in the elderly (Vermeulen J, Neyens J *et.al.* 2011);
- A decline or significantly variation from baseline of the hormone DHEAS (dehydoepiandrosterone is a hormone proposed to be

associated with ageing) is highly predictive of mortality. DHEAS levels in individuals varies, but taken in series, that is as a trajectory, DHEAS levels provide a biological marker of the rate of ageing (Cappola A, O'Meara E *et.al.* 2009);

- Blood pressure declines in the years before death (Rogers M, Ward K *et.al.* 2011);

- Malnutrition in the elderly leads to a downward trajectory leading to poor health and decreased quality of life (Chen C, Schilling L *et.al.* 2001);

- Grip strength declines with age but plateaus in the oldest old (Frederiksen H, Hjelmborg J *et.al.* 2006).

Dementia and Cognition

- Studies of cognitive decline have identified trajectories that are either gradual and linear; or curvilinear and more accelerated – called the 'terminal drop' preceding death in the elderly. However, the observed rate of change in cognition is tempered by the presence or otherwise of other co-morbidities (MacDonald S, Hultsch D *et.al.* 2011; Aarsland D, Muniz G *et.al.* 2011);

- Motor decline (measured by gait speed) increases longitudinally with the development of other signs of dementia (Buracchio T, Dodge H *et.al.* 2010);

- MMSE scores are higher but decline faster in elderly with higher education levels compared with elderly with lower education levels (Castro-Costa E, Dewey M *et.al.* 2011);

- Decline and the rate of decline in Plasma β-amyloid levels is associated with cognitive decline particularly memory loss in dementia (Cosentino S, Stern Y *et.al.* 2010);

- The development of psychosis in Alzheimer's disease is more likely to occur in individuals with a rapid onset of cognitive deterioration compared with Alzheimer's sufferers who do not develop psychosis

suggesting that there are different trajectories for Alzheimer's disease (Emanuel J, Lopez O *et.al.* 2011);

- Cognitive decline is associated with a loss of hippocampal activation over time (O'Brien J, O'Keefe K *et.al.* 2010);

- Cognitive and motor function decline parallels the trajectory of neuropathological changes in AD (Almkvist O and Bäckman L 1993);

- Test scores for memory and speed worsen with age and the decline is hastened by poor health, lower activity and blood pressure. However variability in test scores also increase with age suggesting that the processes involved with cognitive ageing are complex (Christensen H, Mackinnon A *et.al.* 2001);

- In non-demented elderly, poorer scores in cognitive domains predicted sharp functional decline followed by death (Dodge H, Du Y *et.al.* 2006);

- Cognitive decline is associated with decline in hand grip strength (Taekema D, Ling C *et.al.* 2012).

Other disease

- Cognitive decline, not attributable to the ageing process, is significantly associated with cardiac surgery not heart failure in vascular dementia (Okonkwo O, Cohen R *et.al.* 2010).

Psycho-social

- Quality of life worsens in the last 3 months of life before death in cancer patients (Geisinger J, Wintner L *et.al.* 2011);

- Self-esteem declines with ageing (from 60 years), associated with socio-economic status and physical health (Orth U, Trzesniewski K *et.al.* 2010);

- Self-reported health status is a predictor of mortality (Leinonen R, Heikkinen E *et.al.* 2001);

- Preferences for life prolonging therapy in elderly with advanced illness have an inconsistent trajectory, influenced by transient factors rather than stable core values (Fried T, O'Leary J *et.al.* 2007);

- Mild-moderate drinking of alcohol compared to non-drinking was associated with less cognitive decline in the elderly (Ganguli M, Vander Bilt J *et.al.* 2005);

- Association of loss of social networks and cognitive decline (Giles L, Anstey K *et.al.* 2012).

Physical function (ADLS and IADLs)

- Decline in physical activity is associated with increasing functional limitations and self-efficacy (McAuley E, Hall K *et.al.* 2009);

- Age *per se* is not closely correlated with dysfunction (Bortz W 1990).

- Pain increases physical impairment and reduces physical performance over time (Bryant L, Grigsby J *et.al.* 2007);

- Functional impairment in the last year of life for frail elderly is slowly progressive, with a slight acceleration in functional loss prior to death (Covinsky K, Eng C *et.al.* 2003);

- Socio-demographic and chronic conditions predict functional limitation over time (Deeg D 2005).

Policy and health Services

- Integration of palliative care services into the end-of –life trajectory of patients with chronic disease reduced acute care service use and increased satisfaction with care (Brumley R, Enguidanos S *et.al.* 2003).

Carers, family and health professionals

- Physical decline in community living elderly is associated with an increase in informal care supporter, conversely cognitive decline is associated with a net loss of informal care support (Aartsen M, van Tilburg T *et.al.* 2004);

- Caregivers experience trajectories of grief and depression following the death of the cared for patient with AD (Aneshensel C, Botticello A *et.al.* 2004);

- Family members have a poor understanding of the trajectory of disease which made decision making regarding their loved one's care at the end-of-life more painful (Forbes S, Bern-Klug M *et.al.* 2000).

When reviewing the literature relevant to the concept of a 'trajectory' literature it became clear that there is a difference between cross-sectional and longitudinal studies that measured the outcome more than once. That is, with more than two measures, a trajectory could be identified. The studies included in the preceding précis of the available literature have identified changes related to the domains of ageing that could be used in a study of trajectory in an elderly population. This section has been exploratory only. None of the measures identified here will be used specifically in this thesis research. However, there inclusion in the literature review has provided a broader view of potential measures of ageing for trajectory research as well as the strengths and limitations of the method chosen for this research.

2.6.4   What measures are available to identify the trajectories of decline in a nursing home population

In the course of reviewing the literature for this section, it became apparent that 58% of research in this area was undertaken in the USA; followed by the UK (7%); Canada (6%); Australia and The Netherlands (both 5%). Some of the other countries included Sweden, Bangladesh, China, Denmark, Ireland, and Israel at less than 2% of the total (Lawrence S, Robinson A *et.al.* 2008). When considering the evidence available to policy makers in Australia, the chances are that the literature they access will be from another country and publications do not always clarify where the research is sited which is a limitation in studies of ageing (Schram M, Frijters D *et.al.* 2008).

If aged care was purely based on need then every country with a similar population profile would have the same policies and care provision. But caution is needed when comparing literature written in the context of another

country's health system because there are differences (Dixon A, Mossialos E
et.al. 2002).

*The United States is the only industrialized nation without universal health
insurance, and coverage has deteriorated in the past six years. The US spends
twice as much on health care as the median industrialized nation but does not
systematically achieve the best quality care.*

Karen Davis President of the Commonwealth Fund, NY (Davis K 2007)

One of the biggest differences in the health system of the US and Australia is
noted in the statement above. The USA does not have a universal health system
nor is health provision homogenous across the states or comparable across the
states. In Australia, despite there are regional differences most significantly
related to rurality (Australian Institute of Health and Welfare 2010) there is a
degree of homogeneity due to the single funder system supplemented with
optional private health insurance[10]. Medicare in the USA is a Federal program
that covers people aged 65 and older as well as those who have been disabled
for over two years. Medicaid is the responsibility of the States and varies from
state to state as to who is covered and to what extent (Ahronheim J, Mulvihill
M *et.al.* 2001; Davis 2007).

In the late 1990s, papers comparing aged care across nations were quite
popular largely due to the introduction of the Resident Assessment
Instrument/Minimum Data Set (RAI/MDS) in a number of countries including
the USA, Japan and parts of Europe. Because the RAI/MDS is being used in
other countries, cross-national comparisons of nursing home residents are
possible. Research undertaken in Denmark, Italy, Japan, Sweden, Iceland,

---

[10] Figures from the ABS 2007-08 National Health Survey indicate that over half (53%) of the
population aged 15 years and over have private health insurance. Those in the age groups 15-
24 years, 25-34 years and 75 years and over had the lowest rates of private health insurance
(46%, 45% and 45% respectively). (Australian Bureau of Statistics 4102.0 - Australian Social
Trends, Mar 2011)

France, USA found significant differences in age, length of stay, physical and cognitive function suggesting that the term 'nursing home' does not provide a sound basis for cross-national comparisons, and should be replaced with resident-specific descriptors (Fries B, Schroll M *et.al.* 1997). Using the RAI/MDS a number of differences were found across nations:

- Iceland has the highest proportion of low-care need residents in NH (52%) and the USA the lowest (30%). However the authors note that care homes in some countries included domiciliary services as well as post-acute care services for the elderly (Ikegami N, Morris J *et.al.* 1997);

- True reporting of restraint use in the RAI/MDS biased due to laws prohibiting use in some countries;

- While urinary incontinence has a high prevalence in all countries, there are cultural differences in the treatment strategies reported.

Cross national comparisons using a standardised tool is useful but that it is 'local policy and practice' that determines who is in nursing homes and the quality of care vs. population and clinical profiles (Carpenter G, Hirdes J *et.al.* 1999). Other problems in comparison studies arise because the RAI/MDS is mandated for use only in nursing homes funded by Medicaid or Medicare, and in other countries, only some of the measures are used regularly or only in research studies (Chi I 2004). Because of the regulatory requirements for nursing homes in Australia since 1997, all residents are assessed at least once a year with the Resident Classification Scale since replaced by the Aged Care Funding Instrument in March 2008. Hence the RCS (and ACFI) is available for analysis of the trajectory of decline across the entire Australian nursing home population.

2.7   Chapter Summary

Health care services are planned around observed and/or projected need (United Nations: World Population Ageing 2009) with an increasing focus on consumer driven care (Reuben D 2012). In the Introduction the current system

of paying for aged care in Australia was described as being set to undergo a significant change. To meet the demands of the National Health Reform, informed by the Productivity Commission Report, innovative tools such as NITACC, will need to be developed to ensure the needs of the user/s are met by the system. Without the existence of the Productivity Commission Report, driven by the National Health Reform Agenda, this research would be interesting but unlikely to make its way into evidence informed aged care policy.

In this thesis, the 'trajectory of decline' concept will be explored as a way of predicting the care needs of residents of nursing homes. The literature supporting this concept claims this happy possibility. For care providers to be able to predict resource demand in their facility; policy makers could prepare budgets based on evidence; and the community/politicians could be reassured that our vulnerable elders were being cared for appropriately. However, as the Literature Chapter has shown, the policies in place now that use this concept are, in effect, telling the care providers that this is the way to predict care needs yet there is no evidence that these trajectories exist in the nursing home population or how to actually identify when someone is on such a trajectory.

Chapter 3 Methodological Approach

3.0   Introduction

The question to be answered by this research is how the trajectory of decline, as described in the literature, can be identified in the resource intensive, aging population resident in nursing homes in Australia. To date there are two studies that provide empirical evidence supporting the existence of multiple trajectories of decline in US community living elders. To what extent these same trajectories exist in Australia is unknown. Moreover it is not known whether these trajectories exist in residential aged care. This research aims to answer these questions.

The purpose of this Chapter is to document the method used to answer these research questions. Each step of the study design was informed by the literature, or advised upon by senior academics and the participating nursing home staff. The theory of these trajectories has been reviewed in the preceding Chapter. However, any *a priori* evidence of the existence of the trajectories of decline, and how that evidence was gathered will be critically examined for applicability to the research questions.

3.1   Research questions

1. Can a trajectory of decline be identified in the functional profiles of a residential aged care population?

2. How does the trajectory or trajectories of decline identified in the Australian nursing home context compare to the trajectories of decline identified by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2002) and (Lunney J, Lynn J *et.al.* 2003) in US community living elders?

3. Are there multiple diagnostic groups as identified by Lunney and colleagues in US community living elders amongst a residential aged care population or are they all identified as 'frailty'?

3.2   Aims and rationale for the research

1. To develop a methodology that enables tracking of the resident functional trajectory in residential aged care settings using routine data;

2. To explore the degree to which a population of elderly people resident in residential aged care fits within the multiple trajectory functional profiles as found by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2002) and (Lunney J, Lynn J *et.al.* 2003); and

3. To examine the extent to which the trajectory of decline can prospectively predict care needs in an elderly population.

Research undertaken by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2002; Lunney J, Lynn J *et.al.* 2003) shows that multiple trajectories of decline exist in an elderly community population in the USA studied retrospectively. However no work has been done to determine to what extent these results can be generalisable elsewhere or used to plan care prospectively. Despite a lack of evidence these results have been generalised to other populations, in particular residents of nursing homes. The purpose of this research is to determine to what extent the multiple population cohorts exist in a nursing home population in Australia and whether it is possible to prospectively determine an individual's trajectory. If the rate of functional decline can be predicted, as suggested by the trajectory authors, then this concept is a potentially powerful tool for resource planning for the care provider as well as the policy maker at the state and national levels in the uncertain aged care future.

3.3   Developing the method

The methods employed in this study adapt the approach described by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2002) and (Lunney J, Lynn J *et.al.* 2003) and have the following defining characteristics:

1. A quantitative methodology with statistical analysis appropriate for the data.

2. A retrospective data collection of deceased resident records (including information from resident documentation) from nursing homes in southern Tasmania.

3. A sample size that will answer the research questions and aims that will provide generalisable results.

3.3.1   Where the research was undertaken

Conducting research in the nursing home environment is difficult due to the nature of the subjects themselves (Hall S, Longhurst S *et.al.* 2009) and the ethical challenge of gaining informed consent from older people (Harris R, 2001; Hall S, Longhurst S *et.al.* 2009). For this research consent was not obtained from each subject because they were deceased and the records are the legal responsibility of the facility. All requirements for data confidentiality remain the same as if the resident was alive, and the research was conducted under the direction of, and reported annually to, the Tasmania Social Sciences Human Research Ethics Committee (Ethics Ref No:H0009067).

The data for this research was collected from the records of deceased residents of four NHs who consented to the researcher accessing the records, collecting and then de-identifying the data before analysis. The research method was developed in collaboration with the senior management of the participating facilities in an open and transparent manner. Prior to the consent, the researcher met with the CEO of each facility to directly explain the research, the requirements on the research by the Tasmania Social Sciences Human Research Ethics Committee (Ethics Ref No:H0009067) , and to answer any questions. As well, the researcher presented information on the research project to staff meetings before entering the NH to collect data. Each of the NHs approached consented to participate.

3.3.2   Review of existing methodologies to identify trajectories of decline in an elderly population

As discussed in the Introduction, the qualitative researchers Glaser and Strauss (1968) introduced the concept of dying as a temporal process that can be predicted by the health professional. However, graphical representations of the trajectory concept do not appear in the literature until 1988 with the graphs drawn in the Corbin monograph (Corbin J and Strauss A 1988) which provide hypothetical representations of the "work" required to manage illness over time. Up until 2001 there is only limited reference to this concept in the published literature when Joanne Lynn presented a set of graphs to illustrate her argument that the trajectory to death was different depending on the person's underlying diagnosis. As stated previously, these graphs were reproduced in a number of subsequent papers and policy documents but it was not until 2002 that June Lunney, working with Lynn and colleagues, published two papers with any empirical evidence for the existence of these trajectories.

As outlined in the previous chapter, there are two research papers that provide empirical evidence of the existence of the three trajectory profiles as proposed by Joanne Lynn (Lynn 2001). The first paper groups a population of community living, elderly Americans sampled from a Medicare dataset into the five trajectories using Medicare claims data to determine the underlying diagnosis (Lunney J, Lynn J *et.al.* 2002). The second paper uses a subset of a the Established Populations for Epidemiological Studies of the Elderly (EPESE) that follows and measures the functional ability of elderly Americans with their diagnosis determined from death certificate data. The subjects who died whilst in the EPESE study became subject to the study by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2003). These two papers form the starting point for the development of the method used in this PhD research.

3.3.3   "Profiles of Older Medicare Decedents"

June Lunney, Joanne Lynn and Christopher Hogan (Journal of the American Geriatrics Society, 2002)

Data for the study by Lunney and colleagues (2002) came from a randomly selected 0.1% sample of Medicare (USA) claims over five years. Cost data for the last year of life was collected from 7,258 subjects over 65 years old who had died during this period. Cause of death was determined from the physician diagnosis code for each billing item. This methodology for determining cause of death had been validated against death certificate data in a previous study (Hogan W 1997).

Lunney and colleagues tested a four trajectory model. Subjects are to be identified as having one of four diagnostic definitions and were classified accordingly:

Group 1= 'sudden' death comprising subjects who were younger than 80 and had less than $2,000 in total Medicare reimbursements;

Group2 = a plurality of physician claims noting a diagnosis of cancer;

Group 3 = were the organ system failure group with an in hospital claim or inpatient claim for congestive organ failure or chronic obstructive pulmonary disease;

Group 4 = labeled as 'frailty', had at least one Medicare claim in the last year of life associated with a diagnosis of stroke, Alzheimer's Disease, dementia, acute delirium, Parkinson's Disease, hip fracture, incontinence, pneumonia, dehydration, syncope, or leg cellulitis. The frailty grouping uses methodology from a previous study by (Haan M, Selby J *et.al.* 1997);

Group 5= remaining decedents that had not been classified into the preceding four groups were grouped as 'other'. In this paper, the 'other' group was predominantly subjects with heart disease identified as the cause of death.

The resulting groups differed in the measured demographic characteristics of age, sex, race, care delivery (hospice, hospital or nursing home), and Medicare expenditure.

3.3.4   "Patterns of Functional Decline at the End of Life"

June Lunney, Joanne Lynn, Daniel Foley, Steven Lipson and Jack Guralnik (Journal of the American Medical Association, 2003)

The 4,190 subjects for this (2003) study were the deceased cohort of the EPESE study of 14,456 community living, 65 years and older persons recruited over six years from 1981. The subjects were interviewed at baseline and had had a follow-up interview in the 12 months preceding their death. The study collected demographic information followed by, interview (either face to face or phone), in which the subject or proxy was asked if the subject needed help or if they were unable to perform seven measures of (Activities of Daily Living) ADL dependency: walking across a small room, bathing, grooming, dressing, eating, transfers, and using the toilet. Other questions on physical function included ability to walk a half mile, stair climbing or to do heavy housework. Subjects were also questioned on changes to health such as diagnoses changes, hospitalisations, and nursing home stay. The subject data were grouped according to the months between the interview and their death. Function was then derived from the mean number of ADL dependencies for each monthly cohort (Figure 2.17 on page 90).

 The subjects were grouped into four categories, corresponding to the theoretical 'trajectories of decline', based on information from the death certificate as well as information given in the interview. Any decedent with a diagnosis of cancer as the immediate or underlying cause of death was placed into the cancer group. The next grouping included decedents with any diagnosis in any field on the death certificate of congestive heart failure or chronic lung disease. The frailty group comprised those decedents remaining unclassified by cancer, heart or lung failure but who had reported a nursing home stay during any follow-up interview. The sudden death group had no

cancer, heart or lung failure diagnosis and no nursing home stay. Any remaining, unclassified subjects comprised the 'other' group.

After grouping the subjects, analysis of variance (with a Bonferroni correction) was undertaken to describe the demographic characteristics of the groups. A logistic regression model was developed to examine the relationship between group membership and the degree of functional decline before death, adjusting for the effects of age, sex, race, marital status and the time period between the measure of function (interview) and death.

All groups demonstrated a mean decline in function in the year before death. The frailty group had the greatest rate of decline and the highest levels of functional dependency, then in deceasing order the cancer group, the organ failure group and the sudden group had the least change.

3.4   Data required to answer the research question

To replicate the original studies by Lunney (Lunney J, Lynn J *et.al.* 2002) and (Lunney J, Lynn J *et.al.* 2003) in an Australian NH population, it is necessary to identify the two critical measures:

(1) the cause of death to determine group membership; and,

(2) a measure of function in a nursing home population.

3.4.1   Cause of death data

To determine the group into which a subject is to be placed for further analysis, Lunney *et.al.* used the physician diagnosis from Medicare claims (Lunney J, Lynn J *et.al.* 2002) or information from the Death Certificate (Lunney J, Lynn J *et.al.* 2003). Access to Medicare (Australia) claim data were not feasible for this study and Death Certificate information for the participants following consent, is relatively available for research.

In Australia, as well as in the USA, Cause of Death data come from the Death Certificate written by a medical practitioner after the death. In Australia a body cannot be buried or cremated without this certificate. If a certificate cannot be issued by the doctor, or there is some other reason to query the death, then the body is subject to a coronial examination (Bird S 2011) which will delay state registry data entry for that person.

'Cause of Death' (CoD) data are compiled by the Australian Bureau of Statistics (ABS) from what is written on Cause of Death Certificates, collected and transcribed electronically by each State and Territory Registrar of Births, Deaths and Marriages (BDM). How these data are acquired and dealt with statistically by the ABS is summarised by the following diagram:

Figure 3.1: How cause of death information is collated by the Australian Bureau of Statistics
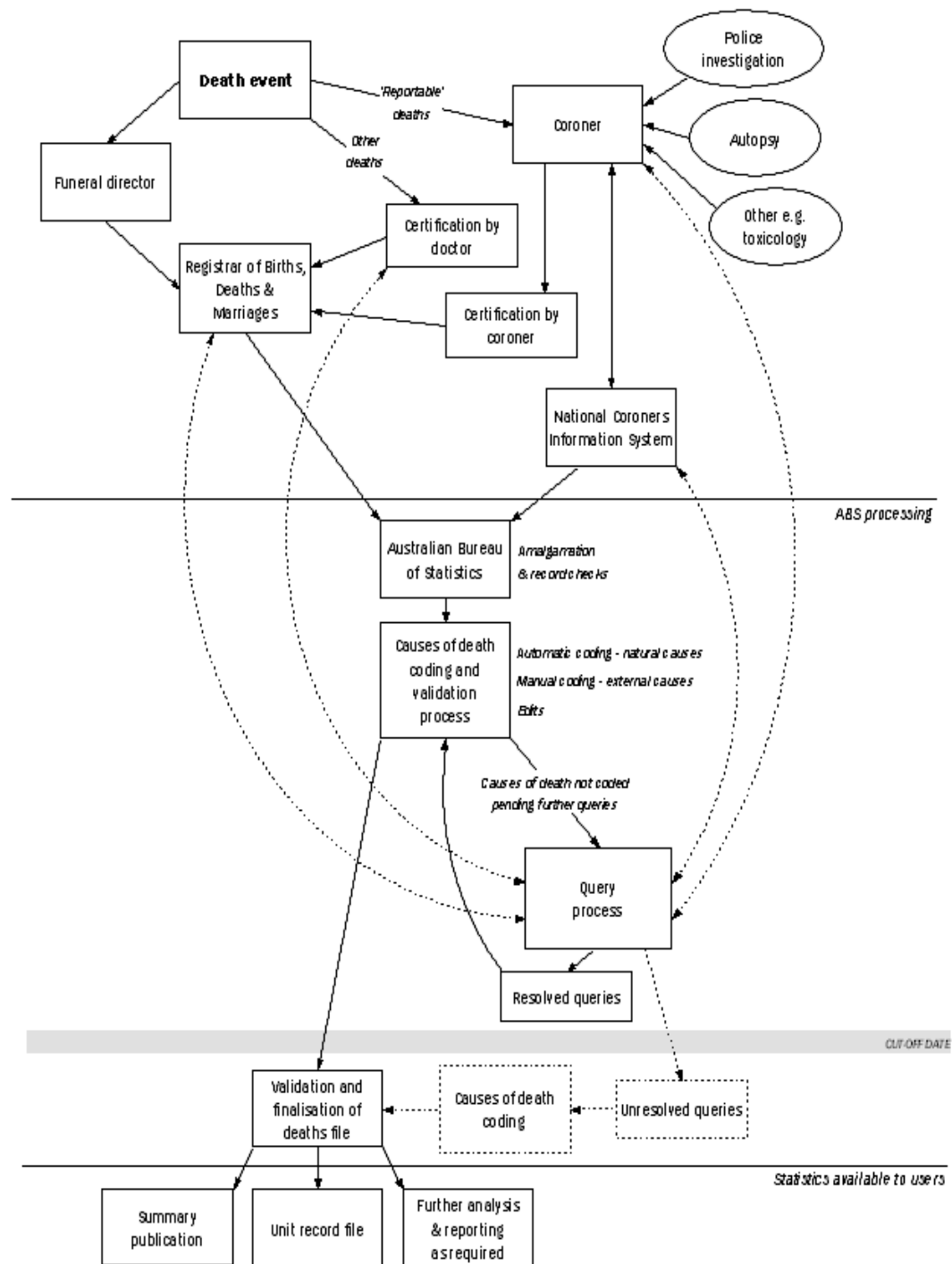
3317.0.55.002 - Information Paper: ABS Causes of Death Statistics: Concepts, Sources and Methods,2006 http://www.abs.gov.au/ausstats/ABS@.nsf/Latestproducts/3317.0.55.002Main%20Features12006?opendocument&tabname=Summary&prodno=3317.0.55.002&iss

Researchers, such as those based in the AIHW, can acquire these data from the ABS, or directly from the individual State or Territory. CoD data is used on a population level to plan public health policy and health resource allocation; at a health service level for quality assurance; at the individual level (Mathers C, MaFat D *et.al.* 2005; Byass P 2007) and it is a legal document (Bird 2011).

Identifying the subjects

In initial discussions with NH management, it was expected that a copy of the Death Certificate would be located in the deceased resident record. However this was not found to be the case and permission (consent) was sought to obtain the data from the Tasmanian Registrar of Births, Deaths and Marriages (BDM). A data matching process using the subject's name, date of birth and date of death enabled the Registrar to match the subjects to the Tasmanian database. The selected data (Table 3.4) were downloaded to an electronic database for the researcher to use. There was a fee to obtain these data. A copy of the Australian Death Certificate is shown in Appendix 1.

Table 3.4 Data items from the Death Certificate

Data name	*Comment*
First name Last name Date of birth Date of death	These data were identified from the deceased resident record then used to data match with the BDM database
Immediate Cause Of Death	The disease or complication which led directly to death. This may be the only condition reported if it did not arise as a consequence of any disease or injury. For example if cardiac arrest is entered here then an underlying cause should also be reported.
Approximate interval between onset and death	If an exact date is not known then an estimate is made. The duration of each condition should not exceed the subsequent entries.
Conditions Leading to Immediate Cause	The certifying doctor considers whether any significant conditions led to the cause of death condition
Other Contributing Conditions	The certifying doctor considers whether any significant conditions led to the contributing cause of death condition
Accidental deaths	The circumstances of the injury should be stated here, for example, fell at home, and how it relates to the cause of death

Based on Bird 2011 "How to complete a death certificate. A guide for GPs" RACGP and ABS 1999

3.4.2   Other diagnoses

Using the cause of death as the method for determining membership of a particular trajectory limits the utility of this concept to retrospective discussion. In order to bring this concept into a useful process for planning care, membership of one of the five trajectories has to be determined prospectively, that is, before the person is dead.

There are two consistent points on the elderly person's journey into residential aged care where a health assessment is made. In Australia, the level of care required is assessed by the Aged Care Assessment Team (ACAT[11]). The standard form used is the Aged Care Client Record (ACCR). The ACCR is the form used to maintain a record of an ACAT client's assessment and approval for submission to Medicare Australia as required by the Aged Care Act 1997. The client is required to consent to this assessment and a copy of the assessment and approval is retained by the client. When the client applies for admission to a nursing home they are required to provide this form to the home. One of the items on this form is the 'diagnosed disease/disorders at assessment' section with five spaces for individual diagnoses. This information is obtained from the medical practitioner – either the client's community GP or hospital doctor[12].

The second point at which the person's health condition is routinely recorded is at admission to the NH. This is a medical admission, done by the resident's General Practitioner (GP). During the course of data collection, it became

---

[11] Eligibility for aged care services funded by the Australian Government is determined by the Aged care Assessment Team that are a quasi-autonomous organization funded by the AG located in population centres across Australia. The assessment teams comprise nurses, occasionally doctors, and allied health professionals.

12 DoHA Aged Care Assessment Guidelines (2006)

http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-acat-acapaag.htm~ageing-acat-acapaag03.htm

apparent that there are limitations to these data. Where the nursing home routinely provided a form for the admitting doctor to complete this was only rarely used. The most frequent admission was handwritten in the medical notes or in the form of a letter from the consulting rooms where the resident previously attended summarising their medical history. There were other points at which the resident had a medical diagnosis recorded in the resident record, for example the hospital discharge letter, but these were not routinely available for all subjects. The level of agreement between the ACAT and medical diagnoses made with the resident was alive and their cause of death was analysed with a Kappa statistic (Section 4.7).

3.4.3   The measure of function used in an Australian NH population

As stated in the Literature Review, a RCS (Resident Classification Scale) has been done on every permanent resident in an Approved Provider facility in Australia since 1997 up to March 2008 when the RCS was replaced by the ACFI (Aged Care Funding Instrument). Hence the ACFI was not available for all cases from admission. There is a high inter- and intra-rater reliability for the RCS and strong agreement between the RCS and Barthel Index (Stepien J, White H *et.al.* 2006). Furthermore, the RCS is a measure that has been validated in this population which is an appropriate methodological approach (Hoppitt T, Sackley C *et.al.* 2009).

The RCS consists of 20 questions, each having a choice of four ratings based on the assessed care needs of the resident (Table 3.5 below) and each question has a weighted response calculated from the amount of staff time required for that level of care (Australian Government Department of Health and Ageing 2006). For example, for the item 'Toileting', the lowest numerical score '0' is for someone who is able to use any type of toilet and is independent; whereas the highest score '13.70' applies to the resident who requires staff to carry out all activities – adjusting clothing, positioning the resident to the receptacle or emptying bag or changing pads, and wiping. A full list of the care responding

to the score for each question is in The Resident Care Manual[13] (Australian
Government Department of Health and Ageing 2005).

Table 3.5 The RCS ratings for each area of assessed need (Question):

Question	Response Weighting			
	A	B	C	D
1. Communication	0.00	0.28	0.36	0.83
2. Mobility	0.00	1.19	1.54	1.82
3. Meals and Drinks	0.00	0.67	0.75	2.65
4. Personal Hygiene	0.00	5.34	14.17	14.61
5. Toileting	0.00	5.98	10.65	13.70
6. Bladder Management	0.00	2.22	3.82	4.19
7. Bowel Management	0.00	3.32	5.72	6.30
8. Understanding and Undertaking Living Activities	0.00	0.79	1.11	3.40
9. Problem Wandering or Intrusive Behaviour	0.00	0.80	1.58	4.00
10. Verbally Disruptive or Noisy	0.00	1.19	1.75	4.60

Question	Response Weighting			
	A	B	C	D
11. Physically Aggressive	0.00	2.34	2.69	3.05
12. Emotional Dependence	0.00	0.28	1.50	3.84
13. Danger to Self or Others	0.00	1.11	1.54	1.98
14. Other Behaviour	0.00	0.91	1.82	2.61
15. Social and Human Needs — Resident	0.00	0.95	1.98	3.01
16. Social and Human Needs — Families and Friends	0.00	0.28	0.55	0.91
17. Medication	0.00	0.79	8.55	11.40
18. Technical and Complex Nursing Procedures	0.00	1.54	5.54	11.16
19. Therapy	0.00	3.64	6.10	7.01
20. Other Services	0.00	0.71	1.46	2.93

Residential Care Manual 2005

The lowest total RCS score possible is zero if the resident was assessed as
having no care needs in any of the questions shown in Table 3.5. The
maximum total RCS score is 100 for the resident who has extensive care needs.
To replicate the 'trajectories of decline' both the X- and Y-axes were reversed

---

[13] This publication is no longer on the Department website since replacement of the RCS with
the ACFI in the current version. A PDF of the Manual is available by emailing Prof Robinson
at andrew.robinson@utas.edu.au

to show a decline in function (from 0 – 100) over the time of their admission to the NH to death (time=0).

For each deceased resident (N=250) their RCS score was calculated as the sum of each RCS question (minimum score=0, maximum score =100) for every RCS assessment undertaken over the entire admission to the NH which resulted in a total of 900 RCS scores for analysis. The individual scores for each question were also recorded in the research dataset for further analysis.

Data collection issues

- The RCS was relatively easy to locate in the resident file because of its distinctive green colour.
- The date of the assessment was within a 12 month period from the initial assessment done within three months of the resident's admission to the NH.

3.4.4   Retrospective vs prospective method?

The first paper by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2002) describes a retrospective method where data were collected after the subject had died. The second study used a prospective method where a population was followed over six years and those that died comprised the analysis but the grouping and analysis was done retrospectively. That is, the subjects were not assigned a trajectory of function group before their death.

To answer the research question '**can a trajectory of decline be identified in the functional profiles of a residential aged care population?'** replicating the methodology described by Lunney 2002, the first step is to determine whether the population can be grouped into the five trajectory groups identified by their cause of death. This requires a cause of death to be determined for each subject. In discussion with the management of the NHs, it became apparent that due to the size of the facilities, the actual number of deaths per year was not likely to provide a sufficient sample size within the time constraints of the PhD candidature. It seemed unlikely (and a risk) that a

satisfactory empirical answer could be achieved. The second issue to be considered in doing a prospective study was that of gaining consent from each elderly subject. Furthermore, as Teno and Mor comment (Teno J and Mor V 2005), *respondent burden* is an important consideration in research at the end of life.

The concern with doing a retrospective study is that the measurement tool, to identify functional change, may be less than ideal. However, given the existence of the RCS, the decision was made to trial a retrospective method based on the RCS. Using a phased approach enabled the flexibility to use an alternative measure of function if the RCS did not prove to be sensitive enough to identify the functional profile of the subject.

3.5   Overview of the research method

A phased approach was adopted to gradually develop the quantitative research method with predetermined analysis points that would inform the next Phase and determine if the research question was worth pursuing. After collecting an adequate sample size, the analysis phase also required trial and testing of alternative models for statistical outcomes.

3.5.1   Phase 1: review of 4 records from each of the 4 NH (n=16)

The first step in this study was to identify the availability of the RCS assessment, ACAT assessment, medical admission and Death Certificate in the deceased resident record. Once the resident had died, their file is stored by the facility for 7 years after death (per statutory requirement). All data was obtained from these stored files. That is, at no time was the file of a living resident examined.

3.5.2   Phase 2: Pilot study to determine measurement tool/s and sample size (n=50)

From the initial review of the deceased resident record, as expected, the most easily identified documents that were also common to each NH were the Aged

Care Client Record (ACCR) and Resident Classification Scale (RCS). Both documents are part of the national funding instrument under which all Australian NH operate. Both documents are also coloured which make them easier to find in a large file.

A data dictionary (Appendix 2) was developed and trialled in this pilot study. The purpose of a data dictionary was to ensure that over the course of the data collection period and between the four participating NHs, the data were collected and entered into the database in a consistent manner. The data dictionary included the codes used to create the patient and facility identification as well as codes for categorical data items such as 'male=1' or 'female=2' and so on. Data were collected from each resident record based on this data dictionary and directly entered into a Microsoft Excel spreadsheet. A trial analysis (ANOVA) of a subset (n=20) of this pilot set (classified by diagnostic group) demonstrated that the RCS would provide a measure of functional decline in this NH population.

A sample size analysis was also conducted using the data (n=50) from this phase. Between the end of Phase 2 and the commencement of the data collection for Phase 3, a total of 40 of the records used in this Phase were archived by the facilities into long term storage and were not able to be accessed for Phase 3 data collection.

3.5.3   Sample size analysis

Prior to the final data collection of Phase 3, a power analysis was undertaken in order to determine the sample size necessary to attain the desired statistical power for a significance level of $\alpha= 0.05$. In this study, the means of the four different trajectory groups classified by the cause of death were analysed for variance (ANOVA). Using the sample size table developed by (Cohen J 1992), for four groups, each group would need to have 45 subjects to have a medium effect at Power=0.80 for $\alpha= 0.05$. However, from the research done by Lunney (Lunney *et.al.* 2002), it was apparent that the proportion between groups would not be equal. Thus a sample size of around 250-300 would give at least 45 in

each of the four groups. However,as reported in the Results Section 4.7, as more subjects were recruited it was found that more were entered into the Frailty group and sampling was ceased at 250 subjects.

3.5.4   Phase 3: Data collection (N=250-300)

The final phase of the research was to collect sufficient data to provide a statistically significant result where $p<0.05$. Results of this analysis are described in the next chapter. Of the 250 records reviewed, three records were excluded (Section 3.6.1). The total number of deceased resident records included in the final analysis is n=247. For these subjects over their admission to the NH a total of 900 RCS scores were available for analysis.

3.5.5   Phase 4: Developing a statistical model

Analysis of the data start with simple descriptive statistics of the subjects as a whole, grouped by their NH, then by membership of each diagnostic group using the classification method used by Lunney (Lunney J, Lynn J *et.al.* 2002 and 2003). The next step was to determine if there was any difference in the means between each group. As the dataset became larger and a significant trend began to emerge, more complex statistical analyses (linear mixed models) were employed to address the lack of independence of the longitudinal data, determine the rate of change in function as well as the level of function at death for each group. This expanded approach meant that results could also be compared between groups.

3.5.6   Phase 5: Developing a statistical model

The key question is not whether these trajectories can be identified in four nursing homes in Tasmania, but whether the trajectories can be identified in an Australian nursing home population. Hence the last phase of this research compares the data obtained and analysed from the four nursing homes in southern Tasmania with State and National data routinely reported by the AIHW.

3.6   Application of the sequential classification method using death certificate data

3.6.1   Exclusions

All deceased resident records made available for review at each of the NH were included in the research unless:

1. The resident was less than 65 years old on admission;

2. There was no RCS in the file;

3. The resident had been discharged to another NH or home;

4. The death certificate was not available at the time of data collection.

Less than 65 year old residents of the participating NHs were excluded on the basis that they had been excluded from previous studies. The trajectory of functional decline could not be mapped without a RCS, and if the subject were still alive or did not have a cause of death, then the trajectory classification could not be determined.

3.6.2   Trajectory group classification

All subjects were classified using the flow chart shown in Figure 3.2. Unlike the community cohort described by Lunney, all subjects in this study had had an interaction with the health system in their last 12 months of life. Hence there were no subjects classified as 'sudden' (Group1). The sequential method described by Lunney first extracted subjects with cancer (Group 2) mentioned in any field on the death certificate. The next classification group is heart or lung failure (Group 3). However, when the Immediate Cause of Death was the generic 'respiratory failure' this required a qualification of, for example COPD, to place the subject into this group. The frailty group (Group 4) included the diagnoses of death associated with stroke, Alzheimer's disease, dementia; acute delirium, fractured hip, Parkinson's disease, incontinence, pneumonia, dehydration, syncope, septicaemia, or leg cellulitis (Lunney *et.al.* 2002). The fifth group 'other' (Group 5) is the 'catch basket' for any ungrouped subjects who did not have any of the required diagnoses in any of the death certificate fields. A small number of subjects in this study did not have a death certificate

issued at the time of data collection. While they were excluded from the final analysis, they were initially placed in a sixth group.

Figure 3.2 Trajectory group classification flowchart using cause of death data

1=SUDDEN GROUP

> No subjects classified as 'sudden'. All residents had a doctor visit in the previous year. In order to have had a death certificate and not an autopsy, the person had to have been a patient of the signing doctor/practice.

2=CANCER GROUP

> Death from cancer as immediate, condition leading, or contributing to the cause of death

3=HEART or LUNG FAILURE GROUP

> Death from heart and/lung failure as immediate, condition leading, or contributing to the cause of death. Exclude the phrase 'respiratory failure' without contributing cause for example COPD.

4=FRAILTYGROUP

> Death associated with stroke, Alzheimer's disease, dementia; acute delirium, fractured hip, Parkinson's disease, incontinence, pneumonia, dehydration, syncope, septicaemia, or leg cellulitis.

5='OTHER' GROUP

> Condition leading to immediate CoD of the remaining decedents are then reviewed and these are reclassified using the other contributing causes. The subjects that cannot be classified into the above groups constitutes the 'other' group.

6=No death certificate/coroners case

> Decedents with no CoD data either because the data is missing or because the certificate has yet to be issued by the coroner.

For analysis, each subject was categorised into their diagnostic group using the cause of death data collected from their Death Certificate. This data were obtained and then collated from the Tasmanian Registrar of Births, Deaths and Marriages (BDM) database. The data from this database were directly transcribed from the Death Certificate which is hand written by a medical practitioner. The format of these data are defined by the format of the Death Certificate itself (Appendix 1).

Figure 3.3 is an extract from the data obtained from BDM. Based on the classification method described by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2002) and (Lunney J, Lynn J *et.al.* 2003), the 'Immediate Cause of Death' was reviewed and the subject grouped. Then the 'Condition Leading to the Cause of Death' was reviewed to check for any clarity to, for example, an initial classification Group 5. Finally if 'Any Contributing Conditions' further clarified the cause of death, then the Group was revised (Figure 3.2).

Using the extract from BDM (Figure 3.3 next page), the following hypothetical cases describe the grouping method:

Betty's Immediate Cause of Death was oesophageal cancer. She was classified into the cancer group (Group 2);

Tom's Immediate Cause of Death was aspiration pneumonia which placed him in the frailty group (Group 4). Checking the Conditions Leading and Other Contributing columns provides no reason to change this initial grouping.

Cheryl's Immediate Cause of Death was cardiac arrest. This diagnosis does not fit the criteria for groups 2, 3 or 4 so she was classified as group 5 'other'. However the Condition Leading to the Immediate Cause of Death is cardiomyopathy which allowed Cheryl to be reclassified into Group 3, heart failure.

Edith's Immediate Cause of Death was a myocardial infarction (MI) which is non-specific and put her into 'other' (Group 5). However the doctor had noted a diagnosis of dementia in Other Contributing Conditions, which replaced her into the frailty group (Group 4).

Figure 3.3 Extract from database provided from Tasmanian Registrar of Births, Deaths and Marriages demonstrating the sequential classification method used in this research

Hypothetical Case	ImmediateCauseOfDeath	1st	ConditionsLeadingImmediateCause	2nd	OtherContributingConditions	3rd
Betty	OESOPHAGEAL CANCER	2				
Tom	ASPIRATION PNEUMONIA	4	VOMITING	4	FUNCTIONAL SMALL BOWEL OBSTRUCTION	
Cheryl	CARDIAC ARREST	5	SEVERE ISCHAEMIC CARDIOMYOPATHY	3		
Edith	ACUTE MI	5		5	DEMENTIA	4
	Group 2 = CANCER Group 3 = HEART or LUNG FAILURE Group 4 = FRAILTY Group 5 = 'OTHER'					

3.6.3   The Data Set

The data available in the resident record is extensive. Maintaining the focus of the data collection on the research question set the limit on the data item that would be collected (Appendix 2_The Data Dictionary). To this end, the following data were collected:

Table 3.6: Data set items and the corresponding data source document in the resident record

Data item	Source document in resident record
Date of birth	Admission
Date of admission to NH	Admission
Date of death	Nursing or medical notes
Sex	Admission
Postcode prior to admission	ACCR
Place of death	Nursing or medical notes
Marital status at admission	ACCR
NH entry level of care	ACCR
Cause of death	Death Certificate *
Diagnosis on admission to NH	Medical notes
Diagnosis prior to admission to the NH	ACCR
Resident Classification Scale (RCS)	Application for Classification Form
RCS 20 question weightings	Application for Classification Form

*If not in the resident record, cause of death data came from the Tasmanian Registrar of births, Deaths and Marriages.

3.7   Statistical Analysis

The statistical analysis follows a path of developing the model based on testing hypotheses before each progression of the analysis.

3.7.1   Null hypothesis

The trajectory of decline as described by Joanne Lynn (2001) and June Lunney (2002 and 2003) cannot be identified in the functional profiles of a residential aged care population.

The initial analysis is a description of the subjects using counts, percentages and standard deviation. Prior to group analysis correlations between variables were assessed. Differences in means of the subject characteristics between the NH and the diagnostic groups are tested using ANOVA. Following confirmation of difference between groups, a multi-level regression analysis is undertaken to evaluate the rate of change (slope), *y*-intercepts within each group, and finally difference in slope and *y*-intercept between the Groups. Also reported in this section is the method (Kappa) used to determine agreement between the three available diagnoses.

3.7.2   Preliminary analysis

Data from the sources described in the preceding sections was collected and collated into an Excel spreadsheet. Each participant (N=4) and subject (N=250) was de-identified using a unique code. A combination of characteristics that describe the data are analysed and the results reported in the Results Chapter (Sections 4.1- 4.4)

3.7.3   The characteristics of the subjects from the resident records:

- sex (male, female)
- age at admission (years) = (date of admission – date of birth) /365
- age at death (years) = (date of death – date of birth) /365
- length of stay (years) = (date of admission – date of death) /365

- level of function at admission = the RCS score (0-100) identified by the date closest to the admission date
- level of function preceding death = the RCS score (0-100) identified by the date closest to the date of death

3.7.4   The characteristics (variables) of the subjects from the ACCR:

- Living arrangements of the subjects prior to admission = married/widowed/never married/divorced or separated/ not specified and lived in own home/lived in rental or independent accommodation/ lived in NH low care/ other/not specified;
- Carer arrangements of the subjects prior to admission = no carer/one or more carers/ not specified/ carer is spouse/ carer is other family/ carer not needed or specified;
- Care requirements (ADLs and IADLs) and services accessed by subjects prior to admission = no care required/ 2-4 care requirements/5-7 care requirements/ 8-9 care requirements/ 10 care requirements/ not specified/ services not required or not used/ CACP or EACH[14]/ HACC[15]/ DVA[16]/ informal care/ not specified;
- Level of care approved = low care or high care. The ACAT assessor uses a different criterion to determine care level but it equates to the RCS score used in the residential care setting.

---

[14] CACP is community aged care package; EACH is extended aged care in the home. Both are programs of community based care funded by the Australian Government after ACAT assessment and approval. Services are provided by community profit and not for profit services, often administered locally by providers of residential aged care services.

[15] HACC is home and community care services provided by community services and funded by the State or Territory government.

[16] DVA are services, usually through the same community providers as CACP, EACH or HACC, funded by the Australian government Department of Veteran's Affairs for eligible veterans of the Australian armed services.

3.7.5   Descriptive statistics

Descriptive statistics *are used to organise and describe the characteristics of a collection of data* (Salkind N 2004, p8). The statistics used here are:

Percentages (%) that are noted to determine the proportion of subjects with that variable; for example, the proportion of females in the dataset.

Mean (mean) is the measure of central tendency, or average of all the scores divided by the total number of scores. The mean is influenced by 'extreme' scores. The data were tested for extreme scores as well as for normal distribution. For example in Figure 3.4 below that shows the normal distribution of age at admission for the subjects.

Figure 3.4 Frequency distribution for age at admission for study subjects (n=247)
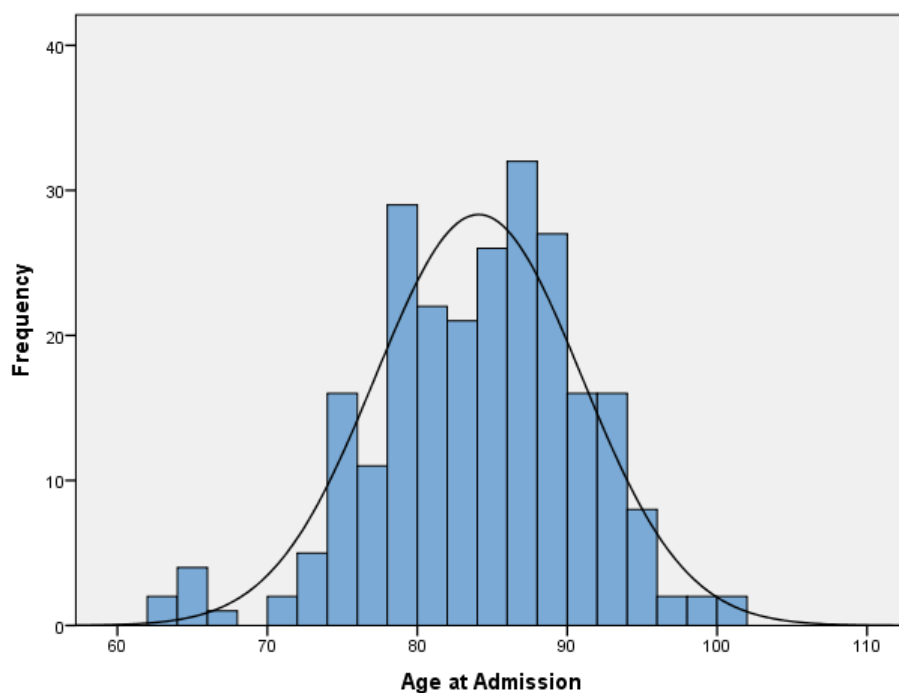
The mean is a model created to summarise the data (Field A 2009, p35) hence in reporting the result a measure of the fit of the model is included. The standard deviation (the square root of the variance) provides a measure of the average error in the same unit as the measure, for example age. A small standard deviation relative to the mean indicates that the mean is a good fit to the actual data. From the distribution of the age data shown in Figure 3.7 above, it would be expected

that the standard deviation will be small and the mean provides a good representation of the data.

3.8   The relationship among variables

Following the preliminary analysis of the subject characteristics, further analysis of the relationship between the variables will be undertaken. This section outlines the statistical tests used and reported in the Results Chapter.

3.8.1   Correlation

The next step in developing the statistical model is to determine if there is any relationship between the dependent variable, the RCS score, and subject characteristics. It could be that the increasing RCS over the course of the admission is due to the resident's increasing age or that there are more women in the study than men. Using a correlation measure, these relationships between the outcome variable, the RCS score, and the subject characteristics – sex, age at admission, and age at death - will be determined before the subjects are grouped into their diagnostic groups and analysis for trajectory.

Because the data are normally distributed, the linear relationship between two variables will be determined using Pearson's product-moment correlation co-efficient (*r*). This is a measure of how much two variables covary, that is, whether change in one variable results in a similar change in the other variable (Field 2009, p167). This test can also be used if one of the variables is categorical. For example does being female increase RCS? The Pearson test standardises the covariance to give a value between -1 and +1. Hence a coefficient of zero indicates no relationship. This analysis was undertaken using SPSS (v20). The output for a Pearson's correlation in SPSS is a matrix of the correlation co-efficient for the included variables as well as the significance of the correlation between each variable.

3.8.2   Comparison of means (ANOVA)

ANOVA (analysis of variance) was undertaken to investigate whether there is a difference between the groups once the subjects have been allocated into a group

based on their cause of death. The method used by Lunney J *et.al.* (2003) took all the measures of function for the subjects in each group over the year before death then analysed the mean level of function by month.

Analysis of variance tests allows for comparison of means of more than two groups. The data analysis for this research compares the means between four discrete groups of NH residents to determine if the groups have different (independent) participants. There are a number of variables (RCS, RCS item/s, age, sex, NH and length of stay). While the variables length of stay, sex, NH and age are measured once on each individual resident in each group, the RCS variables are usually measured at least twice on each individual resident in each group.

3.8.3   Assumptions to be met for ANOVA:

1.   Level of measurement –assumes that the dependent variable is measured on a continuous scale not as a category. In this study RCS is on a scale of 0-100; age is 65 plus years; length of stay is 0 to 4000 days. RCS item however is measured as four 'scores' per item only i.e. categorised. For example the RCS item 'toileting' has a choice of 0; 5.98; 10.65; 13.7.

2.   Random sampling – the data were collected in as random a manner as possible within the limitations of the sampling environment.

3.   Independence of observation – the data are <u>not</u> independent.

4.   Normal distribution – the data are normally distributed.

5.   Homogeneity of variance – to be determined.

The purpose of an analysis of variance is to test the null hypothesis. To reduce the risk of a Type 1 Error, which is to incorrectly reject the null hypothesis, an appropriate alpha level has been selected ($p<0.05$) and the test used is powerful enough to detect a difference between the groups if there is one. There is sufficient *a priori* evidence for this research to compare means between groups without adjusting the analysis with a Bonferroni correction.

3.9   Linear mixed model methodology

To examine changes in functional ability (RCS) over time, a generalised linear model, such as ANOVA and regression, requires that data meet certain conditions – such as equal group size and independence of observations – to reduce Type 1 errors. The data collected for this study do not meet these criteria.

1. Group size is not equal. As described in the sample size section (Section 4.7), recruitment was random which resulted in groups similar in proportion to those found in the Lunney research.

2. Observations are not independent. Following the measure of functional ability at admission, subsequent measures of function are for the same person, not separate individuals.

3. Outcome is measured longitudinally over time.

To overcome these restrictions, statistical methods used to analyse longitudinal repeated-measures data include the random effects model, fixed effects model and the method of generalised estimating equations (Gardiner J, Luo Z *et.al.* 2009). In SPSS these methods are found under two separate analysis menus 'Mixed Model _ linear mixed' (LMM) and the 'Generalized linear models_ generalized estimating equations' (GEE). Using the software to generate these highly complex models is (relatively) easy, the choice of modelling strategy is not (Gardiner J, Luo Z *et.al.* 2009; Hubbard A, Ahern J *et.al.* 2010; Hubbard R and Theou O 2012; Subramanian S and O'Malley J 2010). As stated above, these methods are used in preference to traditional regression because the functional status of the residents in the nursing homes may be correlated, that is, violates the criteria of independence. LMM allows the variance in the outcome to be analysed by 'neighbourhood' or nursing home and at the individual level. The GEE method describes changes in the population mean given changes in the covariates. Unlike LMM, GEE provides an approximation of within-neighbourhood non-independence. This simplification has been argued to be sufficient for most purposes (Hubbard A, Ahern J *et.al.* 2010) but its use may conversely over simplify an otherwise complex relationship between the outcome of interest and the environment in which it is generated (Subramanian and O'Malley 2010).

Perhaps the easiest way for a non-biostatistian to choose the best model for the data to be analysed is to review other, similar research. The methodology used by Lunney and colleagues (2003) used ANOVA on the data grouped into monthly cohorts and dealt with Type 1 error by using a Bonferroni adjustment (Lunney J, Lynn J *et.al.* 2003). In this thesis the data will be treated as continuous despite the variability in the intervals between measurements of the RCS on individual subject over the course of their admission. Hence not only are the data dependent due to being measured in the same nursing home, each data point is related. This is very similar to the growth charts of children in that each measure of a child's height and weight is related to the previous measure. A search of the literature found a number of papers that had similar data analysed using LMM to identify the relationship between time and a marker of ageing.

Two research groups have used LMM to identify the trajectory of terminal cognitive decline in elderly populations. Martin Sliwinski and colleages (2006) in the US modelled within-person (rather than population average) change in cognition as a function of time in the period before death (Sliwinski M, Stawski R *et.al.* 2006) using LMM and random effects. Taking this concept further, Macdonald and colleagues identified five different developmental trajectories of dementia using LMM and random effects to compare the outcomes for individuals on each trajectory (MacDonald S, Hultsch D *et.al.* 2011). A study of functional and health outcomes of NH residents with and without chronic kidney disease used LMM with random effects finding no significant difference between the two measured cohorts (Binder E, White H *et.al.* 2012).

There was only one paper found that used GEE (Pot A, Portrait F *et.al.* 2009) in a study of health service utilisation by elders in the last year of life. The authors note that a limitation of the study was the interaction of the different types of care used by individuals within the measurement period. This interaction could have been estimated with a random effects model.

A paper published in the New England Journal of Medicine by Thomas Gill after the statistical modelling for this thesis had been commenced reports an alternative

estimating procedure for group based trajectory modelling (PROC_TRAJ). Gill references the method to Jones and Nagin (Jones B, Nagin D *et.al.* 2001; Jones B and Nagin D 2007) who developed the SAS (Statistical Analysis System) procedure used in their research. Gill identified the same five trajectories as described by Lunney *et.al.* (2002 and 2003) but using this analysis found that the subjects did not follow a predictable pattern of disablement based on their condition leading to death (Gill T, Gahbauer E *et.al.* 2010). A subsequent refinement of this method using PROJ-TRAJ is described by Zimmer and colleagues (Zimmer Z, Martin L *et.al.* 2012) to estimate prospectively, disability and mortality trajectories over time. Future research would need to consider this and other developments in statistical analysis of complex data with multi-level interactions/dependencies.

The reason that this level of analysis is possible is the proliferation of statistical analysis software in SPSS, Stata, SAS, and R as well as special purpose software such as HLM and MLwiN (Albright J and Marinova D 2007). Also desktop computers can now manage this level of computation (Tabachnick B and Fidell L 2007, p4). Tabachnik also comments that there are differences in how the software handles the analysis to the extent that the output can be different if the same analysis is compared from different software (Albright and Marinova 2010) however Heck's comparison of SPSS with other multilevel software found that SPSS *produces results substantively consistent with other programs* despite there are differences in the algorithms used (Heck R, Thomas S *et.al.* 2010, p9 and p19).

3.9.1   Sample size determination for LMM

The sample size analysis reported in Section 3.5.3 was based on a single-level model (ANOVA). As the analysis of the data collected for this research progressed, the multi-level model was trialled. That is, a sample size determination for each level of the multi-level modelling was not undertaken and hence the sample size may be underpowered for Level 2 LMM in particular for estimating significant differences in random slopes between groups (Heck *et.al.* 2010 p19 and p321). Heck recommends parsimony in developing the model, recognising the shortcomings of the data will not be overcome by a more complex

model. In smaller group samples the estimating method, REML (restricted maximum likelihood estimation method) is recommended over the ML (maximum likelihood estimating method) (Heck R *et.al.* 2010 p 18).

3.9.2   Developing the linear mixed model

For analysis a two level fixed and random effects model will be developed. The Level 1 sub-model specifies the individual (within-person or intra-individual) trajectory of change – which is described by two parameters, the intercept and slope. No predictors are included in the Level 1 sub-model. To identify whether the rate of change is constant (i.e. linear), or is non-linear (i.e. accelerates and/or decelerates), a polynomial trend can be included at this level of analysis. The Level 2 sub-model takes the outcome variables of the Level 1 sub-model (that is the intercept and slope) to determine the effect, if any, of predictors on inter (between) individual variation. Multilevel modelling allows a number of covariance structures to be tested which is a more effective determinant of error covariance than linear modelling or logistic regression. This reduction in error covariance more correctly identifies a model to describe the pattern of change over time - which in this research is the trajectory of functional change - than a logistic regression model (Shek D and Ma C 2011). Having established a model that accounts for the observed variance, it will be possible to compare the outcomes of the analyses between the trajectories of each diagnostic group for any difference.

Following the strategy described by Shek and Ma (2011) the data will be analysed using a mixed effect model in order to determine:

1.   Individual change (in RCS) over time;

2.   The shape of the slope/s;

3.   The systematic differences in the slope/s; and

4.   The effects of covariates (age, diagnostic group, length of stay, NH and sex).

The progressive analysis models are:

Model 1- an unconditional model (equivalent to ANOVA with a random effect) that examines mean differences in the outcome variable (RCS) across individuals without regard to time.

Model 2-an unconditional growth model to identify whether the trajectories are linear or curvilinear in relation to time;

Model 3- fitting a quadratic slope;

Model 4- fitting a cubic slope;

Model 5- a conditional model to identify any relationship between the predictors and the outcome variables;

Model 6 - testing for the 'best fit' structure to assess the error covariance of these data allowing the intercept and slope to vary across individuals.

These models were tested using SPSSv20 (Linear Mixed Model command) with the output copied into a MS Word document. Whilst the output options are extensive, only the SPSS syntax, information criteria (for comparison between models), estimates of fixed effects and co-variances were reproduced and referred to in the analysis.

The final step for the analysis is to determine whether there is a difference between the trajectories themselves. Using the same model identified as having the least error co-variance in the preceding analysis, three of the groups will be compared against a reference group and the resulting parameters reported.

3.10 Chapter Summary

This Chapter has described the process used to obtain and analyse the subject data collected during the course of the research. It has also explained the rationale behind the choice of the data source. An established retrospective method used for an USA community population has been replicated as much as possible in an Australian nursing home population, in order to compare the results from two different elderly populations.

Chapter 4 Results

4.0   Introduction to the results

The previous chapter, the Methods Chapter, described the data collection as being managed with a 'phased' approach to allow a progressive review of the methodology against the research questions. In this Chapter, the results are presented in a progressive format starting with descriptions of the participants and subjects, moving into correlation analyses and population averages. First, descriptive and univariate analysis is presented followed by a more complex multivariate analysis of the variables that may predict functional change in this population and thence toward finding any significant differences between the multiple diagnostic groups proposed by Lynn (Lynn 2001) and identified by Lunney (Lunney J, Lynn J *et.al.* 2002; Lunney J, Lynn J *et.al.* 2003), that would support the utility of the trajectory concept for health resource allocation.

4.1   Characteristics of the participating nursing homes

The participants in this study are the four nursing homes (NH) whose management consented to participate in this research. The four participating NH are all located in southern Tasmania within a ten minute drive of the CBD. Three of the NHs are 'stand-alone' facilities with a non-corporate administrative structure and one is a part of a national corporate administrative body. All facilities have low and high care places with residents moving between care levels within the same facility.

Table 4.1.1 Distribution of care places in the four participating nursing homes

Nursing Home	High Care Places	Low Care Places
NH1	176	123
NH2	79	60
NH3	98	149
NH4	54	68

The distribution of places (as of July 2008) listed in Table 4.1.1 above

 was collected from the public websites of the NH. No variables that could distinguish a particular nursing home were included in the data collection, an explicit requirement of the consent to participate.

The subjects in this study are the administrative and health records of a convenience sample (N=250) of the residents of these four NH who died between December 2000 and October 2008. Data for the study were collected from these records of deceased residents from the four participating nursing homes. The number of subjects included in this research from each nursing home is shown below in Table 4.1.2 and the sampling method is described in Section 4.7

Figure 4.1.2 Number of subjects included in the study
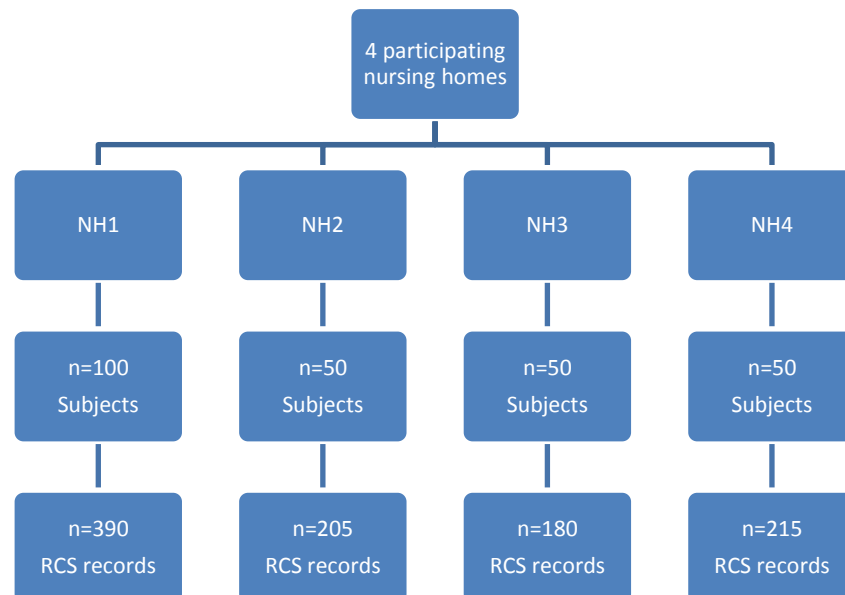
The measure of function used in this research is the Resident Classification Scale (RCS) described in the methods. Each resident had as a minimum to be included in this study one RCS record. Over the course of admission to the NH a resident will be assessed within three months of admission and then annually unless there has been a significant change in care requirements. Hence the number of RCS for a resident will be one for each year of admission to the NH and sometimes more frequently. As shown in Table 4.1.2 above, on average each subject had four RCS records over the course of their admission.

The inclusion/exclusion criteria for this study, as stated in the methods are:

All deceased resident records made available for review at each of the NH were included in the research unless:

1. The resident was less than 65 years old on admission;

2. There was no RCS in the file;

3. The resident had been discharged to another NH or home;

4. The death certificate was not available at the time of data collection.

Of the 250 records reviewed only three records were excluded on this basis. One because the Death Certificate had not been completed; one because the resident was transferred to another NH and; one because the RCS was not found in the records. The final sample is thus 247 and the total number of RCS records available for the analysis is 990.

More records were sampled from NH1 because it has the largest single record repository of all the participating NH.

Principle Finding

From four nursing homes in southern Tasmania, 247 individual resident records were included in this study providing a total of 990 RCS records available for analysis.

4.2   Characteristics of subjects in the participating nursing homes

Using an identifying code (NH1 … NH4) subjects were grouped according to the NH in which they had been resident. The characteristics – age, length of stay, RCS, cause of death – were analysed for the overall population proportions in each NH in order to identify any differences in these subject characteristics between the participating four NHs.

The characteristics of the residents in the participating NHs recruited to this study are summarised in Table 4.2 below. Proportionally there were more women than men in this study (69% female). The mean age of subjects at admission to the NH was 84 years and mean length of stay was 3.3 years. The average level of functioning, as measured by the RCS at admission, was 51.8 and on average this score deteriorated over the period of stay to reach 70.8 by the time of death. The increase in RCS score indicates an increase in care needs of the resident as their functional ability declines.

The most common cause of death was attributed to cardiovascular disease (41%) followed by respiratory causes (27%) 'other' causes (24%) and only 8% attributed to cancer. 'Other' causes included deaths attributed to, for example, diabetes, dementia, renal failure, sepsis.

The NHs were generally similar across these subject characteristics. The NH most at variance with the others on characteristics other than RCS scores was NH4 which contained a higher proportion of females (80%) among their residents who tended to have a longer length of stay than the residents of the other NH. This NH had a higher proportion of deaths attributable to 'other' causes. This included cause of death from dementia, diabetes and renal failure.

Table 4.2 Characteristics of subjects in participating nursing homes (NH)

Characteristic	NH1		NH2		NH3		NH4		ALL	
Female residents % (n/N)	72%	(72/97)	52%	(26/50)	66%	(33/50)	80%	(40/50)	69%	(171/247)
Age at admission, mean (SD), years	84.6	(7.4)	83.1	(5.7)	84.5	(7.4)	83.6	(6.3)	84.0	(6.9)
Age at death, mean (SD), years	87.5	(7.4)	86.5	(6.6)	87.9	(7.6)	87.7	(6.8)	87.4	(7.2)
Length of Stay, mean (SD), years	2.8	(2.3)	3.3	(3.5)	3.4	(3.8)	4.1	(3.9)	3.3	(3.3)
Level of function at admission, mean (SD) RCS score	50.2	(23.8)	59.1	(25.3)	49.3	(21.6)	48.8	(25.1)	51.8	(24.0)
Level of function preceding death, mean (SD) RCS score	72.2	(16.5)	64.7	(15.2)	74.3	(15.6)	71.0	(13.7)	70.8	(15.8)
Cause of death[a]										
Cardiovascular % (n/N)	38%	(37/97)	56%	(28/50)	46%	(23/50)	26%	(13/50)	41%	(101/247)
Cancer % (n/N)	9%	(8/97)	6%	(3/50)	12%	(6/50)	4%	(2/50)	8%	(19/247)
Respiratory % (n/N)	31%	(30/97)	22%	(11/50)	24%	(12/50)	26%	(13/50)	27%	(66/247)
'Other' % (n/N)	22%	(22/97)	16%	(8/50)	18%	(9/50)	44%	(22/50)	24%	(61/247)

[a] Categories for leading causes of death for Australian population, 65+ years (AIHW 2006).

At variance with the other NHs in respect of RCS scores was NH2. Its residents had higher RCS on average at the time of admission, but lower RCS (better function) on average at time of death. This NH had a higher level of deaths attributable to cardiovascular causes, such as stroke and cardiac arrest, and the age at death was slightly lower at this NH.

Principle findings

Proportionally there were more women than men in this study. The mean age of subjects at admission to the NH was 84 years and mean length of stay was 3.3 years.

The average level of functioning, as measured by the RCS at admission, was 51.8 and on average this score deteriorated over the period of stay to reach 70.8 by the time of death.

The NHs were generally similar across subject characteristics.

4.3   The trajectory of functional decline in a nursing home population

The figure below (Figure 4.3) represents the trajectory of functional change or the functional profile of an 'average' resident in this study. The data for all subjects was analysed in two groups. The first group being the RCS on admission to the nursing home where functional ability as measured by the RCS, was on average higher in comparison to the second measurement group taken as the RCS score immediately before the death of the resident.

Figure 4.3 The trajectory of functional decline in the NH subjects (n=247)
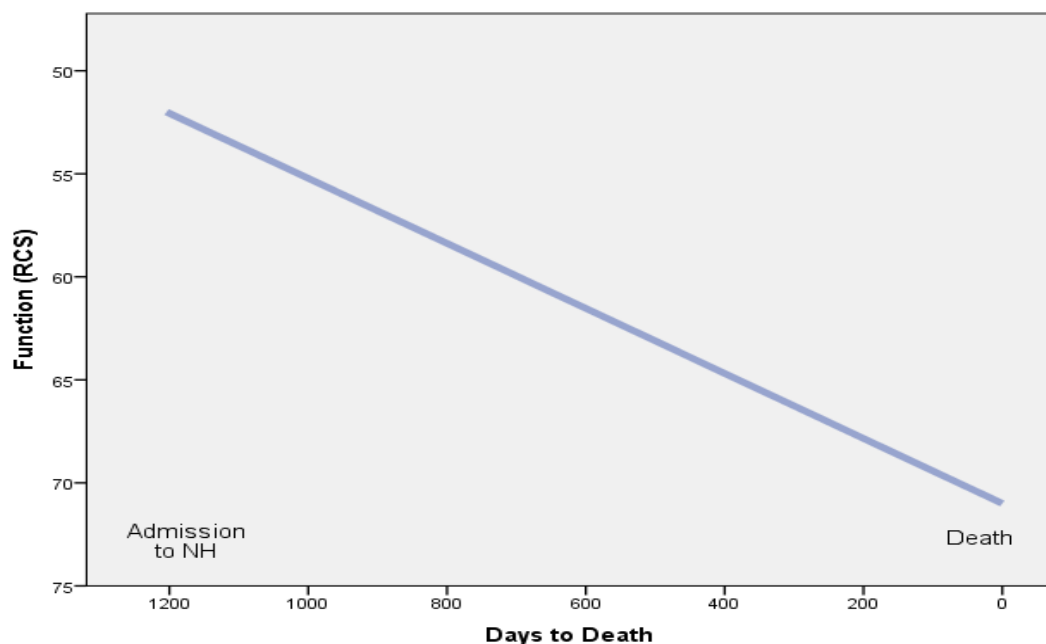
For the total population of deceased NH subjects included in this study (Table 4.2 p149), the mean length of stay is 3.3 (SD=3.3) years or 1204 days with a mean RCS at admission to the NH of 51.8 (SD=24.0). At death the RCS has on average for this population increased to 70.8 (SD=15.8) indicating that for this population, the level of care required increases over the course of the admission to a NH.

Principle Findings

There is a trajectory of functional decline to death in this population.

The RCS is sensitive to this change if residents are routinely reassessed.

4.4   Factors determining level of care assessment before admission to the NH

Of the 247 subjects with both at least one RCS Score and a Death Certificate, 86% (n=213) also had an ACCR (Assessment of Care Requirements) from the Aged Care Assessment Team done prior to admission to the NH in the resident record. The subject characteristics of those subjects with and without an ACCR are shown in Table 4.4.1 to identify any bias contributed to this section of the analysis by missing data.

Table 4.4.1 Characteristics of subjects with ACCR report and without ACCR report

Characteristic	*With ACCR*		*Without ACCR*		*ALL*	
Female residents % (n/N)	66%	(142/213)	81%	(27/34)	69%	(171/247)
Age at admission, mean (SD), years	83.7	(0.6)	83.6	(1.3)	84.0	(6.9)
Age at death, mean (SD), years	87.2	(0.5)	88.6	(1.3)	87.4	(7.2)
Length of Stay, mean (SD), years	3.06	(0.22)	5.06	(0.63)	3.3***	(3.3)

*** two-tailed test of significance p=0.001

While the age characteristics are similar between the two samples shown in Table 4.4.1, there appears to be a bias toward more females missing the ACCR in their records than males. As well, comparison of the mean length of stay (LOS) of the two samples shows a significant difference (p=0.001) between the LOS of the subjects with an ACCR compared with the 31 subjects without an ACCR in their records. The subjects without an ACCR included three subjects who entered the NH prior to the legislative requirement for an ACCR in 1997. That is, three of the subjects with the longest length of stay have missing ACCR reports.

From the available ACCR reports Table 4.4.2 describes characteristics of 86% of the subjects before their admission to the NH.

Table 4.4.2 Living arrangements of subjects before admission to the NH

	Females n=142 (67%)		Males n=71 (33%)	
Married	27	(19%)	33	(46%)
Widowed	88	(62%)	25	(35%)
Never married	16	(11%)	1	(1%)
Divorced/separated	6	(4%)	5	(7%)
Not specified	6	(4%)	7	(10%)
Lived in own home	88	(62%)	46	(65%)
Lived in rental/independent accommodation	31	(22%)	9	(13%)
Lived in NH low care	8	(6%)	1	(1%)
Other	7	(6%)	8	(11%)
Not specified	9	(6%)	7	(10%)

At the time of admission to the NH, nearly half of the men (46%) were still married than women (19%) as shown in Table 4.4.2 above. Women were more than half as likely to be widowed (62%) compared to a third of men (35%). Also, only 1% of the men had never married whereas 11% of the women had never married. This may be a generational effect of the loss of men during WW2. The major difference in accommodation arrangements before their NH admission was that women (22%) were almost twice as likely as men (13%) to be living in rental accommodation or independent living units. More than half of men (65%) and women (62%) in this area of Tasmania lived in their own home before entering NH care.

Table 4.4.3 Care arrangements of subjects before admission to the NH

	Females n=142 (67%)		Males n=71 (33%)	
No carer	41	(29%)	18	(25%)
One or more carers	86	(61%)	45	(63%)
Not specified	15	(11%)	13	(18%)
Carer is spouse	20	(14%)	23	(32%)
Carer is other family	49	(35%)	14	(20%)
Carer not needed or specified	75	(53%)	32	(45%)

More than half of the subjects had one or more carers before entering the NH (Table 4.4.3 above). But for women, because they are more likely to be widowed, their carer if they have one, will be a family member (35%) other than their husband (14%) whereas men will still have their wife to care for them (32%).

In the ACCR, Item 24 asks whether the person requires assistance with any of 10 instrumental activities of daily living (transport, health care, home maintenance, meals) and movement activities. In Table 4.4.4 (below), these tasks have been coded into five categories from no care required up all of the ten items require assistance. For men and women the level of assistance required before entry to the NH was similar except that women (22%) were proportionally more likely to need only 2-4 tasks assisted than men (10%) in this category. Men had slightly more need in the higher categories of task assistance.

Table 4.4.4 Carer requirements and services accessed by subjects before admission to the NH

	Females n=142 (67%)		Males n=71 (33%)	
No care required	7	(5%)	1	(1%)
2-4 care requirements	32	(22%)	7	(10%)
5-7 care requirements	20	(14%)	13	(18%)
8-9 care requirements	18	(13%)	13	(18%)
10 care requirements	41	(29%)	21	(29%)
Not specified	24	(17%)	16	(22%)
Services not required/not utilised	22	(15%)	10	(14%)
CACP/EACH	10	(7%)	2	(3%)
HACC	47	(33%)	20	(28%)
DVA	6	(4%)	11	(15%)
Informal	1	(0.7%)	0	(0%)
Not specified	56	(39%)	28	(39%)

The utilisation of care services in Table 4.4.4 above, was almost equally distributed between men and women except for use of DVA services where men (15%) were more likely than women (4%) to receive services from this department. This item was not answered in 39% of the forms reviewed.

Table 4.4.5 Level of NH care advised before admission to the NH

	Females n=142 (67%)		Males n=71 (33%)	
High care (RCS> 50.01)	84	(59%)	51	(72%)
Low care (RCS<50.00)	53	(37%)	18	(25%)
Not specified	5	(4%)	2	(3%)

The majority of ACCR assessment recommended high level care for the subjects in this study prior to admission to the NH (Table 4.4.5 above). However, proportionally more men (72%) required high care than women (59%). The 'not specified' group is the result of the ACCR assessment process that allows the person the right to refuse classification at the time of assessment.

Principle Findings

There is a difference between men and women in characteristics related to their care and living arrangements before admission to the NH.

Nearly two thirds of the women were widowed and only 14% were cared for by their spouse. In contrast a third of the men of men were cared for by their spouse.

More men (72%) were assessed as having higher care needs before entry to the nursing home than women (59%).

4.5 Level of agreement between diagnoses made before admission to the NH, at admission to the NH, and the cause of death

The 'Trajectory of Decline' literature has used the subject's cause of death (from the death certificate) to identify which diagnostic Group a subject belongs in. However this limits any use of the 'Trajectory' concept to retrospective research. As part of the review of the NH resident record it was expected that all residents would have an 'ACAT' diagnosis (as part of the preadmission Aged Care Assessment); and a medical admission. In reality not every record evidenced these documents, however of the 247 records with RCS data collected; 171 had both the ACAT and medical admission diagnoses.

Using these 171 records, a Cohen's Kappa analysis was undertaken in order to measure the reliability of these alternative diagnoses against the 'gold standard' used by Lunney, the cause of death (from the Death Certificate). The subjects were recruited into one of the four trajectory groups in the same manner (see flow chart Figure 3.2 in methods chapter p131) and by the same person who had grouped the subjects using the Cause of Death data. The analysis was done using the [Crosstab] function in SPPS v19.

Table 4.5.1 Cross tabulation of ACAT diagnoses and death certificate

			Death Certificate:				
			Cancer	Heart or Lung Failure	Frailty	Other	Total
ACAT Diagnosis	Cancer	Count	6	0	2	0	8
		% of Total	3.5%	.0%	1.2%	.0%	4.7%
	Heart or Lung failure	Count	2	5	8	1	16
		% of Total	1.2%	2.9%	4.7%	.6%	9.4%
	Frailty	Count	12	14	65	9	100
		% of Total	7.0%	8.2%	38.0%	5.3%	58.5%
	Other	Count	6	13	23	5	47
		% of Total	3.5%	7.6%	13.5%	2.9%	27.5%
Total		Count	26	32	98	15	171
		% of Total	15.2%	18.7%	57.3%	8.8%	100.0%

From Table 4.5.1 (above), the number of cases where the ACAT diagnosis and the cause of death are in agreement are 81 (47%) the sum of the coloured cells. The Kappa Measure of Agreement is 0.146 (p<0.001) which according to Landis and Koch (1977) represents slight agreement between the diagnosis given by the ACAT assessment made prior to admission to the NH and the cause of death.

The highest level of agreement was for the frailty group (66%). The least agreement was for the heart/lung fail which was only 16%. This group tended to be assessed as frailty or 'other' by ACAT.

Table 4.5.2 Cross tabulation of medical admission diagnoses and death certificate

			Death Certificate:				
			Cancer	Heart or Lung Failure	Frailty	Other	Total
Medical Admission Diagnosis	2	Count	8	2	0	0	10
		% within MedAdmDx	80.0%	20.0%	.0%	.0%	100.0%
	3	Count	4	11	13	2	30
		% within MedAdmDx	13.3%	36.7%	43.3%	6.7%	100.0%
	4	Count	7	11	66	4	88
		% within MedAdmDx	8.0%	12.5%	75.0%	4.5%	100.0%
	5	Count	7	8	19	9	43
		% within MedAdmDx	16.3%	18.6%	44.2%	20.9%	100.0%
Total		Count	26	32	98	15	171
		% within MedAdmDx	15.2%	18.7%	57.3%	8.8%	100.0%

In Table 4.5.2 (above) the number of cases where the medical admission diagnosis and the cause of death are in agreement are 91 (55%). The Kappa Measure of Agreement is 0.298 (p<0.001) which according to Landis and Koch (1977) represents fair agreement between the diagnosis given by the medical Admission made on admission to the NH and the cause of death.

Table 4.5.3 Cross tabulation of medical admission diagnoses and ACAT diagnoses

| | | | ACAT Diagnosis | | | | |
			Cancer	Heart or Lung failure	Frailty	Other	Total
Medical Admission Diagnosis	2	Count	6	0	3	1	10
		% within MedAdmDx	60.0%	.0%	30.0%	10.0%	100.0%
	3	Count	2	10	8	10	30
		% within MedAdmDx	6.7%	33.3%	26.7%	33.3%	100.0%
	4	Count	0	4	71	13	88
		% within MedAdmDx	.0%	4.5%	80.7%	14.8%	100.0%
	5	Count	0	2	18	23	43
		% within MedAdmDx	.0%	4.7%	41.9%	53.5%	100.0%
Total		Count	8	16	100	47	171
		% within MedAdmDx	4.7%	9.4%	58.5%	27.5%	100.0%

In Figure 4.5.3 (above) the number of cases where the ACAT Diagnosis and the Medical Admission Diagnosis are in agreement are 110 (64%). The Kappa Measure of Agreement is 0.416 ($p<0.001$) which according to Landis and Koch (1977) represents moderate agreement between the diagnosis given by the Medical Admission made on admission to the NH and the ACAT Diagnoses. The level of agreement between the diagnosis made while the resident was alive is higher than compared to the cause of death.

Each of the Kappa scores reported are statistically significant. However, values of Kappa from 0.40 to 0.59 are considered moderate, 0.60 to 0.79 substantial, and 0.80 outstanding (Landis J & Koch G, 1977). Most statisticians prefer for Kappa values to be at least 0.6 and most often higher than 0.7 irrespective of significance, before claiming a good level of agreement.

Figure 4.5 Level of agreement between medical diagnosis before admission to the NH (ACAT_Dx); the medical admission (MedAdm_Dx) and the death certificate (BDM_CoD).
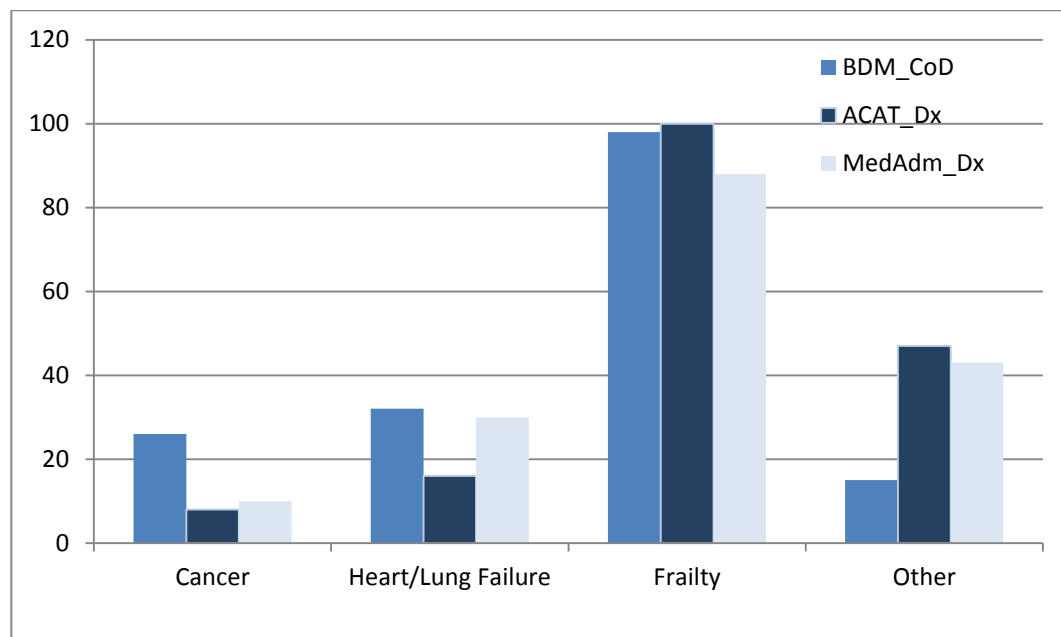
In Figure 4.5 above, the level of agreement appears more consistent for the frailty diagnosis, but while the person is alive they are less likely to be given a diagnosis of cancer compared to their cause of death, and more likely to be given an undifferentiated diagnosis ('Other') while alive compared to what is written by the medical practitioner at death. Heart and Lung Failure is under reported by ACAT compared to either the medical or cause of death diagnoses. As stated above, this group was more likely to be diagnosed with a frailty condition by ACAT.

The documentation for the medical diagnosis was, in the researcher's experience, the most difficult to find in the resident record and was missing from 20% of the records reviewed. The format of the medical admission was also inconsistent between and within facilities further complicating the data collection and analysis.

Principle findings

There is poor agreement between the cause of death and the diagnoses made at the start of the NH admission which limits the utility of this method as a prospective tool.

4.6   Pattern of transfer of residents from NH to acute health services immediately prior to death

A small percentage of residents sampled for this study (7.7%) were transferred to and subsequently died in hospital. Reason for transfer were not always clarified in the resident record, but two of the subjects, classified as being in the Cancer Group, died in inpatient palliative care; one was for unresolved pain; and three were transferred for assessment of injuries - two whilst resident in the NH and one who suffered a fall whilst on leave from the NH. One resident classified into the Heart and Lung Failure Group, requested transfer to hospital for medical care. As shown in Table 4.6 there are differences between those residents who died in the NH compared to those who were transferred and then died in hospital.

The Frailty group had the lowest proportion of subjects transferred to hospital (32%) before death compared to proportion of subjects in the Frailty Group in the total sample (58%) suggesting that this diagnostic group was less likely to be transferred to hospital at a time of health crisis. Likewise, except in the Cancer Group, the proportion of females transferred to hospital (56%) was lower than the total sample (69%). For all Groups except the 'Other' Group, those subjects who were transferred to hospital were younger (86 years) than the total sample (88 years) and the RCS for the transferred subjects (58.23) was less than the total sample (70.83). For example, the average subject in the Cancer Group transferred to hospital to die was 83 years and had an RCS Score of 53. In comparison, the average subject in the Cancer Group total sample was 85 years old at death and their RCS Score before death was higher (68).

While only a small subset of the total sample, there does appear to be a trend toward younger residents with higher functional ability being transferred to hospital for acute care where the outcome was death. Only subjects in the Cancer Group were transferred to palliative care to die.

Table 4.6 Characteristics of subjects who were transferred to hospital immediately prior to death

	Cancer Group	Heart and Lung Failure Group	Frailty Group	'Other' Group	ALL
Transferred subjects (n=19), proportion within each group	16%	32%	32%	16%	100%
Female%	66%	50%	66%	60%	56%
Age at death, mean (SD), years	83.1 (4.5)	82.2 (3.7)	85.0 (2.3)	88.5 (4.7)	86.1 (1.7)
Mean RCS before death (SD)	53.33 (12.88)	63.17 (9.64)	54.33 (13.07)	61.67 (4.41)	58.23 (5.53)
Length of Stay, mean (SD), years	1.4 (1.0)	1.6 (0.9)	2.7 (0.9)	1.6 (0.9)	2.0 (0.5)
Transferred to: Public hospital	33%	50%	80%	66%	63%
Private hospital	-	50%	20%	33%	26%
Palliative care	66%	-	-	-	11%
Total subjects, (n=247), proportion within each group	13%	19%	58%	16%	7.7%
Female%	53%	67%	73%	71%	69%
Age at death, mean (SD), years	87.4 (7.2)	85.5 (7.6)	87.8 (7.6)	86.5 (6.6)	87.8 (7.2)
Mean RCS before death (SD)	68.42 (13.55)	67.86 (17.83)	73.59 (14.53)	63.90 (18.25)	70.83 (15.79)
Length of Stay, mean (SD), years	2.2 (2.6)	3.4 (3.1)	3.3 (2.9)	3.3 (2.9)	3.3 (3.3)

Principle findings

Only a very small proportion of NH subjects were transferred to hospital immediately before death. Of these, there is a trend toward younger, male residents with a diagnosis other than frailty and a better functional ability being admitted.

4.7   Consideration of statistical power

Prior to the data collection, a power analysis was undertaken in order to determine the sample size necessary to attain the desired statistical power for a significance of $\alpha= 0.05$. In this study, the means of 4 different groups were analysed for variance (ANOVA). Using the sample size table developed by Cohen (Cohen J 1992), for four groups, each group would need to have 45 subjects to have a medium effect at Power=0.80 for $\alpha= 0.05$.

However, because of prior research (Lunney J, Lynn J *et.al.* 2002 and 2003) it was already known that the proportion between groups would not be equal. It was determined that a sample size of around 250 would give at least 45 in each of the 4 groups (Table 4.7). In fact, it was found that the Cancer group was smaller than anticipated and 45 was not achieved in this group.

Table 4.7 Estimated proportions of subjects in each Trajectory Group

Trajectory Group	Proportion from Lunney *et.al.* (2002)	Estimated proportion if sample size=250	Actual number (proportion) of subjects in each Group
Cancer	22%	55	32 (13%)
Heart/Lung Failure	16%	40	47 (19%)
Frailty	47%	118	147 (59%)
Other	8%	20	24 (9%)
Sudden death[1]	7%	17	0
	Total=100%	Total=250	Total=250

[1]Lunney *et.al.*(2002) reported a small percentage of deaths in their cohort as being 'sudden', that is, the subject had not been seen/reported in Medicare documentation in the year preceding death. This Trajectory Group is excluded from the research because all NH residents had been seen by a doctor in the year preceding death.

Recruitment was independent of the Trajectory Group, and as more subjects were recruited it was found that more were entered into the Frailty Group and sampling was ceased. Thus the resulting sample may be underpowered for some analyses.

Principle findings

Due to the sampling method, some of the groups are underpowered for analysis.

4.8   Classification of deceased residents into four groups according to the cause of death using the methodology as described by Lunney et.al. (2002)

As explained in the Methods Chapter, the methodology used in the papers by Lunney J, Lynn J *et.al.* (2002) was adapted for use in this NH population. In this section, the results obtained by Lunney are compared with the results of this research to identify the applicability of this methodology in a different population than that of their original research.

Figure 4.8.1 Classification of deceased NH subjects into the four groups identified by Lunney *et.al.* (2002)
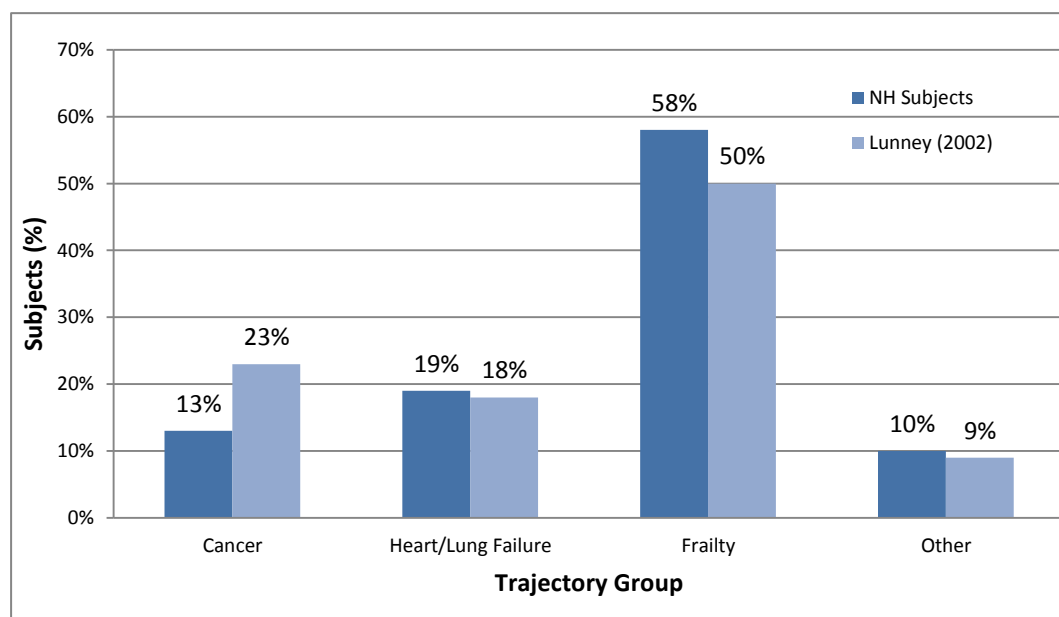
The proportion of deceased NH subjects classified into the four diagnostic groups based on their cause of death is shown in Figure 4.8.1 above. Also shown for comparison is the distribution between those groups of the community subjects studied by Lunney J, Lynn J *et.al.* (2002). The two distributions are generally similar but the Cancer group is under-represented in the NH sample whilst the Frailty Group is over-represented. The Lunney study subjects were recruited from a community sample and their mean age was 79 compared to this study conducted in a NH population where the mean age is 87 years at death. Specifically, the cancer subjects mean age was 77 years; the heart/lung failure subjects were on average 80 years old in the Lunney study.

Table 4.8 Characteristics of subjects in each trajectory group

Characteristic	Group Cancer	Group Heart/Lung Failure	Group Frailty	Group Other	ALL mean	Comparison of means between Groups
Residents % (n/N)	13% (32/247)	19% (46/247)	58% (145/247)	10% (24/247)	100% (247/247)	
Female residents % (n/N)	53% (17/32)	67% (31/46)	73% (106/145)	71% (17/24)	69% (171/247)	p=0.170
Age at admission, mean (SD), years	83.7(7.0)	84.6(8.2)	83.6(6.4)	85.1(7.3)	84.0(6.9)	p=0.644
Age at death, mean (SD), years	85.5(7.6)	87.8(7.6)	86.5(6.6)	87.8(7.2)	87.4(7.2)	p=0.421
Length of Stay, mean (SD), years	2.2(2.6)	3.7(4.2)	3.4(3.1)	3.3(2.9)	3.3(3.3)	p=0.219
Level of function at admission, mean (SD) RCS score	52.2(22.6)	50.3(26.2)	52.9(23.7)	47.2(25.6)	51.8(24.0)	p=0.691
Level of function preceding death, mean (SD) RCS score	68.4 (13.5)	67.9 (17.8)	73.6 (14.5)	63.9 (18.2)	70.8 (15.8)	p=0.007

The characteristics of the residents in the participating NH grouped according to their cause of death using the Lunney (2002) methodology are summarised in Table 4.8 above.

- Frailty accounts for the largest proportion of deceased residents in this study (58%) and 'Other' the least (10%).

- There are proportionally more female residents in the Frailty group (73%) and almost equal proportion of males to females in the Cancer group (53%).

- There is no significant difference between the group means for age at admission, age at death, and length of stay.

- The level of function at admission to the nursing home substantially decreases before death in all groups and the difference in the mean RCS between groups before death is significant (p=0.007).

The Cancer Group (13%) has almost equal proportion of males and females. Their mean age at admission was 83.7 years and their mean age at death was 85.5 years with a mean length of stay in the NH of 2.2 years. Their level of function (RCS) from admission (52.2) to death (68.42) worsens by 16.2.

The Heart and Lung Failure Group (19%) has proportionally more females (67%)than males. Their mean age at admission was 84.6 years and their mean age at death was 87.8 years with the longest mean length of stay of 3.7 years. Their level of function (RCS) from admission (50.3) to death (67.9) declines by 17.6.

The Frailty Group (58%) has proportionally almost three quarters females (73%) to males. Their mean age at admission was the youngest of the groups, 83.6 years, and their mean age at death was 86.5 years with a mean length of stay in the NH of 3.4 years. Their level of function (RCS) from admission (52.9) to death (73.6) shows the greatest change of all the groups, a decline of 20.7.

The 'Other' Group (10%) has proportionally more females (71%) than males. Their mean age at admission was 85.1 years and their mean age at death was one of the oldest at 87.8 years with a mean length of stay in the NH of 3.3 years. Their level of function (RCS) at admission was the best of all the groups (47.2) and at death (63.9) with a decline of 16.7.

Figure 4.8.2 Distribution of subjects classified into diagnostic group between the four participating NHs
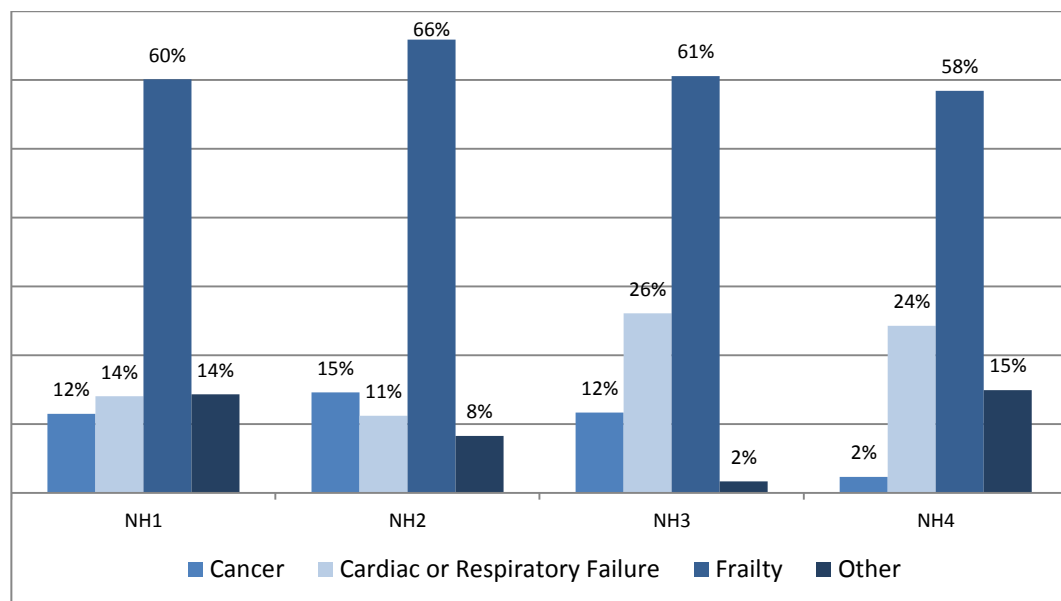
The proportion of subjects in each diagnostic group distributed across the four participating NHs is shown in figure 4.3.2. Of the four groups, Frailty appears to be the most evenly distributed (58% - 66%) with the other three groups showing no particular pattern at all. In NH3 there is a larger proportion of Heart and Respiratory Failure subjects (26%) and only 2% of subjects in the 'Other' Group. NH4 also has a higher proportion of Heart and Lung Failure subjects but with only a small number of the Cancer Group (2%). This uneven distribution of subjects in each group across the NHs may have an 'unbalancing' effect on subsequent statistical analyses where NH is included in the analysis as a variable. Overall the consistent appearance of the Frailty Group is in contrast to the inconsistency of the three other diagnostic groups in this nursing home population sample.

Principle findings

Over half of the subjects are in frailty group and this follows the Lunney findings.

A simple univariate statistical analysis (means) indicates a difference between groups in terms of their functional profile.

4.9   Investigation of the dependent variable (RCS) without reference to classification into diagnostic groups

Any relationship between the dependent variable (RCS) and subject characteristics, investigated using Pearson product-moment correlation co-efficient (r), is shown in Table 4.9 below.

Table 4.9 Relationship of the dependent variable (RCS) on admission to NH and at death for deceased residents (men and women) of participating NH

Study Factor	Mean (SD)	Pearson Correlation		
		RCS on admission	RCS at death	Difference
Men:				
RCS on admission	56.7 (23.1)			
RCS at death	68.6 (16.9)			
Age at Admission, Pearson correlation	82.9 (6.3)	r = -0.18	r = -0.15	r = 0.12
Length of stay (years), Pearson correlation	2.4 (2.3)	r = 0.27*	r = 0.08	r = 0.21
Age at death, Pearson correlation	84.7 (6.7)	r = 0.27*	r = -0.11	r = 0.20
Women:				
RCS on admission	49.7 (24.3)			
RCS at death	71.9 (15.2)			
Age at Admission, Pearson correlation	84.4 (7.2)	r = 0.01	r= -0.13	r = -0.02
Length of stay, Pearson correlation	3.7 (3.6)	r = -0.47**	r = 0.14	r = 0.46**
Age at death, Pearson correlation	87.6 (7.3)	r = -0.22**	r = -0.06	r = 0.22*

* Correlation is significant at the 0.05 level (2-tailed)
** Correlation is significant at the 0.01 level (2-tailed)

Based on these analyses, the following relationships were found:

A   The relationships between RCS on admission and the subject characteristics shown in Table 4.9 are different between men and women. For men on admission to the nursing home, the mean RCS is 56.7 which indicates a lesser ability to care for themselves at home, prior to admission, than women whose mean RCS on admission was 49.7. The RCS at admission for men had a weak, negative correlation with age at admission, suggesting that unlike women

on admission, the men were younger and less able to care for themselves before requiring residential care placement.

B   There is a significant correlation for RCS at admission and length of stay and age at death.

For men this relationship is positive suggesting that if admitted with poor function, they will tend to stay longer and die older; or if a man is admitted with better function, they will have a shorter stay and tend to be younger at death. For women this relationship is reversed. That is, women who are admitted with poor function will have a shorter stay and tend to be younger at death.

C   The relationship between RCS at death and the subject characteristics' are the same for men and women, suggesting that differences in the measures as the subject nears death is not related to their sex.

D   RCS at death is weakly negatively correlated to age at admission and death. There is a weak positive correlation between RCS at death and length of stay. These weak correlations suggest that the care needs at death increase with increasing length of stay for both men and women.

E   The difference between RCS at admission and RCS at death is different for men (RCS difference=17.5) and women (RCS difference =29.1) reflecting the difference in RCS on admission between men and women, rather than the RCS at death.

F   Overall these results indicate that age alone is not a predictor for the dependent variable RCS.

Principle findings

Men have higher care needs before entry to NH than women.

Men enter NH frailer and stay shorter than women who enter NH less frail but stay longer.

Age is not a predictor of care needs.

4.10 The relationship between function, as measured by the RCS, and time from admission to death for residents of NH grouped according to their cause of death

All subjects were grouped (Section 4.8) according to their cause of death using the Lunney methodology (Lunney J, Lynn J *et.al.* 2002). The temporal relationship between the average residents' level of function as measured by their RCS was estimated using a linear mixed model analysis (SPSS v20). Result of this estimation (shown in Table 4.10 below) was used to calculate the population-averaged values for the RCS score for the entire admission to death for each of the four diagnostic groups. The population averaged values are graphed with the individual resident's RCS score line graphs in Figure 4.10 (over).

Using linear mixed modelling (SPSSv20), the fixed effect of time on the dependent variable RCS was analysed for ALL subjects and for the subjects within each diagnostic group. The parameters of the fitted models (linear, quadratic and cubic), their estimated standard errors, and summary values for the fit of each are shown in Table 4.10 below. The population-average lines in Figure 4.10 were estimated from the intercept and slope results of each of the four diagnostic groups.

In this exploratory model no predictors are included. An autoregressive 1 (AR1) covariance structure was specified to account for correlation over time within each resident. This analysis identified that the mean RCS at death for all subjects, adjusted for time, is 73.63 (SE=1.35, $p<0.001$). Over the period from admission to the NH to death (time=0), the population-average rate of change in the RCS is non-linear and negative, that is, declines toward death (rate of change = - 0.03, SE=0.004, $p<0.001$). The group of subjects with the highest mean RCS (most care dependent) at death is the Frailty Group (77.09, SE=1.69, $p<0.001$), and the group of subjects with the lowest mean RCS (least care dependent) at death are within the 'Other' Group (63.77, SE=3.64, $p<0.001$).

Table 4.10 Parameters of the fitted models of functional decline from admission to death in NH residents grouped by cause of death

Parameter	Cancer	Heart and Lung Failure	Frailty	'Other'	All Subjects
RCS SE	70.83*** 3.11	68.60*** 3.09	77.09*** 1.69	63.77*** 3.64	73.63*** 1.35
Rate of change (linear) SE	-0.05*** 0.01	-0.02*** 0.002	-0.03*** 0.004	-0.02*** 0.004	-0.03*** 0.004
Rate of change (quadratic) SE	$4.17E^{-5}$*** $1.08E^{-5}$	ns	$9.24E^{-6}$** $3.53E^{-6}$	ns	$1.19E^{-5}$*** $2.90E^{-6}$
Rate of change (cubic) SE	$-1.05E^{-9}$*** $2.75E^{-9}$	ns	$-2.76E^{-9}$*** $7.57E^{-10}$	ns	$-3.35E^{-9}$*** $6.48E^{-10}$

*** significant to 0.001 level

** significant to 0.01 level

* significant to 0.05 level

ns: not significant

The rate of decline from admission to death is greatest for the subjects in the Cancer Group (rate of change = -0.05, SE-0.01, $p<0.001$) and is non-linear, while the subjects in the Heart and Lung Failure and 'Other' Groups have a slower, constant (linear) rate of decline in functional ability.

At the individual level, within group RCS is significantly related to time. These results identify that the 'trajectory of decline' exists in this population of NH residents and that these results may be generalisable to other populations of NH residents with equivalent characteristics.

Figure 4.10 Multiline graphs of functional change measured by the RCS from admission to death for subjects classified into diagnostic groups and showing the trajectory of the population-averaged subject in each diagnostic group.

Cancer Group

Heart and Lung Failure Group

Frailty Group

'Other' Group
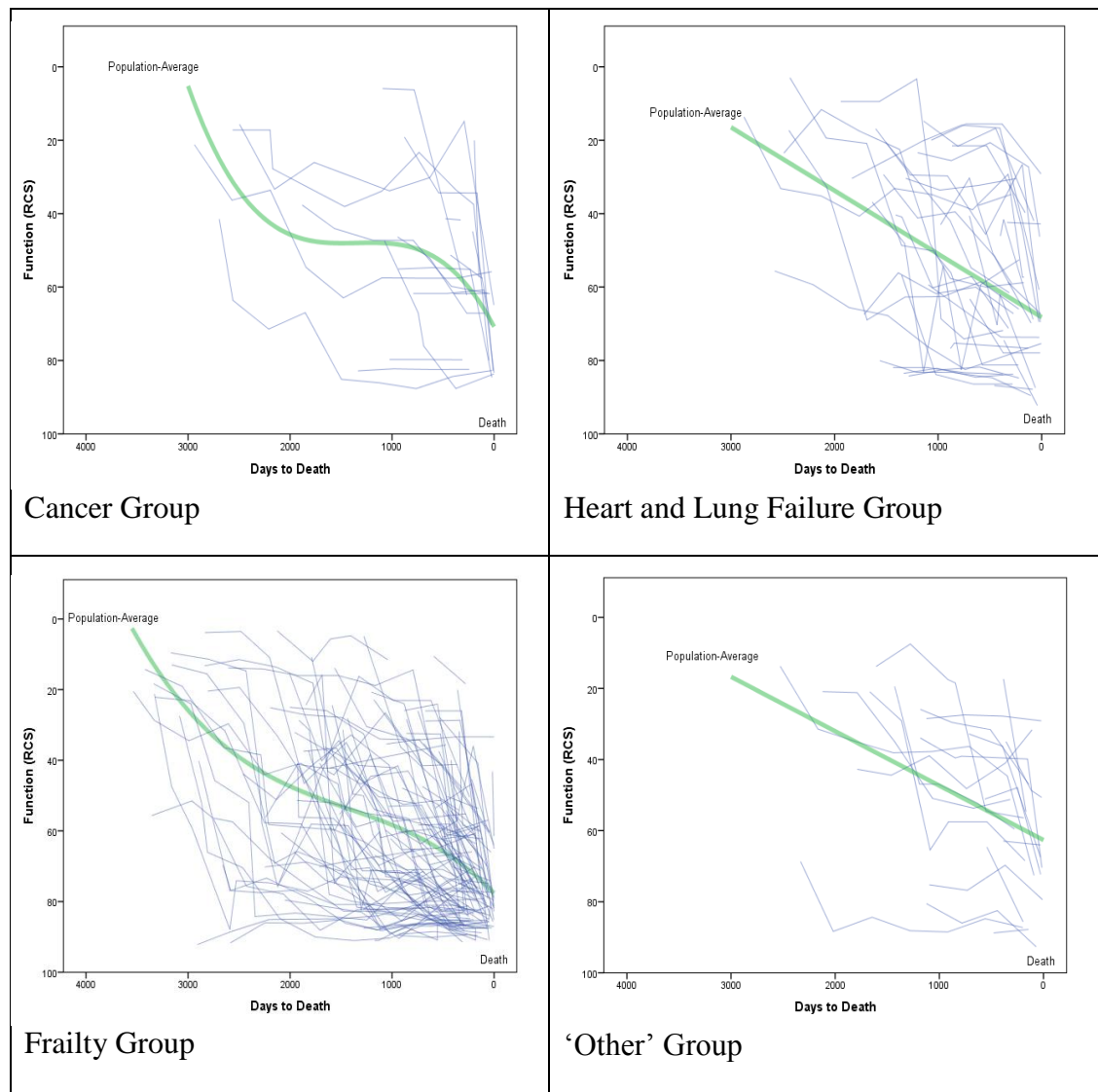
Each thin line in Figure 4.10 above represents an individual resident's trajectory of functional change over the course of admission to the NH. The thick line is the calculated population average of all the individual lines for that diagnostic group.

A. **For the Cancer Group (n=32),** the population averaged rate of decline (thick line) in functional ability as measured by the RCS was non-linear (p=0.001). On average, loss of function is greatest immediately after admission and prior to death with an interval of relative functional stability in between.

B. **For the Frailty Group (n=145)** also, the population-averaged rate of decline was non-linear ($p=0.001$), with a period of decline after admission and again before death but with a less marked intervening stable phase than that of the Cancer Group.

C. **For the Heart and Lung Failure and 'Other' Groups**, the decline was similar, and in each case statistically significant (Heart and Lung Failure ($p=0.001$); 'Other' ($p=0.001$)), but unlike the Cancer and Frailty Groups, the population-averaged rate of decline was constant (linear) over the course of admission to the NH.

The functional trajectory of each NH resident following their admission to the NH classified into the four diagnostic groups show a decline in functional ability similar to the depictions in previous publications (Lunney J, Lynn J *et.al.* 2002; Lunney J, Lynn J *et.al.* 2003). The population-averaged trajectory (depicted by the thick line) in all groups shows a decline in function from admission as the point of death is approached. However, there is large variability in the trajectories of individual residents in each group.

Principle findings

There is a trajectory of decline in each of the four diagnostic groups.

There is a difference between groups in the relationship between time and functional profile. The Cancer and Frailty groups have a non-constant rate of functional decline while the Heart and Lung Failure and 'Other' groups have a constant rate of decline.

 The average subject in the Frailty group has the lowest functional profile at death and the 'Other' group the highest functional profile at death compared with the other groups.

There is a large degree of variation in the trajectory of decline for individuals within each group.

4.11 The relationship between function, as measured by the RCS, and time for the 12 month period before death for residents of NH grouped according to their cause of death

Unlike previously reported empirical evidence of functional decline in the diagnostic groups (Lunney *et.al.* 2002 and 2003) that reported results for the 12 months to death only, this research had access to a measure of function for all subjects from the point of admission to the NH to death and this has been reported in the previous section. However in order to compare this research with the referenced empirical research the analysis in this section restricts the available dataset to just the 12 month period before death for the NH subjects.

The averaged slope in these graphs was recalculated using the Group mean at each 30 day interval in the 12 months before death which replicates the method used by Lunney in the 2003 empirical paper. The results used to create the graphs above, the mean RCS at each 30 day interval in the 12 months before death as well as the change in the rate of decline, are listed in Table 4.11 below. While not as obvious as compared to the slope shown for the entire admission (Figure 4.10 p172), the averaged slope (thick line), does demonstrate despite the restricted dataset, functional decline in all groups with the Cancer Group appearing to have the greatest variability in the rate of decline. Also apparent is the extensive variability in the level of function at 12 months before death and the level of function at death between individuals (thin lines).

Figure 4.11.1 Multiline graphs of functional change measured by the RCS from 12 months before death for subjects classified into diagnostic groups and showing the Group mean RCS and rate of change calculated in 30 day intervals

Cancer

Heart or Lung Failure

Frailty

'Other'
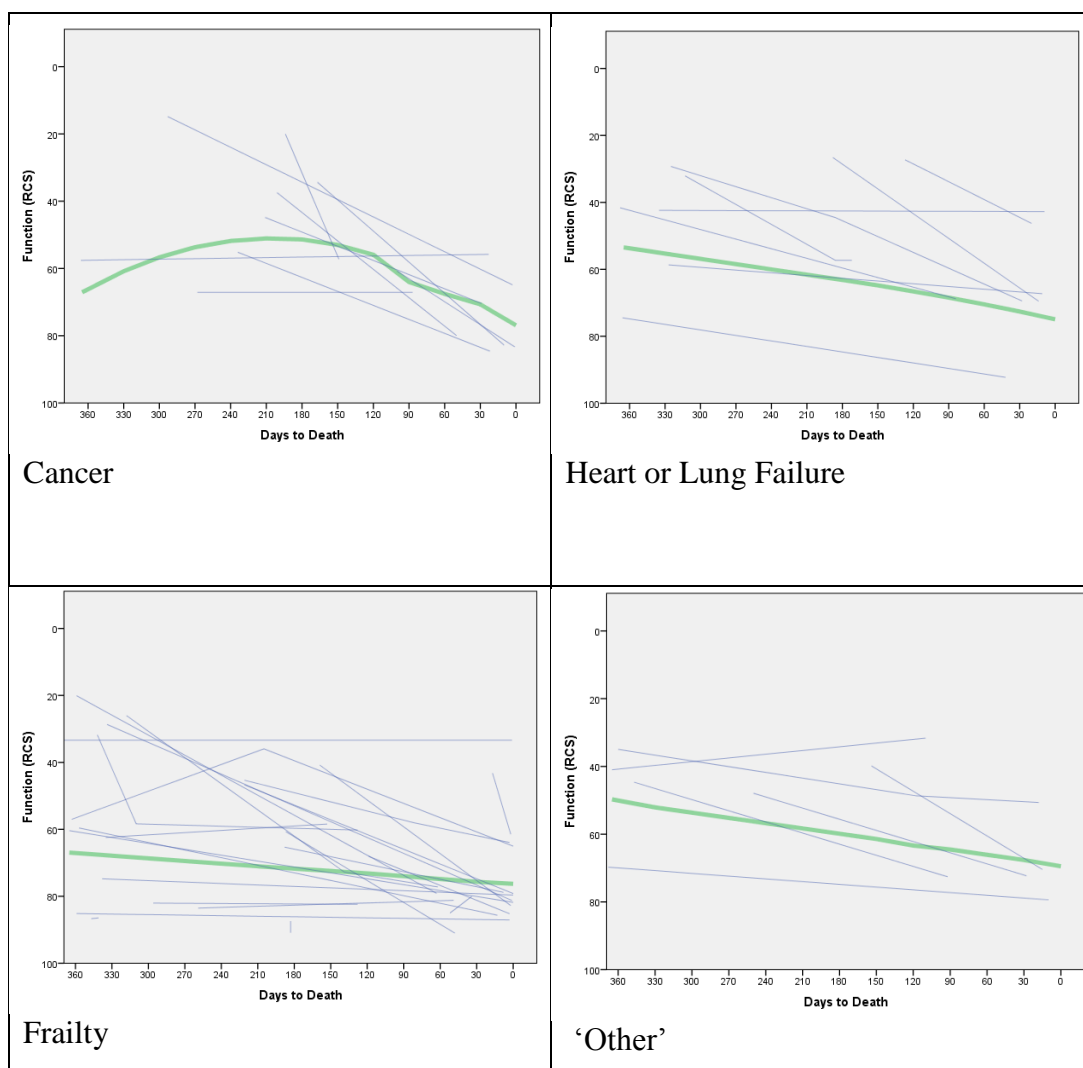
This variability is also demonstrated in Figure 4.11.2 (below) showing the range of the 95% confidence interval for this restricted data set.

Figure 4.11.2 Functional change measured by the mean RCS from 12 months before death for subjects classified into diagnostic groups calculated in 30 day intervals with error bars representing the 95% CI for the mean RCS

Cancer

Heart or Lung Failure

Frailty

'Other'
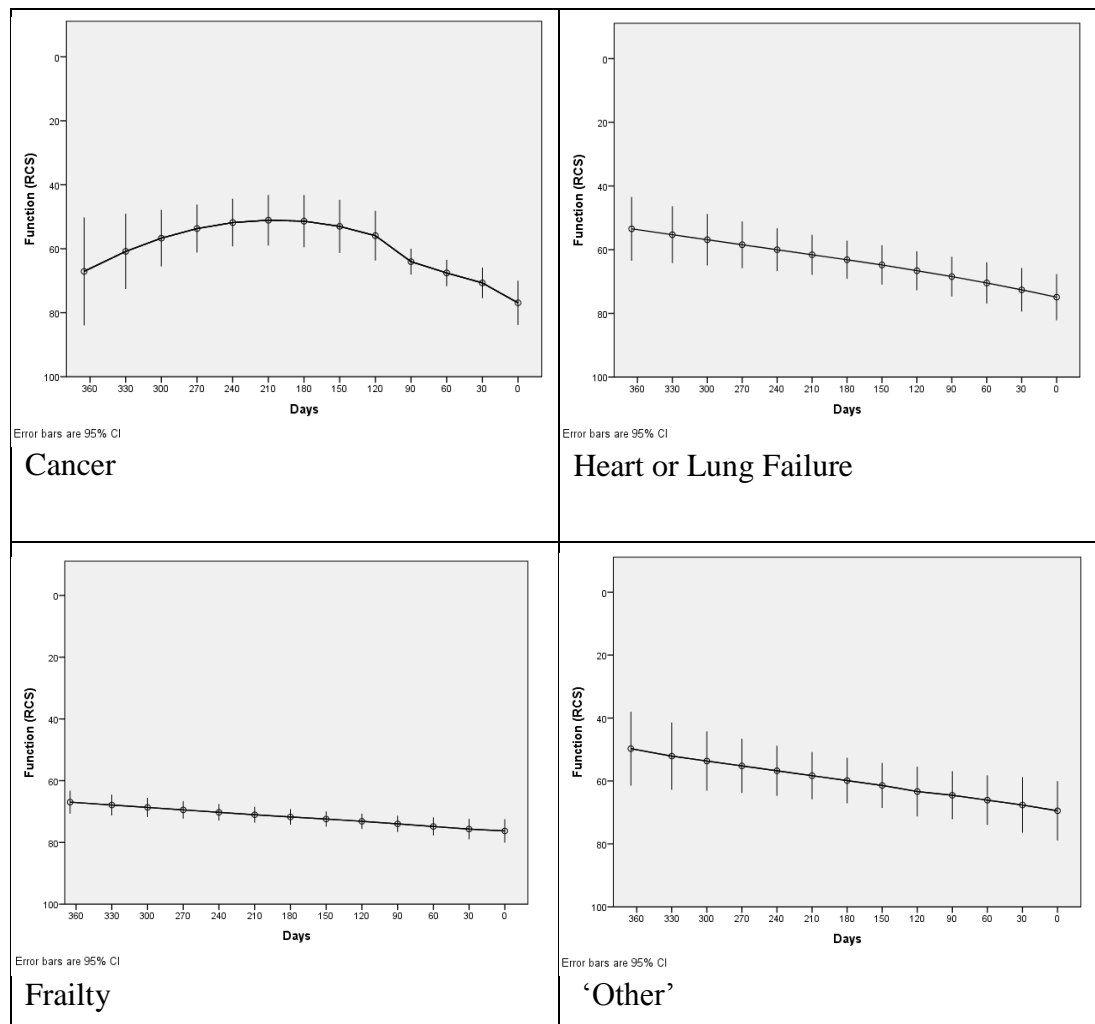
The two figures in this section are different representations of the same data. In the first figure it can be seen that the individual trajectories vary over time. That is, in the 12 months before death, each subject's functional ability varies. However the intention of research such as this is to identify a trend, allowing care providers to more accurately predict the resources required to care for their clients in advance. While the individual variation is true, this research is seeking a mean. In both figures a mean trend calculated from the restricted 12 month dataset (Table 4.11 p178) is represented by the thick line. The 95% confidence interval for the RCS in each 30 day period is shown in Figure 4.11.2 as error bars. The top of the error bar shows the maximum RCS score and the base of the error bar shows the minimum RCS score. That is for any given 30 day period before death,

any nursing home resident in their defined diagnostic group will have, with 95% confidence, an RCS score between the error bars. For example for a nursing home resident in the Cancer Group 12 months before death, the mean RCS is 68. However the error bars shows that in this population, the RCS at 12 months before death could also be 50, or at the other extreme, 85. This range represents a functional ability between moderate care needs to the very highest level of need. In contrast on the same graph at 3 months (90 days) before death, the 95% confidence interval for the mean level of need is an RCS score between 60 and 65.

This variation around the mean demonstrated in the above figures describes the trajectories for a set of subjects with 95% confidence that these findings could be generalised to similar populations. However it does not assist the care provider in predicting the care needs in advance of this population. The next step is to develop a prediction model and to test the results for the prediction model against these results.

Table 4.11 Parameters of the fitted models of functional decline from 12 months (365 days) to death by 30 day intervals for NH residents grouped by cause of death

Days before Death	Parameter	Cancer	Heart and Lung Failure	Frailty	'Other'
365 days	RCS	67.08***	53.46***	66.96***	49.73***
	(SE)	(8.33)	(4.94)	(1.88)	(5.49)
	Rate of change	0.20*	- 0.05**	-0.03***	- 0.05*
	(SE)	(0.09)	(0.02)	(0.007)	(0.02)
330 days	RCS	60.82***	55.30***	67.88***	52.09***
	(SE)	(58.1)	(4.43)	(1.70)	(5.03)
	Rate of change	0.16	- 0.05**	- 0.03***	- 0.05*
	(SE)	(0.08)	(0.02)	(0.007)	(0.02)
300 days	RCS	56.69***	56.87***	68.67***	53.65***
	(SE)	(4.37)	(4.02)	(1.57)	(4.60)
	Rate of change	0.12	- 0.05**	- 0.03***	- 0.05*
	(SE)	(0.07)	(0.02)	(0.007)	(0.02)
270 days	RCS	53.68***	58.45***	69.46***	55.21***
	(SE)	(3.70)	(3.66)	(1.45)	(4.22)
	Rate of change	0.08	- 0.05**	- 0.03***	- 0.05*
	(SE)	(0.05)	(0.02)	(0.007)	(0.02)
240 days	RCS	51.81***	60.02***	70.25***	56.76***
	(SE)	(3.67)	(3.35)	(1.36)	(3.90)
	Rate of change	0.04	- 0.05**	- 0.03***	- 0.05*
	(SE)	(0.04)	(0.02)	(0.007)	(0.02)
210 days	RCS	51.08	61.60***	71.04***	58.32***
	(SE)	(3.90)	(3.11)	(1.30)	(3.65)
	Rate of change	0.006	- 0.05**	- 0.03***	- 0.05*
	(SE)	(0.03)	(0.02)	(0.007)	(0.02)
180 days	RCS	51.38***	63.17***	71.74***	59.87***
	(SE)	(4.06)	(2.97)	(1.27)	(3.50)
	Rate of change	- 0.03	- 0.05**	- 0.03**	- 0.05*
	(SE)	(0.02)	(0.02)	(0.007)	(0.02)
150 days	RCS	53.01***	64.80***	72.43***	61.42***
	(SE)	(4.09)	(3.05)	(1.24)	(3.47)
	Rate of change	- 0.07***	- 0.07**	- 0.03*	- 0.05*
	(SE)	(0.02)	(0.02)	(0.007)	(0.02)
120 days	RCS	55.90***	66.60***	73.15***	63.35***
	(SE)	(3.82)	(3.03)	(1.25)	(3.80)
	Rate of change	- 0.10***	- 0.06**	- 0.03*	- 0.05
	(SE)	(0.03)	(0.02)	(0.007)	(0.02)
90 days	RCS	64.04***	68.45***	74.69***	64.53***
	(SE)	(1.96)	(3.09)	(1.33)	(3.71)
	Rate of change	- 0.09**	- 0.06*	- 0.03***	- 0.05*
	(SE)	(0.03)	(0.02)	(0.007)	(0.02)
60 days	RCS	67.57***	70.46***	74.84***	66.09***
	(SE)	(1.99)	(3.22)	(1.47)	(3.91)
	Rate of change	- 0.09**	- 0.07**	- 0.03*	- 0.05*
	(SE)	(0.03)	(0.02)	(0.007)	(0.02)

continued over…….

Days before Death	Parameter	Cancer	Heart and Lung Failure	Frailty	'Other'
30 days	RCS	70.68***	72.62***	75.67***	67.64***
	(SE)	(2.30)	(3.40)	(1.66)	(4.32)
	Rate of change	- 0.09**	- 0.07**	- 0.03*	- 0.05*
	(SE)	(0.02)	(0.02)	(0.007)	(0.02)
	RCS	76.92***	74.91***	76.28***	69.47***
	(SE)	(3.35)	(3.60)	(1.92)	(4.61)
Death	Rate of change	- 0.23**	- 0.07**	- 0.03*	- 0.05*
	(SE)	(0.08)	(0.02)	(0.007)	(0.02)

***significant to 0.001 level
**   significant to 0.01 level
*   significant to 0.05 level

The data reported in Table 4.11 is pictured in Figure 4.11.1. Except for the Cancer group, the trajectories are linear and negative throughout the 12 month period toward death for these NH residents. Within the overall linear decline in function, the rate of change does show some small variations over that period, in particular for the 30 day period just before death.

The Cancer Group trajectory is quite irregular compared to the other groups. This could be the result of the first two data points being at the extreme ends of the range (Figure 4.11.2 p176). Such a broad variation could be modified by increasing the volume of data in this group.

Principle findings

There is a trajectory of decline in each of the four diagnostic groups in the 12 months prior to death.

The rate of functional decline varies in each of the groups.

There is a large degree of variation in the trajectory of decline for individuals within each group. At 12 months before death the average subject in the Frailty group has the least functional ability and the average subject in the 'Other' group had the highest functional ability as measured by the RCS.

4.12 Investigation of variance in the dependent variable, RCS and rate of change over the entire NH admission for all subjects using a linear mixed effects model

A linear mixed model was developed using SPSS (v20). As described in the Methods, fitting a mixed model correctly is very complex but the benefit of this method is being able to capture the patterns of change by reducing the error variance by capturing the random effects. Comparison of the dependent variable RCS for all subjects with fixed and random effect variables is shown in Table 4.12.1 below.

Table 4.12.1 Fixed and random effects model demonstrating effect of fixed variables, comparison between groups for the intercept and slope and the random effect of NH (n=990)

Fixed Effects[a]	Estimate	SE	(*p*-value)
Intercept ('Other' Group)	91.28	13.57	(*p*<0.0001)
Age at Admission	- 0.33	0.15	(*p*=0.03)
Female	1.89	2.19	(*p*=0.39)
Comparison between groups for effect on the intercept:			
Cancer Group[b]	2.64	4.64	(*p*=0.57)
Heart or Lung Failure Group[b]	3.47	4.32	(*p*=0.42)
Frailty Group [b]	12.27	3.71	(*p*=0.001)
Slope of RCS over time ('Other' Group)	- 0.018	0.004	(*p*<0.0001)
Comparison between groups for effect on the slope:			
Cancer Group rate of change [b]	- 0.0003	0.006	(*p*=0.97)
Heart or Lung Failure Group rate of change[b]	- 0.0007	0.005	(*p*=0.89)
Frailty Group rate of change[b]	- 0.0017	0.004	(*p*=0.69)
Random Effects[a]	Variance	SE	(*p*-value)
Residual effects	117.22	6.94	(*p*<0.0001)
Subject variance	202.61	25.35	(*p*<0.0001)
Slope variance	0.00012	0.00003	(*p*<0.0001)
NH variance	28.11	27.74	(*p*=0.31)
AIC (df)	7808.09 (14)		

[a] Fitted with 'variance components' covariance matrix as model of 'best fit'
[b] Referenced to 'Other' group

In the previous section (Section 4.10 and 4.11), the data were analysed with the same statistical test (SPSS (v20) [linear mixed model]) but without the inclusion of any variables that may account for the degree of variance seen in the individual trajectories. In Table 4.12.1 above, the same data were analysed with a model that includes the variables of age, sex and group (referenced to 'Other' Group) to determine the effect of these fixed variables on the outcome variable RCS measured at death (where time = 0 = the intercept). Also included as a fixed effect is an interaction term (group*time) to determine the effect, if any, of group on the rate of change of the outcome variable RCS. As noted above, NH was included as a random effect.

As age at admission increases by one year, the RCS at death decreases by a third (0.33 year). The effect of sex (female) on the RCS at death is not significant. The effect of group on the mean RCS at death is significant. However when the mean of each group is compared (Table 4.12.2 below), the difference is significant only when the Frailty Group is compared to the other three groups. Each of the groups do not have a significant effect on the slope of RCS over the course of the NH admission in this model.

Figure 4.12.1 Application of predictive model to determine level of function (RCS) in relation to admission time
The following example of a 71 year old, female with a cancer diagnosis entering the NH 340 days before death, demonstrates how these results can be used to develop a prediction model:
RCS on admission (day340 before death) = 91.28+(-0.33 x71)+2.64+(-0.018x340)=64.37
RCS at death (day0)= 91.28+(-0.33 x71)+2.64+(-0.018x0)=70.49

The total amount of variance in this model is 347.94. There is a measurable but non-significant effect when NH is included in the model as a random effect (var=28.11, SE=27.74, p=0.31). A model selection process comparing AIC demonstrates that including NH in the model as a random effect improves the model, accounting for 8% of the variance despite the effect being non-significant. Further inference regarding NH level differences is not warranted with these data due to the limitation of only four NH in a similar geographic area as well as the lack of data collected about the NH that may affect the RCS (such as staffing levels or dementia specific units).The largest source of variance in random effect

comes from the subjects themselves (var=117.22, SE=6.94, $p<0.0001$) which accounts for a third (33.69%) of the variance which can be seen in the multiline graphs of Figure 4.10.

Table 4.12.2 Pairwise comparisons of group mean RCS[a] using estimated marginal means

Group (A)	Group (B)	Mean Difference (A-B)	Std. Error	Sig.[b]
Cancer	Heart Lung Failure	- 0.413	5.191	0.937
	Other	2.430	5.914	0.682
	Frailty	- 8.270	4.521	0.069
Heart Lung failure	Cancer	0.413	5.191	0.937
	Other	2.843	5.187	0.584
	Frailty	- 7.857[*]	3.495	0.026
Other	Cancer	- 2.430	5.914	0.682
	Heart Lung failure	- 2.843	5.187	0.584
	Frailty	-10.700[*]	4.485	0.018
Frailty	Cancer	8.270	4.521	0.069
	Heart Lung Failure	7.857[*]	3.495	0.026
	Other	10.700[*]	4.485	0.018

Based on estimated marginal means
* The mean difference is significant at the .05 level.
a Dependent Variable: RCS score.
b Adjustment for multiple comparisons: Least Significant Difference (equivalent to no adjustments).

Pairwise comparison of group means (EMMs), shown in Table 4.12.2 above, confirms that the Frailty Group RCS mean is significantly different when compared with the other three groups, but none of the other three groups RCS means are comparatively different to a significant level.

Table 4.12.3 Fixed and random effects model demonstrating effect of fixed variables, comparison between groups for the intercept and slope and the random effect of NH in the <u>12 month period</u> to death (n=286)

Fixed Effects[a]	Estimate	SE	p-value
Intercept ('Other' Group)	86.785	13.409	p<0.0001
Age at Admission	- 0.224	0.150	p=0.138
Female	0.563	2.217	p=0.800
Comparison between groups for effect on the intercept:			
Cancer Group[b]	3.994	5.822	p=0.494
Heart or Lung Failure Group[b]	0.310	5.765	p=0.957
Frailty Group [b]	8.527	5.064	p=0.094
Slope of RCS over time ('Other' group)	- 0.044	0.027	p=0.103
Comparison between groups for effect on the slope:			
Cancer Group rate of change [b]	- 0.026	0.035	p=0.453
Heart or Lung Failure Group rate of change[b]	0.009	0.034	p=0.791
Frailty Group rate of change[b]	0.014	0.029	p=0.640
Random Effects[a]	Variance	SE	.
Residual effects	175.083	37.960	p<0.0001
Subject variance	46.244	35.791	p=0.196
Rate of change variance	0.001	0.001	p=0.047
NH variance	24.761	24.816	p=0.318
AIC (df)	2416.61 (14)		

[a] Fitted with 'variance components' covariance matrix as model of 'best fit'
[b] Referenced to 'Other' group

Restricting the analysis to the data for the period 12 months to death only, has identified that increasing age at admission has a negative but non-significant effect on the RCS. Sex has a non-significant effect. However there is no significant effect of group on the intercept or slope for these data when referenced to the 'Other' Group.

The results of the predictive model shown in Table 4.12.3 should not be compared with the whole dataset results in Table 4.12.1 because the difference in the results is either because the variation is harder to capture in the last 12 months of life using the RCS as the outcome or the dataset is too small and that the model does not fit as well/is less predictive.

> **Principle findings**
>
> In relation to functional profile at death, the Frailty Group is different to the other three groups. The other three groups are not different to each other. In relation to the slope there is no difference between the four groups over the entire admission.

4.13 Effect of variables within each diagnostic group on RCS and rate of functional change

Subjects were allocated to their diagnostic group based on their cause of death (Lunney J, Lynn J *et.al.* 2002) and the statistical model developed in Section 4.12 was applied to the subjects in each diagnostic group. There are insufficient data available in this study to fit the model for the period 12 months to death.

Table 4.13 Estimates of fixed effect and random effects of variables for subjects grouped by their cause of death over the <u>entire admission</u> period

Fixed Effects	*Cancer*	*Heart or Lung Failure*	*Frailty*	*'Other'*
Mean RCS at death (SE)	84.61 * (30.71)	84.06** (30.66)	105.70*** (17.23)	124.43** (41.44)
Age at admission (SE)	-0.23 (0.37)	-0.19 (0.35)	-0.37 (0.20)	-0.73 (0.49)
Female (SE)	4.28 (5.25)	0.01 (6.50)	2.58 (3.02)	1.68 (4.09)
Rate of change (SE)	- 0.019 ** (0.005)	-0.018*** (0.002)	-0.019 *** (0.001)	-0.018 *** (0.004)
Residual variance (SE)	133.65 *** (25.45)	115.32 *** (15.91)	121.41 *** (9.15)	74.81*** (14.20)
Subject variance (SE)	113.73 (59.59)	319.51 *** (86.31)	176.81 *** (30.79)	272.44** (94.38)
Rate of change variance (SE)	$2.21E^{-4}$ $(1.86E^{-4})$	$8.70E^{-5}$ $(4.51E^{-5)}$	$1.29E^{-4}$*** $(3.94E^{-5})$	$1.34E^{-4}$ $(8.15E^{-5})$
NH variance (SE)	57.42 (74.24)	47.73 (75.15)	13.15 (17.56)	[b]

[a] Fitted with 'variance components' covariance matrix as model of 'best fit'
[b] Random effect of FID could not be fitted in this model
*** significant to 0.001 level
**   significant to 0.01 level
*   significant to 0.05 level

Over the entire course of their admission to the NH, fixed effects included in this model, age at admission and sex, did not significantly predict RCS at death in any of the subjects grouped according to their diagnosis. For all groups, the rate of change did significantly and negatively predict the RCS. The relationship between RCS and rate of change showed significant variance across subjects in all groups. There was a measurable effect of NH, but this was not significant in any of the groups. The random effect of facility could not be measured in this model

for the 'Other' group due to the small sample size and the unbalanced data for this Group in all NH (Figure 4.8.2 p166).

Principle findings

The rate of change predicts the RCS at death.

There is a large amount of subject and residual variance within each group over the 12 month period before death in this NH population.

In the smaller data set for the 12 month period before death in this NH population, is no significant difference between groups for the RCS or rate of change of the RCS over time to death.

4.14 Nursing homes in Tasmania and the generalisability of this research

A total of four nursing homes in southern Tasmania (Australia) were convenience sampled for this research. In this section, the characteristics of the four participating nursing homes will be discussed and the results from this research compared with data annually reported by the Australian Institute of Health and Welfare (AIHW) and related population data from the Australian Bureau of Statistics (ABS) to show that the results of this study can be generalised to the broader Australian nursing home population.

Figure 4.14.1 Proportion of admission and deaths to the participating NH for the research data period.
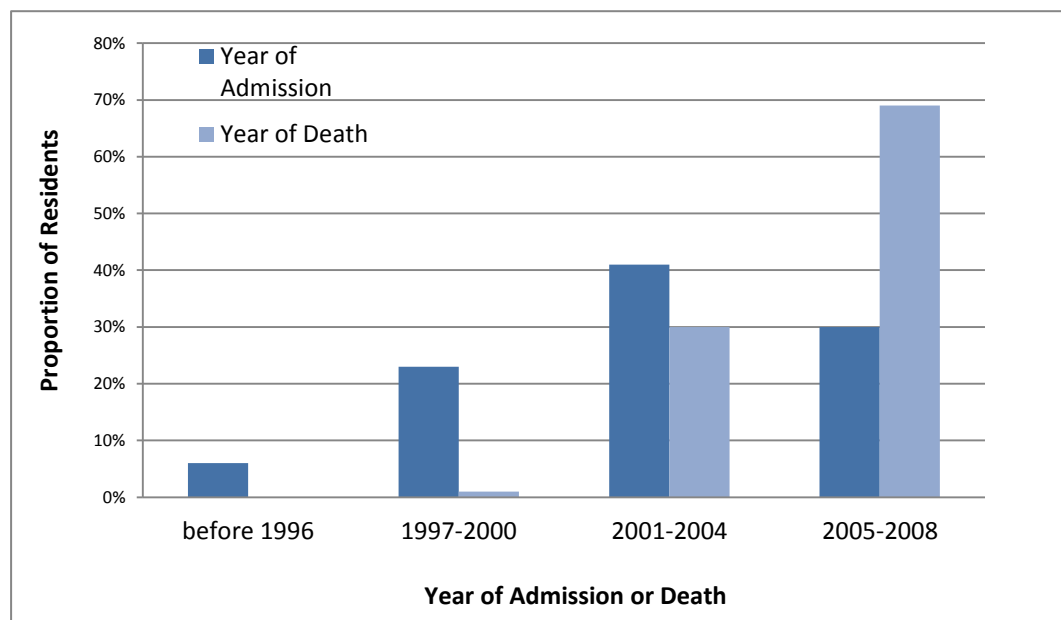
The data collected for this research included residents whose admission to the NH started in 1984 up to 2007 (Figure 4.14.1 above) and the period for their deaths was 1999 to early 2008 (before the commencement of ACFI). For the purpose of comparing these data with Australian data, the period that includes 71% of the admissions and 99% of the deaths is 2001-2007 with 2006 being the median year.

The total number of residents in NH in Australia as of 30 June 2006 was 166,291. Tasmania had one of the highest provision ratios per 1000 persons 70 years and older and the total number of residents in 2006 was 1,594 or 3% nationally

(Australian Institute of Health and Welfare 2007). Hence this research has included approximately 15% of the total number of NH residents in Tasmania at the time of the data collection.

The distribution of high care and low care places vary in all the NHs (Table 4.1.1 p145). All NH in Australia operate under the same funding formula and accreditation requirements for staffing and facility standards (Australian Institute of Health and Welfare, 2007) so no confounding effects related to the individual NH environment were expected or measured. The four nursing homes consented to participating in this research on the basis that no identifiable characteristics are included in the data.

The four NHs included in this research are representative of NHs in Tasmania. In 2006 there were 90 residential aged care services in Tasmania which was 3% of the national total. More than half of the services in Tasmania, and the four researched NHs, were located in 'inner regional' areas of the state. All four NHs were in the largest size of service range for Tasmania and were all not-for-profit (charitable or religious type). Less than one in ten NHs in Tasmania are classified as private type (Australian Institute of Health and Welfare, 2007).

The proportion of females included in this study ranged from 52% to 80% across the four participating NHs. The proportion of females in this study overall was 69% which is slightly less than the Tasmanian proportion which was 74% in 2006. The average age of admission was 84 years and there was very little variation in average age for the four NHs. The distribution of age on admission for residents of NHs in Tasmania and Australia compared to the research sample is shown in Figure 4.14.2 below.

Figure 4.14.2 Percentage of residents in admission to NH age groups for Tasmania and Australia compared to the research subjects.
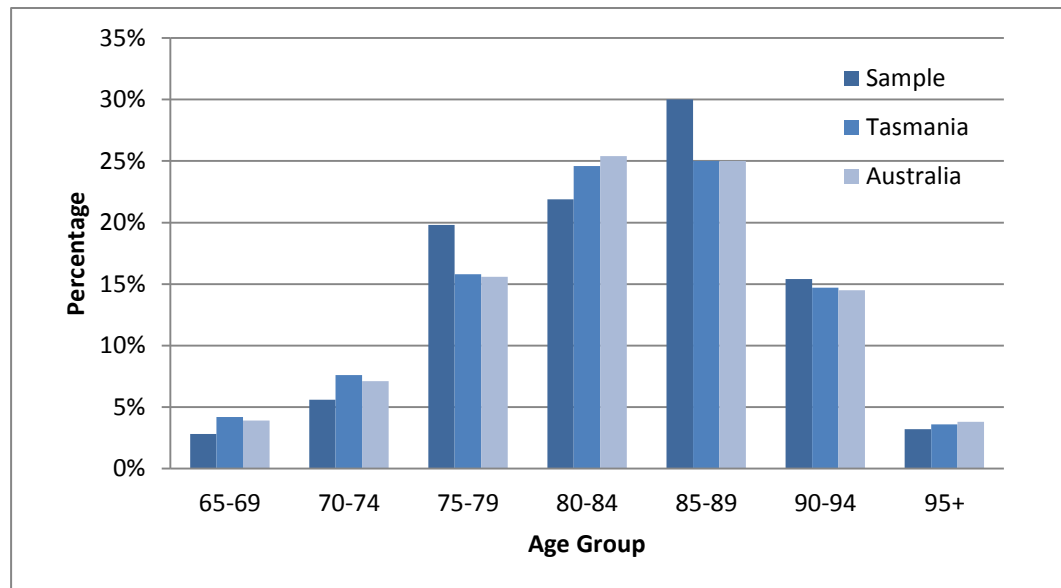
Data source for Tasmania and Australia is from (Australian Institute of Health and Welfare, 2007)

In comparison (Figure 4.14.2), Tasmania is generally similar in the age distribution of residents admitted to NHs in Australia in the period 2005-2006. The subjects included in this research have a higher proportion of admissions in the 75-79 and 85-89 age groups (20% and 30%) compared to Tasmania (16% and 25%) and Australia (16% and 25%) and fewer admissions in the 80-84 year age group.

The average length of stay for the research sample was similar to a Tasmanian and Australian NH population. For the research sample the average length of stay was 3.3 years (SD 3.3) ranging across the four NHs from 2.8 years (SD 2.3) in NH1 to 4.1 years (SD 3.9) for NH4 which may be accounted for because this NH also had the highest proportion of female residents. In Tasmania (2006) the average length of stay for females was longer, 3.5 years compared to males at 2.3 years and overall was 3.1 years which is longer compared to the Australian average length of stay in a NH in 2006 which was 2.8 years overall, being for females= 3.2 years and males=2.1 years (Australian Institute of Health and Welfare 2007).

4.14.1 Separation of residents to hospital before death

The pattern of transfer of residents from the NH to hospital prior to death was analysed. These data do not include residents who may be transferred to hospital for the statutory period of 30 days (RCS Manual 2005, p5:8) which would then be classified as a hospital separation even if they returned to the same NH place. Hence in regard to comparison with the national data the research data may be underrepresented for this mode of separation. The proportion of male and female residents transferred to hospital nationally was 5.2% and 4.5% and in Tasmania 2.4% and 1.8%. Similarly this research found that proportionally more male residents were transferred to hospital than female. The age of the residents transferred to hospital were also younger (86 years, SD=1.7) than the sampled NH population as a whole (88 years, SD=7.2). National data are not available to compare.

National data are available to make a comparison with the research sample for length of stay by separation mode. This comparison is shown for separation by death and separation by transfer to hospital for permanent residents in Figures 4.14.3 and 4.14.4 below.

Figure 4.14.3 Separation by death of permanent residents by length of stay (2006)
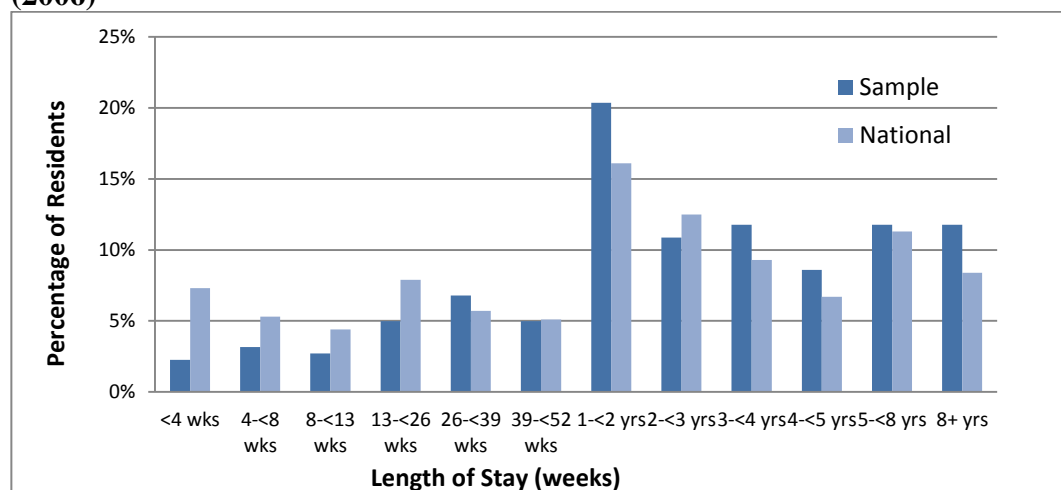
National data from Australian Institute of Health and Welfare, 2007:32)

The research sample shows a trend of longer length of stay before death than the national data (Figure 4.14.3). For example, only 2% of the research sample died

less than four weeks into their NH admission compared to the national NH population where 7% died less than four weeks into their admission. This suggests that unlike the national NH population Tasmanian NH's, or this sample of Tasmania NHs, have less short stay permanent residents and this has implications in regard to the workload associated with higher bed turnover in the facility.

Figure 4.14.4 Separation by transfer to hospital of permanent residents by length of stay
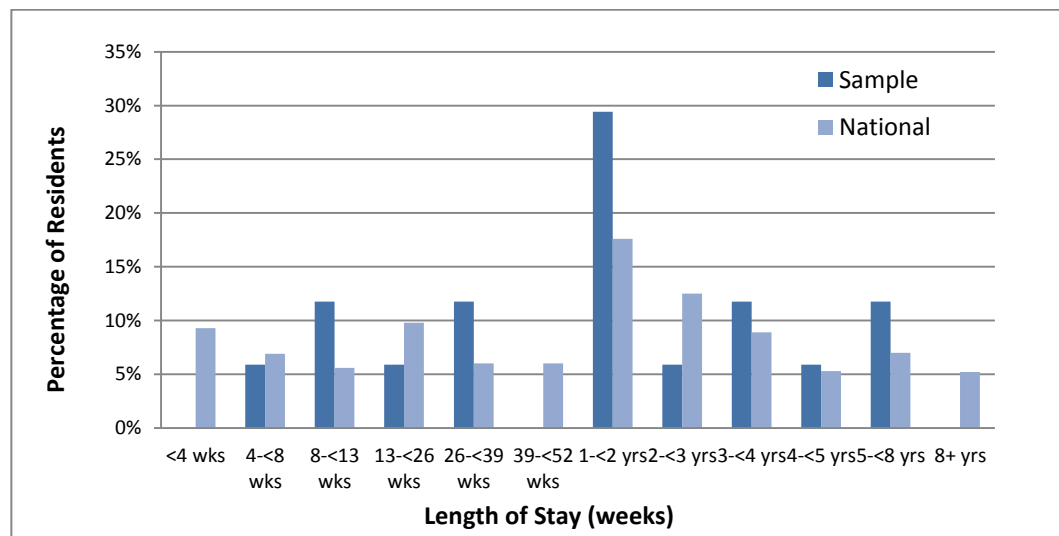
National data from Australian Institute of Health and Welfare, 2007:32)

From Figure 4.14.4 above, it appears that the pattern of transfer of residents to hospital has a similar distribution over the course of their admission to the national data with a 'spike' in the one to two year admission period which may be related to the higher proportion of males in these data whom have a shorter length of stay than female residents.

The majority of separations from NHs in Australia are by death - the national average being 87%. Tasmania and ACT had the highest percentage of separations through death (95%) (Australian Institute of Health and Welfare 2007).

4.14.2 Characteristics of residents before entry to the nursing home

In order to identify the functional profile of the subject before entry to the NH, the data from the ACAT assessment was collected. This section compares the research data with the Tasmanian and national data.

Figure 4.14.5 Marital status of permanent residents on entry to NH
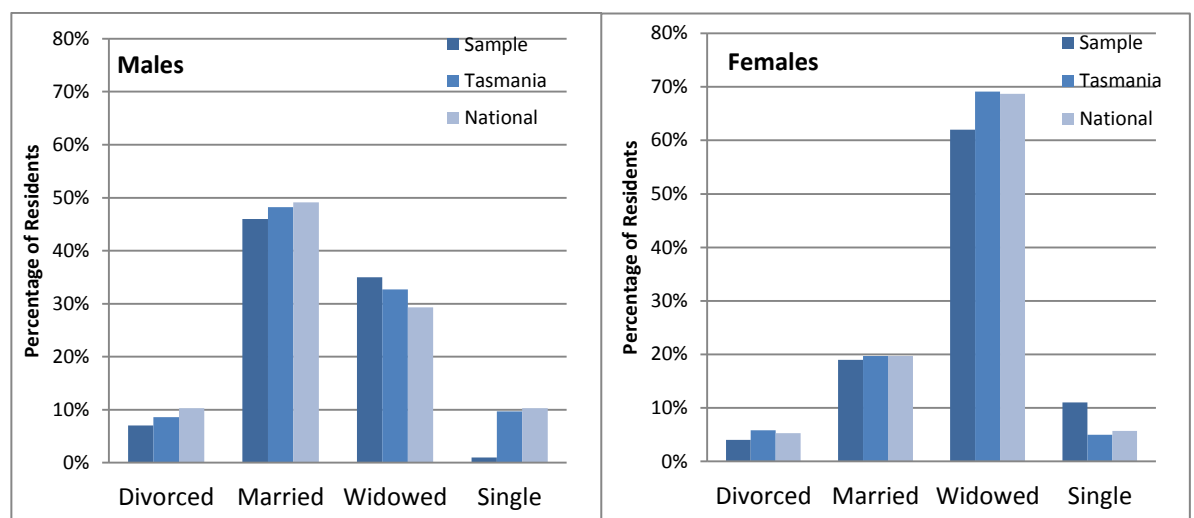
Tasmanian and National data from Australian

Institute of Health and Welfare, 2007 #1723 (p61); research data from Table 4.4.2

Data on marital status is collected from the Aged Care Application and Approval (ACAA) form completed by an Aged Care Assessment Team (ACAT) officer in the 12 months before admission. The proportion of residents married *etc,* are generally similar between the research sample, Tasmania and nationally (Figure 4.14.5 above) including the nearly double difference between the proportions of widowed males (35%) and females (62%). There is a difference in the proportion of single (never married) males and females in this sample and this may reflect the impact of the loss of a generation of males during WW2 having a greater impact on the smaller Tasmanian population as well as the lower rates of migration to the state post-war (Jackson N 2005).

Figure 4.14.6 Living arrangements of permanent residents before entry to NH
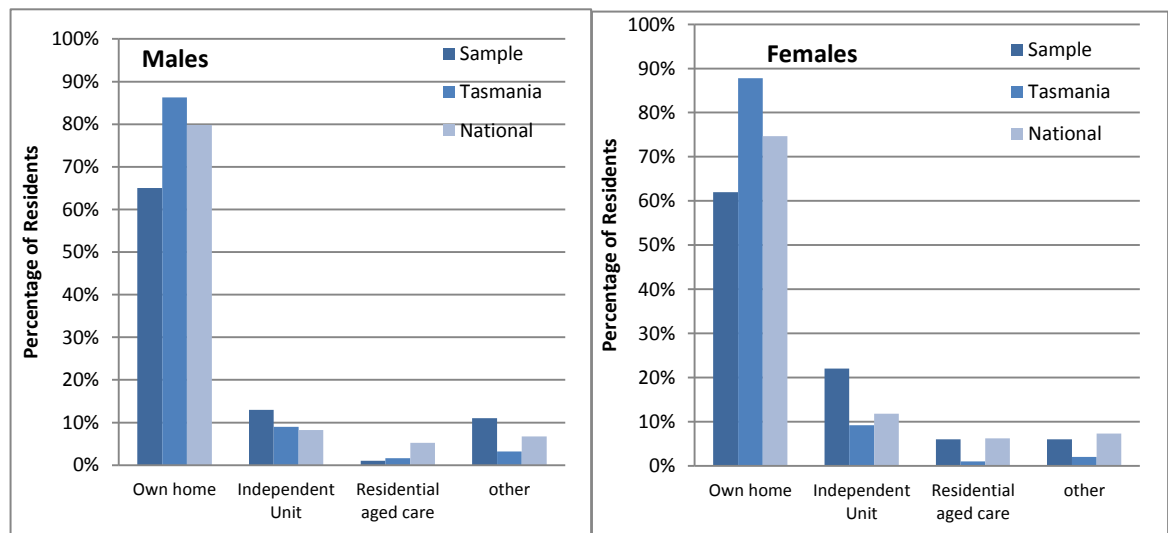
Tasmanian and National data from AIHW_RAC_2006 (p65); research data from Table 4.4.2

Proportionally fewer males and females in the research sample lived in their own home prior to their NH admission compared to the Tasmanian and national proportions (Figure 4.14.6 above). More females in particular resided in an independent unit or residential aged care before entering permanent residential care.

Before entry to the nursing home, the level of care is assessed by an ACAT official independent of the aged care provider and documented on the ACCR form. The data from the research sample is compared with the Tasmanian and national data for level of care requirements on admission, high or low, and before entry to residential aged care (from the ACAT assessment) in Figure 4.14.7 below.

Figure 4.14.7 Dependency levels for residents before admission and on admission to NH
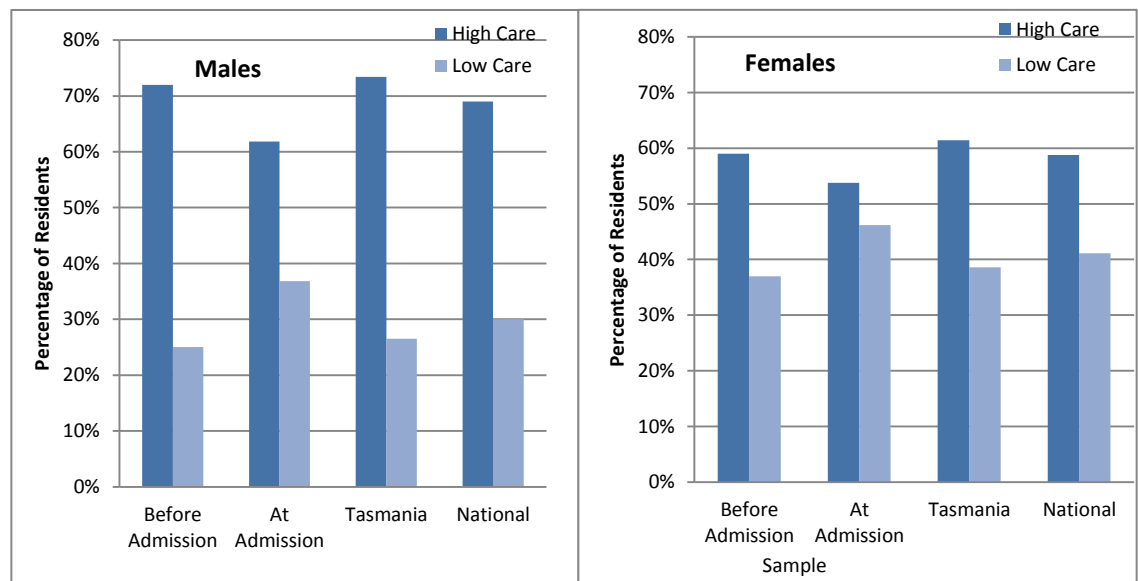
Tasmanian and National data from Australian Institute of Health and Welfare, 2007:71); research data from Tables 4.2 and 4.4.5

The most striking difference between males and females before and on admission to the NH is that for males the proportion of High Care assessments is nearly double the number of Low Care assessments. This difference has implications for predicting the future care needs of the elderly population. A recent study by McCann (McCann M, Donnelly M *et.al.* 2012) has demonstrated that this difference is due to women marrying men older than themselves and hence when the time comes, the male spouse is older and frailer and less able to care for his younger wife when needed (McCann et.al. 2012). These authors suggest that as the gap in life expectancy continues to decrease this difference between males and females will also narrow. Hence the rates of home care by either partner will increase and the demand for residential aged care will both decrease while the acuity at admission will increase for both males and females.

The data for the level of dependency for the research data and the Tasmanian and national data is similar except that there appears to be more admissions in the Low Care range in Tasmania. Also the level of care on admission is less compared to the ACAT assessment done before the actual admission. That is, when measured

in their own home or in hospital, the level of care required is higher than when measured on admission to the NH which is in contrast to the research by Robinson that using a self-rated questionnaire of nursing home staff, found a 11% rate of reassessment of residents from low to high care on admission compared to the ACAT assessment (Robinson A, Rumble R *et.al.* 2006). The difference between the research data and the national data may be because of data missing on 14% of the subjects who did not have an ACAT assessment available for this analysis.

4.14.3 Effect of nursing home on subject characteristics

Using a univariate statistical analysis (Section 4.1) some variance in the characteristics of the residents for age at admission, sex, RCS on admission and RCS at death is observed between the participating NH (Table 4.1.1). Later in the analysis, NH was included in the multivariate statistical model as a 'random' variable (Table 4.8) that shows that NH accounts for a small (12%), but non-significant amount of subject variance.

Because all registered nursing home places in Australia are funded by just one source and regulator, the Australian Government, a degree of homogeneity between facilities is be expected and the results of this research supports this assertion.

Principle findings

Despite there are some differences between characteristics of this small research data set compared with the Tasmanian and National data, there is overall homogeneity which supports generalisability of this research.

Chapter 5 Discussion and Conclusion

5.0   Introduction

This final chapter begins with a restatement of the research questions and aims for the thesis. Following a summary of the findings these research questions are then answered. The discussion focusses on three issues raised by the key finding of the research that there are two trajectories of decline in an Australian nursing home population. Implications of the use of the trajectory of decline in aged care in Australia in the current policy and care contexts are proposed before noting the strengths and weaknesses of the research. The chapter concludes with recommendations for further research to identify ways to improve the utility of the trajectory of decline model in policy and care provision and then a final conclusion.

5.1   Restatement of the research questions and aims

5.1.1   Research questions

1. Can a trajectory of decline be identified in the functional profiles of a residential aged care population?
2. How does the trajectory or trajectories of decline identified in the Australian nursing home context compare to the trajectories of decline identified by Lunney and colleagues(Lunney J, Lynn J et.al. 2002) and (Lunney J, Lynn J et.al. 2003) in US community living elders?
3. Are there multiple diagnostic groups as identified by Lunney and colleagues in US community living elders amongst a residential aged care population or are they all identified as 'frailty'?

5.1.2   Aims and rationale for the research

1. To develop a methodology that enables tracking of the resident functional trajectory in residential aged care settings using routine data;
2. To explore the degree to which a population of elderly people resident in residential aged care fits within the multiple trajectory functional profiles as found by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2002) and (Lunney J, Lynn J *et.al.* 2003); and

3. To examine the extent to which the trajectory of decline can prospectively predict care needs in an elderly population.

5.2   Summary of the findings

This research has established that using the RCS scores of a small subset of elderly Australians resident in a nursing home their level of function at admission to the nursing home is higher than their level of function at death (Section 4.3). While this is not new information, the research has demonstrated that the RCS is sensitive to this change which is encouraging of further research. Furthermore, using the methodology described by Lunney (Lunney J, Lynn J *et.al.* 2002) this subset of elderly NH residents was grouped according to their cause of death with proportions of the population in each group being found to be similar to the Lunney research. On this basis, the analysis progressed to identifying any difference in the functional profile of the NH subjects in each group as compared to the Lunney and colleagues community sample (Lunney J, Lynn J *et.al.* 2003).

In Section 4.8 of the Results, the characteristics of the subjects in each of the four diagnostic groups were compared (Table 4.8 on page 165). The means for age at admission, age at death, length of stay and level of function at admission were not significantly different. The comparison of the mean level of function at death does show a significant (p=0.007) difference between the groups. The group with the highest level of care need is the frailty group (RCS =73.6, SD=14.5) and the group with the least level of care need is the 'other' group (RCS = 63.9, SD=15.8). This result is similar to the finding of Lunney (Lunney J, Lynn J *et.al.* 2003) who report that the frailty group was more dependent at death and the 'other' group having a less marked decline. However comparison with the Lunney and colleagues research of functional decline for the trajectory groups is difficult. The Lunney research used functional data based on self-reported or proxy-reported ability on seven ADLs appropriate for community living elders. The RCS in contrast has 20 domains of care needs including behavioural support associated with dementia care and is determined by aged care nurses.

The identified relationship between length of stay and decline in functional ability in this population is clearly seen in the multiline graphs of the individual trajectories of decline for each subject in this study (Figure 4.10 on page 171). The population-average line for each diagnostic group was estimated from the intercept and slope results from a linear mixed model. This analysis determined that the mean RCS at death for all subjects is 73.63 (SE=1.35, $p<0.001$) and the rate of change was non-linear and negative, meaning that the rate of decline had periods of slowing down, speeding up and relative stability, but that dependency always increases toward death (rate of change= -0.03, SE=0.004, $p<0.001$). The frailty group (Table 4.10 on page 171) have the highest mean RCS at death (RCS = 77.09, SE=1.69, $p<0.001$). The graphs shown in Figure 4.10 (p172) graphically demonstrate that there is a large degree of variability between the individual trajectories of the subjects in each diagnostic group and this required further analysis.

To identify the source of the variance shown in the multiline graphs in Figure 4.10 (p172) the linear mixed model used to identify the average RCS for each group was further developed to include possible variables. From the data item, the variables included in this model were the subject characteristics of age at admission, sex, and the diagnostic group. To test whether the unknown characteristics of the nursing home had an effect of the variance, nursing home was included as a random effect in this model. The relationship between these variables and the RCS was tested (Table 4.12.1 on page 180). It was found that age had a negative effect on the RCS at death (estimate= -0.33, SE=0.15, $p=0.03$). That is as age at admission increases, the RCS at death decreases by a third. This means that the older the person is at admission to the NH the less dependent they are at death, which seems counter-intuitive. However, as an example, a 70 year old admitted to a NH is more likely to have health problems and high care needs that could not be cared for in the community, compared to an 85 year old who has stayed in the community for longer and is needing NH care because of conditions associated with ageing (Weiss C 2011). This provides an insight to the different resource requirements of different age groups on entry to NH and the difference in causes of mortality for different age groups (Payne G, Laporte A *et.al.* 2007) and

this finding is confirmed by the AIHW (Australian Institute of Health and Welfare 2011, p58).

Sex did not have a significant effect on the RCS at death which contrasts with findings in some studies of community elders (Kannegaard P, van der Mark S *et.al.* ; Romoren T and Blekeseaune M 2003; Yi Z, Yuzhi L *et.al.* 2003) but not others (Meinow B, Kahyreholt I *et.al.* 2004; Nayak S, Moore D *et.al.* 2006; Savla G, Moore D *et.al.* 2006). The effect of gender in a nursing home population is not clear from the literature, and this may be due to admission to NH selecting out the factors responsible for gender differences in function in community living elders.

The nursing home environment has a small but non-significant effect on the RCS (var=28.11, SE=27.74, *p*=0.31). This finding was expected due to the same regulatory requirements for all RAC facilities in Australia. A study comparing outcomes for residents suffering dementia but cared for in two different types of nursing home in Germany found no difference in outcomes measured that were not associated with the resident themselves (Wolf-Ostermann K, Worch A *et.al.* 2012). But as these authors reported, it was difficult to compare across the different settings due to different documentation in each facility. There may be an association between socio-economic status and the nursing home, for instance if the nursing home is located in and a low or high socio-economic suburb and the residents are from the same locale. However this was not tested in this study and in comparison to well-documented socioeconomic differences seen in primary and acute care services the same socio-economic disparity is not found in nursing homes (Goodridge D, Hawranik P *et.al.* 2012).

A significant finding from Section 4.12 is that when 'group' is included in the analysis as a variable the effect is significant but only when the frailty group is compared to the other three groups (Table 4.12.1 on page 180). None of the three diagnostic groups are significantly different to each other. This finding was confirmed with a separate statistical analysis that estimated a pairwise comparison of the mean RCS between the groups (Table 4.12.2 on page 182). This analysis confirmed the results of the linear mixed effects model reported in Table 4.12.1

(p180). Only the frailty group had any significant difference with the other three groups.

A further finding from Section 4.12 is that a third of the variance is unexplained by this predictive model and that the majority of this variance comes from the subjects themselves as can be seen in the multiline graphs shown in Figure 4.10 (page 171). Further research is required to correctly identify the source of this variance to further develop the accuracy of the predictive model. The results of this study provide the basis of a predictive model using the trajectory of decline. As demonstrated in Figure 4.12.1 (p180) including the significant variables of age at admission to the nursing home and diagnostic group enabled the calculation of the RCS score for a defined period of a resident's admission to an Australian nursing home.

The linear mixed effects model developed in Section 4.12 for the entire admission (maximum 10 years) was applied to the RCS data available for the admission period 12 months before death (Section 4.13). The effects for the 12 months before death were the same as found for the entire admission period but they were not significant. There was a difference in the amount of data available for analysis between the entire admission (n=990) and the 12 months before death (n=288). Hence, the variation was harder to identify in 12 month to death sample using the RCS as a measure of function due to the usual period between measurements of 12 months. Using RCS limited the ability of this research to identify the variability in the subject functional profile in the 12 month period before death as reported by Lunney (Lunney J, Lynn J *et.al*. 2003).

It was found that the Tasmanian sample was sufficiently representative of the national profile (Section 4.14). Accordingly, the results from this study can be generalised to the Australian nursing home population.

In relation to the research questions the findings can be summarised as follows:

1. The trajectory of decline can be identified in the functional profiles of a residential aged care population over the course of their admission to a nursing home.

2. The results of this research in four nursing homes in southern Tasmania can be generalised to the Australian nursing home population.

3. Multiple trajectories based on the residents' cause of death were identified in this research. However, only the functional profile of the frailty group was significantly different to the functional profiles of the diagnostic groups (cancer, organ failure and 'other'). Thus in an Australian nursing home population there are only two trajectories of decline. One is for those residents with conditions related to frailty. The second is for those residents with a diagnosis that will ultimately cause their death.

4. The RCS, which was routinely collected by Australian nursing homes for all residents from 1997 to 2008, is sensitive to the changes in the residents' functional profile in order to identify the trajectory of decline. The RCS was replaced by the ACFI in March 2008 and while this tool has not been tested in this research, the ACFI has extended the domains in higher care needs, palliative care and dementia.

5. This research found poor agreement between the resident's cause of death and the medical diagnosis made at the beginning of their NH admission.

6. Using a linear mixed effect model, the variables in this research that predicted function, were age at admission, diagnostic group and time. Nursing home had a measurable but non-significant effect. From these results a predictive model was derived based on the trajectory of decline model.

7. Having developed a predictive model that incorporated age at admission , diagnosis group and time, this study found that over a third of the variance remained unexplained. That is, there are yet to be identified variables related to the subjects themselves that are required to improve the accuracy of the predictive model.

5.3   The trajectories of decline in an Australian nursing home population

This research has shown that there are just two trajectories of decline in an Australian nursing home population classified by cause of death.

Figure 5.1 The two trajectories of decline for an Australian nursing home population in the 12 months before death
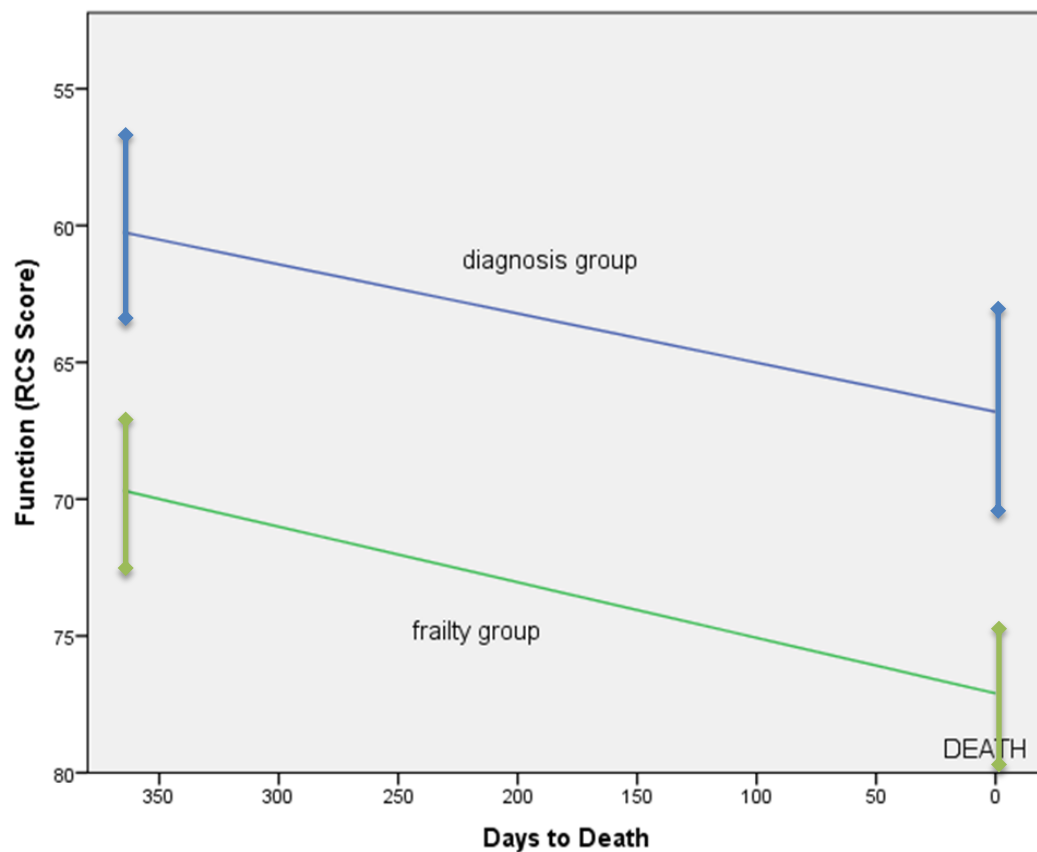
Error bars represent 95% confidence interval

In an exploratory analysis with the subjects reclassified as either diagnostic (cancer, heart or lung failure, and 'other') or frailty, the entire dataset was reanalysed using a linear mixed model (LMM) limited to the 12 month period before death. The results of this exploratory analysis (Table 5.1 below) are

represented graphically in Figure 5.1 above, the two trajectory groups have significantly different functional profiles with non-overlapping 95% confidence intervals (error bars). The diagnostic group has less dependency at 12 months than the frailty group. The rate of decline was the same for both groups (rate = -0.018, SE = 0.002, $p<0.001$). Thus, the level of dependency is higher for the frailty group 12 months before death but the rate of increasing dependency is the same for both groups. This suggests that for a nursing home population, functional decline is the same for all residents but that the starting point (at 12 months before death) based on the diagnostic profile is significantly different.

The two trajectory groups for this exploratory analysis comprise the original frailty group (n=145) and the diagnostic group (n=102) combining the subjects with a cause of death of cancer, heart or lung failure or 'other'. The characteristics of the subjects grouped this way, and the parameters from the LMM analysis for each group are summarised in Table 5.1 below.

Table 5.1 Characteristics of the two NH trajectory groups

Characteristic	Frailty Group	Diagnostic Group
Female	73%	64%
Age at Admission (SD)	83 (6)	84 (7)
Age at Death (SD)	89 (6)	89 (7)
Length of stay (years) (SD)	5.5 (3.6)	5.3 (4.2)
Mean RCS at Admission (SD)	52.9 (23.7)	49.9 (24.8)
Parameter		
RCS at 12 months (SE)	69.69***(1.38)	60.25***(1.84)
95% CI	66.97 - 72.42	56.60 - 63.90
RCS at Death (SE)	77.10***(1.04)	66.81***
95% CI	75.05-79.15	63.08-70.54

*** significant to 0.001 level

While there are proportionally more females in the frailty group, the groups do not differ by age. The length of stay is shorter for the diagnostic group on average by

only 2 months. At the time of admission there is very little difference in the mean RCS for the frailty group (mean RCS=52.9) and the diagnosis group (mean RCS=49.9). At death, however, there is a significant difference between the functional means for each group (Results Section 4.10) indicating that as shown in the graphs in Figure 4.10 (on page 172) the rate of decline over the entire admission varies between the groups. Overall, the average rate of decline for the level of dependency frailty group must be faster at some stage in the admission period to be so much higher at death than the diagnosis group. From the results of this research, the residents in the frailty group have significantly higher levels of care needs 12 months before death before death and at the time of death than the diagnosis group.

The characteristics of a typical resident in each of the two trajectories of decline identified in this research and shown if Figure 5.1 above are described as follows:

(1) Frailty Group. The largest group comprises those residents with a cause of death associated with frailty. The elderly person in this group has multiple co-morbidities that singly would not be fatal. For example conditions such as stroke, diabetes, blindness, anaemia, recurrent urinary tract infection, hip fracture, pneumonia, dementia or sepsis. In the absence on the death certificate of an immediate cause of death from cancer, heart or lung failure or non-specific causes such as myocardial infarction, renal failure or aortic aneurysm. This group has the significantly higher care needs compared with the diagnosis group.

(2) Diagnosis Group. The elderly person in this group has a medical diagnosis that will ultimately be their direct cause of death. For example cancer, organ failure or coronary artery disease. This group were also identified as being more likely to be transferred to hospital to die and were the only residents in this subset to have been transferred from the NH to a specialist palliative care unit to die.

The distinguishing feature of the trajectory of decline theory is that there is a difference in function due to the diagnosis (Taylor M and Lynch S 2011). The connection between diagnosis and functional loss becomes clearer with the

understanding brought by the research in this thesis, of just two trajectories of decline, not five as identified in community living elders by Lunney and colleagues (2002 and 2003). In light of these findings, the small group of studies in community living cohorts of oldest-old that found an association between functional disability and two diagnosis cohorts (Bootsma-van der Wiel A, de Craen A *et.al.* 2005; Cesari M, Onder G *et.al.* 2006; Takayama M, Hirose N *et.al.* 2007; Ferrer A, Formiga F *et.al.* 2008; Wu H, Flaherty J *et.al.* 2012) supports the use of trajectory to monitor the functional profile of elders in the community and then mapping the two trajectories into the residential aged care environment.

These findings also support the original hypothesis shown in the prototypical trajectories of decline of Joanne Lynn (shown in Figure 1.1 on page 27). That is, 12 months before death, the NH resident classified as being in the diagnosis group (cancer, heart or lung failure, or other) will have significantly less dependency than a resident classified into the frailty group.

Further research is required to confirm the equivalent ACFI level of dependency, but as recommended by 'The Palliative Approach Guidelines for Residential Aged Care':138-139) the *terminal phase* can now be predicted in an Australian nursing home resident. Before this research, the NH staff had no reference point to make that decision. As shown in Table 5.2, a resident with a medical assessment that identifies them as being in the diagnosis group, it can be said with 95% confidence that when the level of dependency as measured by the RCS score is between 57 and 64, the resident will die within the next 12 months. In contrast, the resident classified into the frailty group will have a much higher level of dependency, with an RCS score between 75 and 79 before death can be expected.

Using this information will assist residential aged care providers in discussing advance care plans with the resident and family. In the case of 'Julie's Pop' in the Acknowledgement (page 6), he was in the diagnosis group and at a level of dependency for that group where death was likely in the next 12 months. So a decision not to transfer him away from the NH if his condition worsened could have been made and his inevitable death kinder. So despite having less

dependency, the diagnosis group are approaching death at the same rate as the frailty group.

5.4   The trajectory of dementia

For this research in a nursing home population as well as the community sample studied by Lunney Lunney *et.al.* 2002 and 2003) a proportionally large frailty group in both the NH (58%) and community living (50%) elderly populations was found. In future research the frailty group needs to be 'unpacked' to more clearly identify trajectories within this large cohort that may be specific for diseases such as dementia (McConnell E, Pieper C *et.al.* 2002; Dodge H, Du Y *et.al.* 2006; Nikolova R, Demers L *et.al.* 2009) using the dementia specific domains in the ACFI. Due to the methodology used in this research, any variations that may have resulted from diagnoses related to dementia were not identified. More recent research has identified the trajectory of decline specifically for dementia.

Figure 5.2 From (Gill T, Gahbauer E *et.al.* 2010), p1177: Trajectories of disability in the last year of life among 383 decedents
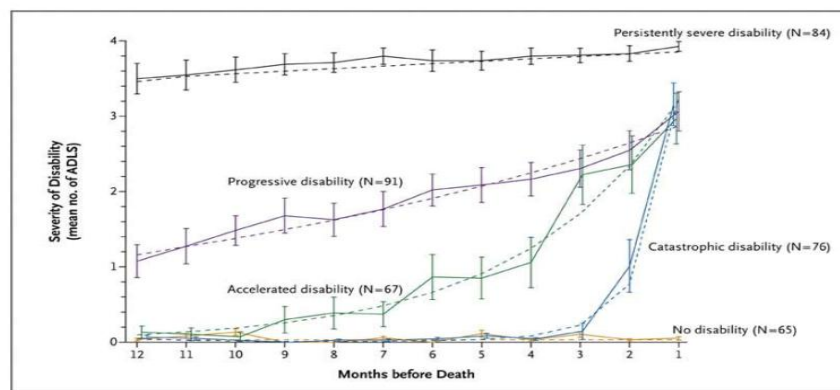
The research by Thomas Gill (Gill T, Gahbauer E *et.al.* 2010), published after data collection for this thesis was completed, is shown in Figure 5.2 in an elderly community cohort, classified the conditions leading to death into the five groups identified by Lunney and Lynn (2002) adding an advanced dementia group based on the death certificate as well as assessment when the subject was alive. The trajectory for advanced dementia was predominant with more than two thirds of the subjects having a *trajectory of persistently severe disability* (Gill T, Gahbauer E *et.al.* 2010, p1173) which is the trajectory at the top of Figure 5.2. Except for

sudden death, the trajectories classified for cancer, frailty, organ failure and 'other' were not distinctly different for disability in the last year of life.

Figure 5.3 From(Mitchell S, Teno J *et.al.* 2009), p1533: Overall mortality and cumulative incidences of pneumonia, febrile episodes, and eating problems among nursing home residents with advanced dementia
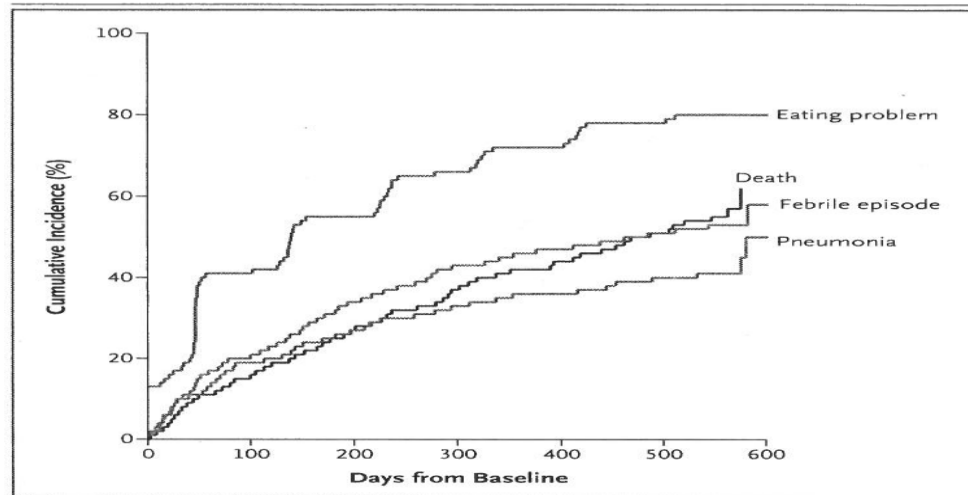
A study of nursing home residents with advanced dementia found that life expectancy was reduced to the same extent as other end-of-life conditions and that the patients in the study died of conditions caused by dementia and not other fatal events such as a myocardial infarction (Mitchell S, Teno J *et.al.* 2009, p1535). The graph from this study reproduced in Figure 5.3 shows the increasing accumulation of symptoms (eating problems, febrile episode, and pneumonia) of advanced dementia in the two years before death. The study also demonstrated that survival was reduced by the onset of these symptoms.

The study by Gill (2010) found that 67% of the trajectory cohort with the highest care needs died of dementia. This means that 33% of elderly in the study were not on this high care trajectory. Hence while the majority of the trajectory for dementia may be most like the frailty group in this research, further research is required to determine if there is a trajectory, or trajectories, for dementia as well as the two trajectories identified in this study.

5.5   Nursing home resident transfer to hospital

With the increasingly frailty of NH residents there is concern that the current Australian model of residential aged care whereby medical care is primarily provided by often scarce general practitioners will result in increasing numbers of residents being transferred to hospitals (Ingarfield S, Finn J *et.al.* 2009).

In the USA, nursing home residents account for more than 2.2 million emergency room visits annually and compared to a matched non-nursing home cohort, had higher acuity, were more likely to be admitted and more than twice as likely to die (Wang H, Shah M *et.al.* 2011). Better chronic disease case management, information transfer and on-site specialist support may reduce the incidence of acute admission to hospital for NH residents (Bowman C, Elford J *et.al.* 2001). Hospitalisation for the elderly is associated with increased risk of functional decline (Conforti D, Basic D *et.al.* 2004; Hoogerduijn J, Buurman B *et.al.* 2012).

However, about three quarters of NH transfers to hospital were for unavoidable changes in condition (Jones J, Firman R *et.al.* 1997; Lamb G, Tappen R *et.al.* 2011) and number of NH transfers, as a proportion of total emergency room admissions is less than 3% and of this only 1% died in the emergency room (Arendts G and Howard K 2010) which is less than the total number of transfers in this study. For the 247 deceased nursing home residents in this study, 8% were transferred to hospital immediately before their death. However the destinations of these 19 transfers were not identified and may have included direct admissions to palliative care units for example.

As reported in Section 4.6, two thirds of the hospital transfers were for residents in the diagnosis group and these residents also had lower RCS (RCS=66) than the third of residents in the frailty group transferred with a mean RCS of 74. These findings confirm the difference in dependency levels between the two trajectory groups before death. However, these finding may also indicate that the apparent bias in the decision to transfer to hospital care for residents in the diagnosis group than the frailty group may be related to dependency level not diagnosis.

5.6   Policy Implications

Because the RCS score is directly related to price of care (AG subsidy increases with increasing RCS) then these results confirm the concerns expressed by residential aged care providers that the resourcing of the increasing numbers of frail residents is a burden (Finnbakk E, Skovdahl K *et.al.* 2012). It is reasonably expected that as more elderly are cared for at home (per AG policy) the proportion of frailty in NH will grow further increasing the demand on resources in this sector. A further application of the work of this thesis could be to analyse factors contributing to the accumulated costs of late care life in NH and community aged care.

The predictive model developed in this research, indicates that as the proportion of residents in the category of frailty grows, this will have increasing demand on resources in this sector. This would help explain the findings from The Report on the ACFI (Australian Government Department of Health and Ageing 2011) which identified unexpectedly high levels of increasing cost of care for residents at the highest care levels, that is, residents that are characterised by frailty. Application of this predictive model will potentially enable governments to identify the impact on their budgets that they can reasonably expect from the increasing proportion of residents classified as frailty. As the proportion of residents with frailty increases then their dependency is going to increase and hence the cost of providing their care is going to increase.

The RCS has been replaced by the ACFI which is more sensitive to the highest end of the care scale than the RCS (Australian Government Department of Health and Ageing 2011). Current reimbursement for care is based on the ACFI that is re-assessed annually and reported monthly to DoHA. These data could be analysed routinely using the methodology described in this research to identify trends in costs at a national, state and facility level and replacing the RCS with the ACFI will provide a more accurate estimate for funding residential aged care.

This predictive model would have the potential to provide an evidence base for budgeting and other resource planning bringing certainty into this growing area. As an example, NH with more residents in the frailty group will have higher costs associated with care services than a NH with proportionally more residents in the Diagnostic Group. Thus subsidy could be based on the proportion of diagnostic and frailty groups. Furthermore this research has shown that there is potential to develop a predictive model that will use the variables identified in the findings of this thesis as well as variables to be identified in future research to account for the unexplained variance found.

In order to operationalise the trajectory of decline as a policy tool, a standardised medical admission is required to identify which trajectory group a resident should be classified into. This research has shown a poor level of agreement between the diagnosis made on admission to the NH and the cause of death written on the death certificate. This opens new opportunities for Medicare to provide item numbers for GPs to conduct admission assessments for all people admitted to nursing homes to ensure that an accurate assessment of whether the resident is identified as being in the diagnostic group or the frailty group. The poor agreement between the admission diagnosis and cause of death may also be because the diagnosis that ultimately leads to a person's death may change over time which needs further investigation to the effect on the resident's trajectory of decline. Hence the medical assessment needs to be repeated at intervals – yet to be determined – in order to adjust the trajectory to reflect the resident's changing needs.

From this research, the level of care from which it is unlikely that the resident will recover function and inexorably decline to death is an RCS score of 60. This point would then be a trigger point at which the facility discusses future care options (advance care plan). Currently advance care planning is not mandated in RAC and there is variation between facilities in the approach to advance care planning (Shanley C, Whitmore E *et.al.* 2009). An advance care plan has been shown to reduce unnecessary admissions to hospital (Caplan G, Meller A *et.al.* 2006) and for a resident with such high care levels, a hospital admission is associated with

further and more rapid deterioration in function (Dixon T, Shaw M *et.al.* 2004; Wagner J, Bachmann L *et.al.* 2006; Walsh B, Addington-Hall J *et.al.* 2012; Mudge A, Denaro C *et.al.* 2012). This has the potential to prevent the *burdensome interventions* described by Mitchel and Teno (Mitchell S, Teno J *et.al.* 2009, p1529). Further research is needed to identify the accuracy of this prediction, and the ACFI equivalence.

The identification of just two trajectories in NH also brings the possibility of an alternative funding model to this sector based on casemix[17]. The diagnostic group can be funded using modified DRGs and the frailty group can be funded using care-based funding (Lee L, Eagar K *et.al.* 1998).

5.7   Care Implications

This thesis has identified the existence of the trajectory of decline in a nursing home population. The trajectory of decline is a clinically intuitive concept that policy makers can also understand and use in planning resource use:

(1) From the point of admission to a NH the resident's care needs will increase until death;

(2) The rate of increase in care needs may be constant or accelerate/decelerate over the course of the admission;

(3) The trajectory of decline of an individual can be identified, and possibly predicted, using routinely collected data;

(4) Routine evaluation of the resident's trajectory will identify changes related to interventions or deterioration due to clinical or psycho-social events;

(5) The diagnostic group will be more independent of care before death than the frailty group resident and hence their death may seem more unexpected to the family and staff.

---

[17] Equivalent to the US version of case-mix funding

These findings can be translated into care practice with skilled nursing care that is able to assess and modify the care plans of residents based on their changing trajectory. For example, the highest level of dependency comes at the end of life for both the diagnostic and frailty group. A community living elder will receive end-of-life care either in the acute setting or with in-home palliative care services. In contrast, an elder living in a nursing home will receive palliative care from the staff of the nursing home with the occasional support of the GP (Zerzan J 2000; Froggatt K, Poole K *et.al.* 2002; Hanson L, Reynolds K *et.al.* 2005; Parker D 2005). The care requirements of the trajectories identified in Australian nursing home's will require the same level of carer skills as is provided in other care contexts. Strengths and weaknesses of this study

5.7.1 Study strengths

Before discussing the weaknesses of this study it is appropriate to identify the strengths. A key strength of the study was the identification and use of each subject's trajectory into the analysis. Unlike previous studies, the data were not grouped in monthly cross-sections of time for the purposes of comparison between the diagnostic groups. In this study the data were treated as longitudinal. That is, the dependency of each functional measure was taken into account by the statistical model to obtain a more realistic rendition of the trajectory.

Furthermore, a routinely used measure of function, the Resident Classification Scale was shown to be sensitive to the changes in the subject's functional profile over the course of their admission to the nursing home. Further research is required to identify whether the Aged Care Funding Instrument will provide the same outcome. However if routinely collected data, within the current skill base of nursing home staff, can provide evidence of the resident trajectory, then it is possible to make the study of trajectory a routine tool in Australian nursing home research and evaluation now.

A strength of this study is that the results of this study are generalisable to the broader Australian nursing home population.

The sample size was sufficient to apply robust statistical testing, grounded in a methodology tested in similar health service research settings. The statistical methodology used by previous studies of the trajectories of decline were restricted not by the sample size, but by the data collection method which was not longitudinal as discussed above (Sliwinski M, Stawski R *et.al.* 2006). As well as the ability of computers and supporting software to analyse data over ten years ago compared to what is available to the researcher today. Reanalysis of the same data from the very large study by Lunney and colleagues (Lunney J, Lynn J *et.al.* 2003) identifying individual trajectories if possible and using linear mixed modelling for the analysis would bring a better understanding of the trajectory of decline in an elderly community population.

This study was successful using a retrospective methodology. As discussed in the methods chapter, this was a pragmatic choice because of needing the residents' cause of death within the timeframe of a doctoral thesis. However this method also allowed access to a large enough sample for statistical analysis within the timeframe and without the added task of obtaining consent from the resident (Coll-Planas L and Salva A 2010; Hall S, Longhurst S *et.al.* 2009; Zermansky A, Alldred D *et.al.* 2007). Consent to access the deceased resident record was considered by the local ethics committee to be the responsibility of the senior management of the nursing home as long as the data were de-identified and secured.

The timing of this research in the current policy context is also a strength. There is a strong imperative for innovative models to guide policy makers and service providers concerned with the resource uncertainties already apparent in the aged care sector.

5.7.2   Study weaknesses

There are a number of weaknesses in this study. Firstly a convenience sample was used for the research. This was done for pragmatic reasons in a small area of a small state of Australia. However, as previously shown this potential limitation was overcome by ensuring a sample size was collected that would provide the necessary power for statistical analysis for the population sampled. Secondly the

results from the sample population are comparable with national data reported for the equivalent period (Results Section 4.14).

Retrospective studies have disadvantages compared with prospective studies. If done prospectively the indictors for the trajectory such as listed in the literature chapter could have been used. Also instead of the focus being on functional profiles, additional domains of ageing could have been measured, such as quality of life. Or an alternative perspective of the trajectories of decline could be determined through interviews with the resident and carers.

A further weakness of retrospective studies is that they are subject to bias. The most significant risk of bias for this research is sampling bias which could reduce the generalisability of the results from the study because the population being studied is not objectively sampled (Bland M 1995, p28). The exclusion criteria (Methods Section 3.6.1) were defined at the start of the data collection hence all eligible records accessed were objectively sampled, and in the study up to the determined sample size was reached to further reduce risk of this bias. Information bias could not be controlled for. In this study, data accuracy relied on measures collected routinely by clinical nursing and medical staff. This bias was consistent through the data and because the same level of staff are responsible for data collected and used nationally, this bias is systematic and not affect the generalisability of this research.

A weakness of this study was that the resident's functional profile could only be tracked if they had at least two RCS measures. For the purpose of identifying changes in the aged care resident's functional profile in the 12 months before their death, the routine frequency of reporting the RCS was once in 12 months. In the original trajectory of decline model proposed by Joanne Lynn (see Figure 1.1 on page 27) a time over which the person's function declined before death was not specified. Subsequent research identified these trajectories in the 12 months before death (Lunney J, Lynn J *et.al* 2003).

5.8   Recommendations for further research

This research has identified that when grouped by their diagnosis or frailty condition, elderly residents of Australian nursing homes have significantly different trajectories of functional decline. The measure of dependency used, the RCS, identified the individual functional profile of each subject in a retrospective review of the deceased resident record. Having identified the strengths and weaknesses of this study in the previous section, this section will propose further research that will address the weaknesses of this study while building on the strengths and original findings.

Replicate the methodology using the current measure of dependency

This research has demonstrated an effective methodology to identify the trajectories of decline in an elderly nursing home population using the Resident Classification Scale (RCS). This measure of dependency was replaced by the Aged Care Funding Instrument (ACFI) in 2008. This study should first be replicated to determine if the RCS used in this research to identify the residents' functional profile, can be substituted with the Aged Care Funding Instrument (ACFI) currently used in Australian residential aged care. The ACFI is comprised of a number of subscales. The study should be replicated to determine if particular subscales are more sensitive to the trajectory profile than the total dependency score, as was used in this research using the RCS.

Identify the trajectories of decline using a prospective methodology

Having established that the ACFI can identify the functional profile using the same retrospective methodology used in this research, a prospective methodology should be developed and trialled in a sample of nursing home residents to validate the methodology in the current nursing home environment. For comparison, additional assessments specific to an oldest-old and nursing home population as identified in the research literature should be trialled. Particular focus should be given to frailty measures because this is the largest trajectory group and encompasses the largest sub-set of health conditions. More recent research has focussed on frailty and also the geriatric syndrome since Lunney and colleagues developed the trajectory methodology over ten years ago.

Develop and trial a standardised medical assessment tool

This research identified that there was poor agreement between the medical diagnosis made at the time of the resident's admission to the nursing home and their subsequent cause of death. It has been proposed that this may be due to changes in the resident's diagnosis over the course of their admission. A study over one year looking at changes in the diagnostic profile of the resident is required to identify the reasons for changes in the residents' diagnostic profile. This study would provide the basis for a policy of regular medical reassessment that may prove to be specific to the resident's trajectory. A study that measures the number and type of services used by the resident over a year to understand the links between health service use with the diagnostic and functional profiles should be undertaken at the same time. This research will demonstrate the utility of the trajectory model in not only predicting functional and diagnostic changes in regard to increasing dependency (the ACFI) and resource use in the nursing home, but also for health service resource demand external to the nursing home.

Identify the trajectory of dementia

In this research the frailty group included residents with a diagnosis of dementia. Previous research suggests that dementia may have three levels of functional decline. To test this theory in the Australian residential aged care population, research to identify the trajectory or trajectories of dementia should be undertaken. The ACFI does include assessments specific to dementia, however further research will include additional assessments as determined by the research literature and current clinical practice.

Improve the prediction model

This research has shown that it is possible to develop a model that will predict the level of function in relation to length of stay in the nursing home. However over 30% of the variance remain unexplained. Further research is required to identify additional variables that could be added into the model to reduce the observed variability within each trajectory group that would improve the predictive value of this model.

5.9   Conclusion

The personal impetus for embarking on this thesis was the desire to improve the health system so people like Julie's Pop (page 6) did not come to the end of their life leaving their family traumatised. Broad experience in the clinical and bureaucratic realms of Australia's health system has provided lessons in the effect of policy on health care. This experience has been confirmed by the literature. No health care innovation will progress into practice without financial support – and this support comes from policy. Policy, on the other hand, needs evidence. The trajectories of decline have been incorporated into aged care policy as evidence that can be put to use by aged care health practitioners. The research undertaken for this thesis has demonstrated that the trajectories of decline do exist in an elderly nursing home population. That is the answer. The next step is to identify how this model can be used in practice.

This thesis has argued that aged care services are under pressure now at least 15 years before the arrival of the baby-boomer generation into the 80 years and older cohort – the current age at which aged care services are most in demand. The policy and health service literature expresses concern about how the current models of care for the elderly will resource the increased demand for services into this near future. At present there is no understanding of how costs can be better managed without compromising the quality of aged care and this is a challenge for all countries with increasing demands for aged care.

The identification of just two trajectories of decline in residential aged care provides the opportunity to develop more efficient and effective models of care that are targeted to the needs of the resident in either trajectory. Monitoring the trajectories will provide a better understanding of the impact of changing models of care and funding arrangements on residents and their outcomes.

The case of Julie's Pop is an example of the use of the trajectory of decline on an individual level. Here, a poor decision was made for a hospital transfer by care staff under pressure. Using the trajectory of decline model to identify how close

he was to death and support care decisions may have avoided the trauma of an inefficient and ineffective hospital transfer.

If you cannot measure it, you cannot improve it.
Sir William Kelvin

Chapter 6References

Aarsland D, Muniz G and Matthews F (2011). "Nonlinear decline of mini-mental state examination in Parkinson's Disease." Movement Disorders **26**(2): 334-337.

Aartsen M, van Tilburg T, Smits C and Knipscheer K (2004). "A longitudinal study of the impact of physical and cognitive decline on the personal network in old age." Journal of Social and Personal Relationships **21**(2): 249-266.

Access Economics (2010). The future of aged care. A report prepared for national Seniors Australia, National Seniors Australia.

Albright J and Marinova D (2007) "Estimating Multilevel Models Using SPSS, Stata, and SAS."

Almkvist O and Bäckman L (1993). "Progression in alzheimer's disease: Sequencing of neuropsychological decline." International Journal of Geriatric Psychiatry **8**(9): 755-763.

Alwin D (2012). "Integrating Varieties of Life Course Concepts." The Journals of Gerontology Series B: Psychological Sciences and Social Sciences **67B**(2): 206-220.

American Geriatrics Society Expert Panel on the Care of Older Adults with (2012). "Guiding Principles for the Care of Older Adults with Multimorbidity: An Approach for Clinicians." Journal of the American Geriatrics Society **60**(10): E1-E25.

Andel R, Hyer K and Slack A (2007). "Risk Factors for Nursing Home Placement in Older Adults With and Without Dementia." Journal of Aging and Health **19**(2): 213-228.

Andrews-Hall S, Howe A and Robinson A (2007). "The dynamics of residential aged care in Australia: 8-year trends in admission, separations and dependency." Australian Health Review **31**(4): 611-622.

Aneshensel C, Botticello A and Yamamoto-Mitani N (2004). "When caregiving ends: the course of depressive symptoms after bereavement." J Health Soc Behav **45**(4): 422-440.

Arendts G and Howard K (2010). "The interface between residential aged care and the emergency department: a systematic review." Age Ageing: afq008.

Australian Bureau of Statistics (2000). Australian Demographic Statistics Dec 1999. ABS_3101.0.

Australian Bureau of Statistics (2004). "Australian Social trends - 2004: Scenarios for Australia's ageing population."

Australian Bureau of Statistics (2010). "Tasmanian State and Regional Indicators." **1307.6**.

Australian Bureau of Statistics (2011). Retirement and Retirement Intentions, Australia, July 2010 to June 2011 Canberra, Australian Bureau of Statistics. **6238.0**.

Australian Government Department of Health and Ageing (2002). Ageing in place. A guide for providers of residential aged care.

Australian Government Department of Health and Ageing (2004). Guidelines for a Palliative Approach to Residential Aged Care, Rural Health and

Palliative Care Branch, Australian Government Department of Health and Ageing, Canberra.

Australian Government Department of Health and Ageing (2005). "The Residential Care Manual."

Australian Government Department of Health and Ageing (2006). Aged Care Assessment Guidelines 2006. Ageing and Aged Care Division. Canberra, Australian Government Department of Health and Ageing.

Australian Government Department of Health and Ageing (2011). "Report on the Operation of the Aged Care Act 1997, 2010-2011."

Australian Government Department of Health and Ageing (2011). The review of the Aged Care Funding Instrument. Canberra, Australian Government Department of health and Ageing.

Australian Government Department of Health and Ageing (2012). Aged care Workforce Flexible Fund. Canberra, Australian Government.

Australian Government Department of Health and Ageing (2012). Need Identification Tool for Aged Care and Carers (NITACC). Canberra, Australaian Government.

Australian Government Department of Treasury (2010). Intergenerational Report 2010. Australia to 2050: future challenges. Canberra, Commonwealth of Australia.

Australian Institute of Health and Welfare (2006). "The ins and outs of residential respite care." AIHW Bulletin(4 3).

Australian Institute of Health and Welfare (2006). Life expectancy and disability in Australia 1988 to 2003. Canberra, AIHW. **Dis47**.

Australian Institute of Health and Welfare (2006). Life expectancy and disbility in Australia 1988 to 2003. Canberra, Australian Institute of health and Welfare. **Dis 47**.

Australian Institute of Health and Welfare (2007). Residential aged care in Australia 2005-2006. A statistical overview. Canberra, Australian Institute of Health and Welfare. **Aged care statistics series**.

Australian Institute of Health and Welfare (2008). "Residential aged care in Australia 2006-07: a statistical overview." Aged care statistics series **26**(AGE 56).

Australian Institute of Health and Welfare (2010). "Residential aged care in Australia 2008-09: a statistical overview." Aged care statistics series **31**(AGE 62).

Australian Institute of Health and Welfare (2011). "Dementia among aged care residents: first information from the Aged Care Funding Instrument." Aged care statistics series **32**(AGE 63).

Australian Institute of Health and Welfare (2011). "Residential aged care in Australia 2009-10: a statistical overview." Aged care statistics series **35**(AGE 66).

Australian Institute of Health and Welfare (2012). Dementia in Australia. Canberra, AIHW. **Cat. no. AGE 70**.

Australian Institute of Health and Welfare (2012). Residential aged care in Australia 2010–11: a statistical overview. Aged care statistics series no. 36. Cat. no. AGE 68. Canberra, AIHW. **:** .

Avlund K (2003). "Onset of mobility disability among community-dwelling old men and women. The role of tiredness in daily activities." Age and Ageing **32**: 579-584.

Binder E, White H, Resnick B, McClellan W, Lei L and Ouslander J (2012). "A Prospective Study of Outcomes of Nursing Home Residents with Chronic Kidney Disease with and without Anemia." Journal of the American Geriatrics Society: n/a-n/a.

Bird S (2011). "How to complete a death certificate: a guide for GPs." Australian Family Physician **40**(6): 446-449.

Blakely J and Ribeiro V (2008). "Early retirement among registered nurses: contributing factors." Journal of Nursing Management **16**: 29-37.

Bland M (1995). An introduction to medical statistics. Second Edition. Oxford, Oxford University Press.

Bootsma-van der Wiel A, de Craen A, Van Exel E, Macfarlane P, Gussekloo J and Westendorp R (2005). "Association between chronic diseases and disability in elderly subjects with low and high income: the Leiden 85-plus Study." The European Journal of Public Health **15**(5): 494-497.

Bortz W (1990). "The trajectory of dying: functional status in the last year of life." Journal of the American Geriatrics Society **38**: 146-150.

Boumans N, de Jong A and Vanderlinden L (2008). "Determinants of early retirement intentions among Belgian nurses." Journal of Advanced Nursing **63**(1): 64-74.

Bowling A and Iliffe S (2006). "Which model of successful ageing should be used? Baseline findings from a British longitudinal survey of ageing." Age and Ageing **35**(6): 607-614.

Bowman C, Elford J, Dovey J, Campbell S and Barrowclough H (2001). "Acute hospital admissions from nursing homes: some may be avoidable." BMJ **77**: 40-42.

Boyd C (2012). "Guiding Principles for the Care of Older Adults with Multimorbidity: An Approach for Clinicians." Journal of the American Geriatrics Society: n/a-n/a.

Branch L, Katz S, Kniepmann K and Papsidero J (1984). "A prospective study of functional status among community elders." American Journal of Public Health **74**: 266-268.

Branch L and Ku L (1989). "Transition probabilities to dependency, institutionalization and death among the elderly over a decade." Journal of Ageing and Health **1**(3): 370-408.

Bridgman P and Davis G (2004). The Australian Policy Handbook 3rd Edition. Sydney, Allen and Unwin.

Brodaty H, Breteler M, DeKosky S, Dorenlot P, Fratiglioni L, Hock C, Kenigsberg P, Scheltens P and De Strooper B (2011). "The World of Dementia Beyond 2020." Journal of the American Geriatrics Society: no-no.

Brodaty H, Seeher K and Gibson L (2012). "Dementia time to death: a systematic literature review on survival time and years of life lost in people with dementia." International Psychogeriatrics **24**(07): 1034-1045.

Bruen W (2005). "Aged care in Australia: past, present and future." Australasian Journal on Ageing **24**(3): 130-133.

Brumley R, Enguidanos S and Cherin D (2003). "Effectiveness of a home-based palliative care program for end-of-life." J Palliat Med **6**(5): 715-724.

Bryant L, Grigsby J, Swenson C, Scarbro S and Baxter J (2007). "Chronic pain increases the risk of decreasing physical performance in older adults: the

San Luis Valley Health and Aging Study." <u>J Gerontol A Biol Sci Med Sci</u> **62**(9): 989-996.

Buracchio T, Dodge H, Howieson D, Wasserman D and Kaye J (2010). "The trajectory of gait speed preceding mild cognitive impairment." <u>Archives of Neurology</u> **67**(8): 980-986.

Byass P (2007). "Who needs cause-of-death data?" <u>PLoS Medicine</u> **4**(11): 1715-1716.

Caley M and Sidhu K (2010). "Estimating the future healthcare costs of an aging population in the UK: expansion of morbidity and the need for preventative care." <u>Journal of Public Health</u> **33**(1): 117-122.

Caplan G, Meller A, Squires B, Chan S and Willett W (2006). "Advance care planning and hospital in the nursing home." <u>Age and Ageing</u> **35**(6): 581-585.

Cappola A, O'Meara E, Guo W, Bartz T, Fried L and Newman A (2009). "Trajectories of dehydroepiandrosterone sulfate predict mortality in older adults." <u>Journal of Gerontology A: Biological Science and Medical Science</u> **64**(12): 1268-1274.

Castro-Costa E, Dewey M, Uchoa E, Firmo J, Lima-Costa M and Stewart R (2011). "Trajectories of cognitive decline over 10 years in a Brazilian elderly population: the Bambui Cohort Study of Aging." <u>Cadernos de Saúde Pública</u> **27**(3): s345-350.

Cesari M, Onder G, Russo A, Zamboni V, Barillo C, Ferruci L, Pahor M, Bernabei R and Landi F (2006). "Comorbidity and physical function: results from the aging and longevity study in the Sirente geographic area." <u>Gerontology</u> **52**(1): 24-52.

Chen C, Schilling L and Lyder C (2001). "A concept analysis of malnutrition in the elderly." <u>J Adv Nurs</u> **36**(1): 131-142.

Chi I (2004). "Cross-national comparison of the profiles of nursing home residents." <u>Geriatrics and Gerontology International</u> **4**: S286-S288.

Christensen H, Mackinnon A, Korten A and Jorm A (2001). "The "common cause hypothesis" of cognitive aging: Evidence for not only a common factor but also specific associations of age with vision and grip strength in a cross-sectional analysis." <u>Psychology and Aging</u> **16**(4): 588-599.

Cohen J (1992). "A power primer." <u>Psychological Bulletin</u> **112**(1): 155-159.

Colebatch H (2004). <u>Policy Second Edition</u>. New York, Open University Press.

Coll-Planas L and Salva A (2010). "from epidemiological and clinical research to models of care." <u>IAGG?WHO/SFGG Workshop</u>.

Collard R, Boter H, Schoevers R and Oude Voshaar R (2012). "Prevalence of Frailty in Community-Dwelling Older Persons: A Systematic Review." <u>Journal of the American Geriatrics Society</u> **60**(8): 1487-1492.

Conforti D, Basic D and Rowland J (2004). "Emergency department admissions, older people, functional decline, and length of stay in hospital." <u>Australasian Journal on Ageing</u> **23**(4): 189-194.

Cook N, Evans D, Scherr P, Speizer, Taylor J and Hennekens C (1991). "Peak expiratory flow rate and 5-year mortality in an elderly population." <u>American Journal of Epidemiology</u> **133**(8): 784-794.

Coorey M (2004). "Ageing and healthcare costs in Australia: a case of policy-based evidence?" <u>Medical Journal of Australia</u> **180**: 581-583.

Corbin J and Strauss A (1988). <u>Unending Work and Care</u>. San Francisco, Jossey-Bass Publishers.

Cosentino S, Stern Y, Sokolov E, Scarmeas N, manly J, Tang M, Schupf N and Mayeux R (2010). "Plasma β−amyloid and cognitive decline." <u>Archives of Neurology</u> **67**(12): 1485-1490.

Covinsky K, Eng C, Lui L, Sands L and Yaffe K (2003). "The last 2 years of life: functional trajectories of frail older people." <u>Journal of the American Geriatrics Society</u> **51**: 492 - 498.

Covinsky K, Hilton J, Lindquist K and Dudley R (2006). "Development and validation of an index to predict activity of daily living dependence in community-dwelling elders." <u>Medical Care</u> **44**(2): 149-157.

Cowen P and Moorhead S, Eds. (2006). <u>Current Issues in Nursing Seventh Edition</u>. St Louis Mosby.

Crimmins E and Beltran-Sanchez H (2010). "Mortality and morbidity trends: is there compression of morbidity?" <u>Journal of Gerontology: Social Sciences</u> **66B**(1): 75-86.

Crimmins E and Saito Y (1993). "Getting better and getting worse: transitions in functional status among older Americans." <u>Journal of Ageing and Health</u> **5**(1): 3-36.

Crisp D, Windsor T, Anstey K and Butterworth P (2012). "Considering relocation to a retirement village: Predictors from a community sample." <u>Australasian Journal on Ageing</u>: n/a-n/a.

Davis K (2007). "Uninsured in America: problems and possible solutions." <u>BMJ</u> **334**: 346-334.

De Rouck and Leys (2012). "Illness trajectory and Internet as a health information and communication channel used by parents of infants admitted to a neonatal intensive care unit." <u>Journal of Advanced Nursing</u>: n/a-n/a.

Deeg D (2005). "Longitudinal characterization of course types of functional limitations." <u>Disability and Rehabilitation: An International, Multidisciplinary Journal</u> **27**(5): 253-261.

Dixon A, Mossialos E and eds (2002). "Healthcare systems in eight countries: trends and challenges." <u>European Observatory on Health Care Systems</u>.

Dixon T, Shaw M, Frankel S and Ebrahim S (2004). "Hospital admissions, age, and death: retrospective cohort study." <u>British Medical Journal</u> **doi:10.1136/bmj.38072.481933.EE**.

Dodge H, Du Y, Saxton J and Ganguli M (2006). "Cognitive domains and trajectories of functional independence in nondemented elderly persons." <u>J Gerontol A Biol Sci Med Sci</u> **61**(12): 1330-1337.

Dy S and Lynn J (2007). "Getting services right for those sick enough to die." <u>BMJ</u> **334**: 511-513.

Dy S, Shugarman L, Lorenz K, Mularski R and Lynn J (2008). "A Systematic Review of Satisfaction with Care at the End of Life. (See editorial comments by Dr. Jean S. Kutner, 160-162)." <u>Journal of the American Geriatrics Society</u> **56**(1): 124-129.

Emanuel J, Lopez O, Houck P, Becker J, Weamer E, Demichele-Sweet M, Kuller L and Sweet R (2011). "Trajectory of cognitive decline as a predictor of psychosis in early Alzheimer Disease in the Cardiovasular Health Study." <u>American Journal of Geriatric Psychiatry</u> **19**(2): 160-168.

Ferrer A, Formiga F, Ruiz D, Mascaro J, Olmedo C and Chang R (2008). "Predictive items of functional decline and 2-year mortality in nonagenarians-the NonaSantfeliu study." <u>European Journal of Public Health</u> **18**(4): 406-409.

Field A (2009). Discovering statistics using SPSS (Third Edition). London, Sage Publications Ltd.

Field M and Cassel C, Eds. (1997). Approaching death. Improving care at the end of life. Washington DC, National Academy Press.

Finnbakk E, Skovdahl K, Blix E and Fagerström L (2012). "Top-level managers' and politicians' worries about future care for older people with complex and acute illnesses – a Nordic study." International Journal of Older People Nursing: no-no.

Flinders Consulting (2008). National Evaluation of the Transition Care Program: Final Evaluation Report. Crotty M.

Flory J, Young-Xu Y, Gurol I, Levinsky N, SAsh A and Emanuel E (2004). "Place of death: US trends since 1980." Health Affairs 23(3): 194-200.

Forbes S, Bern-Klug M and Gessert C (2000). "End-of-life decision making for nursing home residents with dementia." J Nurs Scholarsh 32(3): 251-258.

Frederiksen H, Hjelmborg J, Mortensen J, McGue M, Vaupel J and Christensen K (2006). "Age trajectories of grip strength: cross-sectional and longitudinal data among 8,342 Danes aged 46 to 102." Ann Epidemiol 16(7): 554-562.

Fried L, Ferrucci L, Darer J, Williamson J and Anderson G (2004). "Untangling the concepts of disability, frailty, and comorbidity: implications for improved targeting and care." Journal of Gerontology: Medical Sciences 59(3): 255-263.

Fried T, O'Leary J, Van Ness P and Fraenkel L (2007). "Inconsistency over time in the preferences of older persons with advanced illness for life-sustaining treatment." Journal of the American Geriatrics Society 55(7): 1007-1014.

Fries B, Schroll M, Hawes C, Gilgen R, Jonsson P and Park P (1997). "Approaching cross-national comparisons of nursing home residents." Age and Ageing 26(S2): 13-18.

Fries J (1980). "Aging natural death, and the compression of morbidity." The New England Journal of Medicine 303: 130-135.

Friis K, Ekholm O, Hundrup Y, Obel E and Gronbaek M (2007). "Influence of health, lifestyle, working conditions, and sociodemography on early retirement among nurses: The Danish Nurse Cohort Study."

Frijters D, Mor V, DuPaquier J, Berg K, Carpenter G and Ribbe M (1997). "Transitions across various continuing care settings." Age and Ageing 26(S2): 73-76.

Froggatt K, Poole K and Hoult L (2002). "The provision of palliative care in nursing homes and residential care homes: a survey of clinical nurse specialist work." Palliative Medicine 16: 481-487.

Ganguli M, Vander Bilt J, Saxton J, Shen C and Dodge H (2005). "Alcohol consumption and cognitive function in late life: a longitudinal community study." Neurology 65(8): 1210-1217.

Gardiner J, Luo Z and Roman L (2009). "Fixed effects, random effects and GEE: what are the differences?" Statistics in Medicine 28: 221-239.

Gargett S (2010). "Public policy and the dependency of nursing home residents in Australia: 1968-69 to 2006-07." Health Policy 96(2): 143-153.

Gaugler J, Duval S, Anderson K and Kane R (2007). "Predicting nursing home admission in the U.S: a meta-analysis." BMC Geriatrics 7(1): 13.

Geisinger J, Wintner L, Oberguggenberger A, Gamper E, Fiegl M, Denz H, Kemmler G, Zabernigg A and Holzner B (2011). "Quality of life trajectory

in patients with advanced cancer during the last year of life." Journal of Palliative Care **14**(8): 904-912.

Gibson D (1998). Aged Care. Old Policies, New Problems, Cambridge University Press, UK.

Giles L, Anstey K, Walker R and Luszcz M (2012). "Social networks and memory over 15 years of followup in a cohort of older Australians: Results from the Australian longitudinal study of ageing." Journal of Aging Research **2012: 856048**.

Gill T, Baker D, Gottschalk M, peduzzi P, Allore H and Byers A (2002). "A program to prevent functional decline in physically frail, elderly presons who live at home." The New England Journal of Medicine **347**(14): 1068-1074.

Gill T, Gahbauer E, Han L and Allore H (2010). "Trajectories of disability in the last year of life." The New England Journal of Medicine **362**(13): 1173-1180.

Glaser B and Strauss A (1968). Time for Dying. Chicago, Aldine Publishing Company.

Goldstein N and Lynn J (2006). "Trajectory of end-stage heart failure: the influence of technology and implications for policy change." Perspectives in Biology and Medicine **49**(1): 10-18.

Goodlin S (2009). "Palliative Care in Congestive Heart Failure." Journal of the American College of Cardiology **54**(5): 386-396.

Goodridge D, Hawranik P, Duncan V and Turner H (2012). "Socioeconomic disparities in home health care service access and utilization: A scoping review." International Journal of Nursing Studies **49**(10): 1310-1319.

Guralnik J and Ferrucci L (2009). "The Challenge of Understanding the Disablement Process in Older Persons: Commentary Responding to Jette AM. Toward a Common Language of Disablement." The Journals of Gerontology Series A: Biological Sciences and Medical Sciences **64A**(11): 1169-1171.

Haan M, Selby J, Quesenberry C, Schmittdiel J, Fireman B and Rice D (1997). "The Impact of Aging and Chronic Disease on Use of Hospital and Outpatient Services in a Large HMO: 1971-1991." Journal of the American Geriatrics Society **45**(6): 667-674.

Hall P, Schroder C and Weaver L (2002). "The Last 48 Hours of Life in Long-Term Care: A Focused Chart Audit." Journal of the American Geriatrics Society **50**(3): 501-506.

Hall S, Longhurst S and Higginson I (2009). "Challenges to conducting research with older people living in nursing homes." BMC Geriatrics **9**(38).

Hamilton M and Hamilton C (2006). "Rich boomer, poor boomer."

Hanson L, Reynolds K, Henderson M and Pickard C (2005). "A quality improvement intervention to increase palliative care in nursing homes." Journal of Palliative Medicine **8**(3): 576-584.

Health Workforce Australia (2012). Health Workforce 2025. H. W. Australia.

Heck R, Thomas S and Tabata L (2010). Multilevel and longitudinal modeling with IBM SPSS. New York, Routledge, Taylor and Francis Group.

Hjaltadottir I, Hallberg I, Ekwall A and Nyberg P (2011). "health status and functional profile at admission of nursing home residents in Iceland over 11-year period." International Journal of Older People Nursing **7**: 177-187.

Hogan C, Lunney J, Gabel J and Lynn J (2001). "Medicare beneficiaries' costs of care in the last year of life." Health Affairs **20**(4): 188-195.

Hogan W "Review of Pricing Arrangements in Reidential Aged Care."

Hoogerduijn J, Buurman B, Korevaar J, Grobbee D, de Rooij S and Schuurmans M (2012). "The prediction of functional decline in older hospitalised patients." Age and Ageing.

Hoppitt T, Sackley C and Wright C (2009). "Finding the right outcome measures for care home research." Age Ageing: afp189.

Hubbard A, Ahern J, Fleischer N, Van der Laan M, Lippman S, Jewell N, Bruckner T and Satariano W (2010). "To GEE or not to GEE: comparing population average and mixed models for estimating the associations between neighborhood risk factors and health." Epidemiology **21**(4): 467-474.

Hubbard R and Theou O (2012). "Frailty: enhancing the known knowns." Age and Ageing **41**(5): 574-575.

Humpel N, O'Loughlin K, Wells Y and Kendig H (2010). "The health of Australian baby boomers." Australasian Journal on Ageing **29**(1): 8-13.

Ikegami N, Morris J and Fries B (1997). "Low-care cases in long-tem care settingz: variation among nations." Age and Ageing **26**(S2): 67-71.

Ingarfield S, Finn J, Jacobs I, Gibson N, Holman C, Jelinek G and Flicker L (2009). "Use of emergency deprtments by older people from residential care: a population based study." Age and Ageing.

Jackson N (2001). "The policy-maker's guide to population ageing: key concepts and issues." Department of Family and Community Services **Policy Research Paper No.13**.

Jackson N (2005). Tasmania's Turnaround? Migration in the Apple Isle. Recent patterns of migration within Australia. Job P and Graeme H. **Dialogue 44** 25-37.

Jagger C, Matthews R, Lindesay J, Robinson T, Croft P and Brayne C (2009). "The effect of dementia trends and treatments on longevity and disability: a simulation model based on the MRC Cognitive Function and Ageing Study (MRC CFAS)." Age and Ageing **38**(3): 319-325.

Jeste D, Depp C and Vahia I (2010). "Successful cognitive and emotional aging." World Psychiatry **9**(2): 78-84.

Jones B and Nagin D (2007). "Advances in group-based trajectory modeling and an SAS procedure for estimating them." Sociology Methods Research **35**: 542-571.

Jones B, Nagin D and Roeder K (2001). "A SAS procedure based on mixture models for estimating developmental trajectories." Sociology Methods Research **29**: 374-393.

Jones J, Firman R, White L and Dwyer P (1997). "Patient transfer from nursing home to emergency department: outcomes and policy implications." Academies in Emergency Medicine **4**(9): 854-845.

Kannegaard P, van der Mark S, Eiken P and Abrahamsen B "Excess mortality in men compared with women following a hip fracture. National analysis of comedications, comorbidity and survival." Age Ageing **39**(2): 203-209.

Katz S, Ford A, Moskowitz R, Jackson B and Jaffe M (1963). "Studies of Illness in the Aged. The Index of ADL: A standardized measure of biological and psychosocial function." JAMA **185**(12): 914 - 919.

Kendig H, Browning C, Pedlow R, Wells Y and Thomas S (2010). "Health, social and lifestyle factors in entry to residential aged care: an Australian longitudinal analysis." Age Ageing **39**(3): 342-349.

Kristjanson L, Walton J and Toye C (2005). "End-of-life care challenges in residential aged care facilities: a case for a palliative approach to care." International Journal of Palliative Nursing **11**(3): 127-129.

Lamb G, Tappen R, Diaz S, Herndon L and Ouslander J (2011). "Avoidability of hospital transfers of nursing home residents: perspectives of frontline staff." Journal of the American Geriatrics Society **59**: 1665-1672.

Landis R and Koch G (1977) "The measurement of observer agreement for categorical data" Biometrics **33**: 159-174

Latham K (2011). "Nursing Home Stays and the Pace of Severe Disability Onset." Research on Aging **33**(6): 637-660.

Lee L, Eagar K and Smith M (1998). "Subacute and non-acute casemix in Australia." Medical Journal of Australia **169**: S22-S25.

Leinonen R, Heikkinen E and Jylhä M (2001). "Predictors of decline in self-assessments of health among older people - A 5-year longitudinal study." Social Science and Medicine **52**(9): 1329-1341.

Lunney J, Lynn J, Foley D, Lipson S and Guralnik J (2003). "Patterns of functional decline at the end of life." JAMA **289**(18): 2387-2392.

Lunney J, Lynn J and Hogan C (2002). "Profiles of Older Medicare Decedents." Journal of the American Geriatrics Society **50**(6): 1108-1112.

Luppa M, Luck T, Weyerer S, Konig H, Brahler E and Riedel-Heller S (2009). "Prediction of institutionalization in the elderly. A systematic review." Age Ageing: afp202.

Lynn J (2001). "Serving Patients Who May Die Soon and Their Families: The Role of Hospice and Other Services." JAMA **285**(7): 925-932.

Lynn J and Adamson D (2003). "Living Well at the End of Life." Rand Health.

Lynn J, DeVries K, Arkes H, Stevens M, Cohn F, Murphy P, Covinsky K, Hamel M, Dawson N and Tsevat J (2000). "Ineffectiveness of the SUPPORT intervention: review of explanations." Journal of the American Geriatrics Society **48**(5).

Lynn J, Straube B, Bell K, Jencks S and Kambic R (2007). "Using population segmentation to provide better health care for all: the "Bridges to Health" model." The Milbank Quarterly **85**(2): 185-208.

Lynn J, Teno J and Harrell F (1995). "Accurate prognostications of death. Opportunities and challenges for clinicians." Western Journal of Medicine **163**: 250-257.

MacDonald S, Hultsch D and Dixon R (2011). "Aging and the shape of cognitive change before death: terminal decline or terminal drop?" The Journals of Gerontology Series B: Psychological Sciences and Social Sciences **66**(3): 292-301.

Mathers C, MaFat D, Inoue M, Rao C and Lopez A (2005). "Counting the dead and what they died from: an assessment of the global status of cause of death data." Bulletin of the World Health Organization **83**(3): 171-177.

McAuley E, Hall K, Motl R, White S, Wojcicki T, Hu L and Doerksen S (2009). "Trajectory of decline in physical activity in community-dwelling older women: social cognitive influences." Journal of Gerontology B: Psychological Science and Social Science **64**(5): 543-550.

McCallum J, Simons L, Simons J and Friedlander Y (2007). "Delaying Dementia and Nursing Home Placement." Annals of the New York Academy of Sciences 1114(1): 121-129.

McCann M, Donnelly M and O'Reilly D (2012). "Gender differences in care home admission risk: partner's age explains the higher risk for women." Age and Ageing.

McConnell E, Branch L, Sloane R and Pieper C (2003). "Natural history of change in physical function among long-stay nursing home residents." Nursing Research 52(2): 119-126.

McConnell E, Pieper C, Sloane R and Branch L (2002). "Effects of cognitive performance on change in physical function in long-stay nursing home residents." J Gerontol A Biol Sci Med Sci 57(12): M778-784.

Meinow B, Kahyreholt I, Parker M and Thorslund M (2004). "The Effect of the Duration of Follow-Up in Mortality Analysis: The Temporal Pattern of Different Predictors." Journals of Gerontology: Series B: Psychological Sciences and Social Sciences 59B(3): S181-S189.

Merkes M and Wells Y (2003). "Women of the baby boom generation and unpaid work - what are the indications for the future?" Australasian Journal on Ageing 22(4): 186-190.

Mitchell S, Teno J, kiely D, Shaffer M, Jones R, Prigerson H, Volicer L, Givens J and Hamel M (2009). "The clinical course of advanced dementia." The New England Journal of Medicine 361(16): 1529-1538.

Mor V, Gruneir A, Feng Z, Grabowski D, Intrator O and Zinn J (2011). "The Effect of State Policies on Nursing Home Resident Outcomes." Journal of the American Geriatrics Society 59(1): 3-9.

Mor V, Wilcox V, Rakowski W and Hiris J (1994). "Functional transitions among the elderly; patterns, predictors, and related hospital use." American Journal of Public Health 84(8): 1274 -1280.

Moschetti K, Cummings P, Sorvillo F and Kuo T (2012). "Burden of Alzheimer's Disease–Related Mortality in the United States, 1999–2008." Journal of the American Geriatrics Society 60(8): 1509-1514.

Mudge A, Denaro C and O'Rourke P (2012). "Improving hospital outcomes in patients admitted from residential aged care: results from a controlled trial." Age and Ageing.

Murray S, Kendall M, Boyd K and Sheikh A (2005). "Illness trajectories and palliative care." BMJ 330(30 April 2005): 1007-1011.

Murray SA, Boyd K, Kendall M, Worth A and Benton T (2002). "Dying of lung cancer or cardiac failure:prospective qualitative interview study of patients and their carers in the community." British Medical Journal 325: 929 - 932.

Murtagh F, Addington-Hall J, MacDonald L, Anderson H and Higginson I (2011). "End-Stage Renal Disease: A New Trajectory of Functional Decline in the Last Year of Life." Journal of the American Geriatrics Society: no-no.

Murtagh F, Preston M and Higginson I (2004). "Patterns of dying: palliative care for non-malignant disease." Clinical Medicine 4(1): 39-44.

National Seniors Australia Productive Ageing Centre (2012). Ageing baby boomers in Australia: understanding the effects of the global financial crisis.

Nayak S, Moore D, Roesch S, Heaton R, Jeste D and Palmer B (2006). "An evaluation of longitudinal neurocognitive performance among middle-

aged and older schizophrenia patients: use of mixed-model analyses." Schizophr Res **83**(2-3): 215-223.

Nikolova R, Demers L and Béland F (2009). "Trajectories of cognitive decline and functional status in the frail older adults." Archives of Gerontology and Geriatrics **48**(1): 28-34.

O'Brien J, O'Keefe K, LaViolette P, DeLuca A, Blacker D and Dickerson B (2010). "Longitudinal fMRI in elderly reveals loss of hippocampal activation with clinical decline." Neurology **74**(24): 1969-1976.

O'Connor M (2009). "Decrepit death as a discourse of death in older age: implications for policy." International Journal of Older People Nursing **4**(4): 263-271.

Okonkwo O, Cohen R, Gunstad J, Tremont G, Alosco M and Poppas A (2010). "Longitudinal trajectories of cognitive decline among older adults with cardiovascular disease." Cerebrovascular Disease **30**(4): 362-373.

Oliver D, Porock D and Zweig S (2004). "End-of-life care in US nursing homes: a review of the evidence." Journal of the American Medical Directors Association **5**: 147-155.

Organisation for Economic Co-operation and Development (2011). Health at a Glance 2011.

Orth U, Trzesniewski K and Robins R (2010). "Self-esteem development from young adulthood to old age: a cohort-sequential longitudinal study." Journal of Personality and Social Psychology **98**(4): 645-658.

Palliative Care Australia (2012). Submission to the Australian Senate Standing Committee on Community Affairs Inquiry into Palliative Care in Australia on behalf of Palliative Care Australia. Canberra, Palliative Care Australia.

Parker D (2005). "A Palliative Approach or Specialist Paliatiev Care? What Happens in Aged Care Facilities for Residents With a Noncancer Diagnosis?" Journal of Palliative Care **21**(2): 80-87.

Partington L (2006). "The challenges in adopting care pathways for the dying for use in care homes." International Journal of Older People Nursing **1**(1): 51-55.

Payne G, Laporte A, Deber R and Coyte P (2007). "Counting Backward to Health Care's Future: Using Time-to-Death Modeling to Identify Changes in End-of-Life Morbidity and the Impact of Aging on Health Care Expenditures." Milbank Quarterly **85**(2): 213-257.

Penrod J and Liu C (2006). Theory of Illness Trajectory. Nursing theorists and their work (6th Edition). Tomey A and Alligood M. St Louis, Mosby Elsevier**:** 664 - 678.

Pijpers E, Ferreira I, Stehouwer C and Nieuwenhuijzen-Kruseman A (2012). "The frailty dilemma: Review of the predictive accuracy of major frailty scores." European Journal of Internal Medicine **23**(2): 118-123.

Pot A, Portrait f, Visser G, Puts M, Groenou M and Deeg D (2009). "Utilization of acute and long-term care in the last year of life: comparison with survivors in a population-based study." BMC Health Services Research **9**(139).

Price K, Alde P, Provis C, Harris R and Stack S (2004). "what hinders and what helps? Searching for solutions to mature aged unemployment and the residential aged care workforce crisis." Australasian Journal on Ageing **23**(4): 177-183.

Productivity Commission (2011). Caring for Older Australians. Canberra. **Report No.53**.

Proof Committee Hansard (2012). Senate: Community Affairs Legislation Committee Estimates. T. A. Senate. Canberra, Australian Government.

Quine S, Bernard D and Kendig H (2006). "Understanding baby boomers' expectations and plans for their retirement: findings from a qualitative study." Australasian Journal on Ageing **25**(3): 145-150.

RAND Health (2006). Redefining and reforming health care for the last years of life. Research Highlights. Santa Monica, USA, RAND Corporation**:** 1-3.

Ranzijn R, Harford J and Andrews G (2002). "Ageing and the economy: costs and benefits." Australasian Journal on Ageing **21**(3): 145-151.

Ranzijn R, Patrickson M, Carson E and Lesueur E (2004). "Independence and self-provision in old age: how realistic are these goals?" Australasian Journal on Ageing **23**(3): 120-124.

Richardson S and Martin B (2004). "the care of older Australians. A picture of the residential aged care workforce."

Robinson A, Rumble R and Francis B (2006). "The reclassification of elderly people following admission to residential aged care." Australasian Journal on Ageing **25**(2): 101-103.

Rochat S, Cumming R, Blyth F, Creasey H, Handelsman D, Le Couteur D, Naganathan V, Sambrook P, Seibel M and Waite L (2010). "Frailty and use of health and community services by community-dwelling older men: the Concord Health and Ageing in Men Project." Age and Ageing **39**: 228-233.

Rockwood K, Abeysundera M and Mitnitski A (2007). "How shoulf we grade frailty in nursing home patients?" Journal of the American Medical Directors Association **8**(9): 595-603.

Rockwood K, Mitniski A, Song X and Steen B (2006). "Long-term risks of death and institutionalization of elderly people in relation to deficit accumulation at age 70." Journal of the American Geriatrics Society **54**: 975-979.

Rogers M, Ward K, Gure T, Choe H, Lee P, Bernstein S and Blaum C (2011). "Blood pressure trajectories prior to death in patients with diabetes." Diabetes Care **34**(7): 1534-1539.

Romoren T and Blekeseaune M (2003). "Trajectories of disability among the oldest old." J Aging Health **15**(3): 548-566.

Rosenberg T (2012). "Acute Hospital Use, Nursing Home Placement, and Mortality in a Frail Community-Dwelling Cohort Managed with Primary Integrated Interdisciplinary Elder Care at Home." Journal of the American Geriatrics Society: n/a-n/a.

Salkind N (2004). Statistics for people who (think they) hate statistics (2nd Edition). Thousand Oaks California, Sage Publications.

Savla G, Moore D, Roesch S, Heaton R, Jeste D and Palmer B (2006). "An evaluation of longitudinal neurocognitive performance among middle-aged and older schizophrenia patients: Use of mixed-model analyses." Schizophrenia Research **83**(2-3): 215-223.

Schofield D and Beard J (2005). "Baby boomer doctors and nurses: demographic change and transitions to retirement." Medical Journal of Australia **183**(2): 80-83.

Schram M, Frijters D, van de Lisdonk E, Ploemacher J, de Craen A, de Waal M, van Rooij F, Heeringa J, Hofman A, Deeg D and Schellevis F (2008).

"Setting and registry characteristics affect the prevalence and nature of multimorbidity in the elderly." Journal of Clinical Epidemiology **61**(11): 1104-1112.

Shanley C, Whitmore E, Khoo A, Cartwright C, Walker A and Cumming R (2009). "Understanding how advance care planning is approached in the residential aged care setting: a continuum model of practice as an explanatory device." Australasian Journal on Ageing **28**(4): 211-215.

Shek D and Ma C (2011). "Longitudinal data analyses using linear mixed models in SPSS: concepts, procedures and illustrations." The Scientific World Journal **11**: 42-76.

Shugarman L, Lorenz K and Lynn J (2004). "End-of-life care: and agenda for policy improvement." Clinics in Geriatric Medicine **21**: 255-272.

Skidmore P and Huber J (2003). "Ageing, values and baby boomers."

Sliwinski M, Stawski R, Hall C, Katz M, Verghese J and Lipton R (2006). "Distinguishing preterminal and terminal cognitive decline." European Psychologist **11**(3): 172-181.

Snoke M, Kendig H and O'Loughlin K (2011). "Australian Evidence of Baby Boomers Financial Security: A Review." Journal of Economic and Social Policy **14**(1): 8.

Stepien J, White H, Wundke R, Giles L, Whitehead C and Crotty M (2006). "The Resident Classification Scale: is it a valid measure of functional dependence?" Australasian Journal on Ageing **25**(1): 42-45.

Stevenson J, Abernethy A, Miller C and Currow D (2004). "Managing comorbbidities in patients at the end of life." British Medical Journal **329**: 909-912.

Strauss A, Corbin J, Fagerhaugh S, Glaser B, Maines D, Suczek B and Weiner C (1984). Chronic Illness and the Quality of Life. St Louis, Mosby.

Subramanian S and O'Malley J (2010). "Modeling neighborhood effects: the futility of comparing mixed and marginal approaches." Epidemiology **21**(4): 475-478.

Tabachnick B and Fidell L (2007). Using multivariate statistics. Fifth Edition. Boston, Pearson Education Inc.

Taekema D, Ling C, Kurrle S, Cameron I, Meskers C, Blauw G, Westendorp R, de Craen A and Maier A (2012). "Temporal relationship between handgrip strength and cognitive performance in oldest old people." Age and Ageing.

Takayama M, Hirose N, Arai Y, Gondo Y, Shimizu K, Ebihara Y, Yamainura K, Nakazawa S, Inagaki H, Masui Y and Kitagawa K (2007). "Morbidity of Tokyo-Area centenarians and its relationship to functional status." Journals of Gerontology Series a-Biological Sciences and Medical Sciences **62**(7): 774-782.

Taylor M and Lynch S (2011). "Cohort differences and chronic disease profiles of differential disability trajectories." The Journals of Gerontology Series B: Psychological Sciences and Social Sciences **66**(6): 729-738.

Teno J and Mor V (2005). "Resurrecting treatment histories of dead patients."

Tinetti M, McAvay G, Murphy T, Gross C, Lin H and Allore H (2012). "Contribution of Individual Diseases to Death in Older Adults with Multiple Diseases." Journal of the American Geriatrics Society **60**(8): 1448-1456.

Tomiak M, Berthelot J, Guimond E and Mustard C (2000). "Factors associated with nursing home entry for elders in Manitoba Canada." Journal of Gerontology: Social Sciences **55**(5): M279-287.

Tschanz J, Corcoran C, Skoog I, Khachaturian A, Herrick J, Hayden K, Welsh-Bohmer KA, Calvert T, Norton M, Zandi P and Breitner J (2004). "Dementia: the leading predictor of death in a defined elderly population." Neurology **62**(1156-1162).

Verbrugge L and Jette A (1994). "The disablement process." Social Science and Medicine **38**(1): 1-14.

Vermeulen J, Neyens J, Van Rossum E, Spreeuwenberg M and De Witte L (2011). "Predicting ADL disability in community-dwelling elderly people using physical frailty indicators: A systematic review." BMC Geriatrics **11**.

Vita A, Terry R, Hubert H and Fries J (1998). "Aging, health risks, and cumulative disability." New England Journal of Medicine **338**(15): 1035-1041.

Wagner J, Bachmann L, Boult C, Harari D, von Renteln-Kruse W, Egger M, Beck J and Stuck A (2006). "Predicting the Risk of Hospital Admission in Older Persons-Validation of a Brief Self-Administered Questionnaire in Three European Countries." Journal of the American Geriatrics Society **54**(8): 1271-1276.

Walsh B, Addington-Hall J, Roberts H, Nicholls P and Corner J (2012). "Outcomes After Unplanned Admission to Hospital in Older People: Ill-Defined Conditions as Potential Indicators of the Frailty Trajectory." Journal of the American Geriatrics Society **60**(2): 2104-2109.

Walshe K and Rundall T (2001). "Evidence based management: from theory to practice in health care." The Milbank Quarterly **79**(3): 429-457.

Wang H, Shah M, Allman R and Kilgore M (2011). "Emergency department visits by nursing home residents in the United States." Journal of the American Geriatrics Society **59**: 1864-1872.

Weaver F, Hickey E, Hughes S, Parker V, Fortunato D, Rose J, Cohen S, Robbins L, Orr W, Priefer B, Wieland D and Baskins J (2007). "Providing All-Inclusive Care for Frail Elderly Veterans: Evaluation of Three Models of Care." Journal of the American Geriatrics Society **56**: 345-353.

Weinert B and Timiras P (2003). "Physiology of Aging Invited Review: Theories of aging." Journal of Applied Physiology **95**: 1706-1716.

Weiss C (2011). "Frailty and chronic diseases in older adults." Clinics in Geriatric Medicine **27**: 39-52.

Williams B, Fries B, Foley W, Schneider D and Gavazzi M (1994). "Activities of daily living and costs in nursing homes." Health Care Financing Review **15**(4): 117-135.

Wolf-Ostermann K, Worch A, Fischer T, Wulff I and Gräske J (2012). "Health outcomes and quality of life of residents of shared-housing arrangements compared to residents of special care units – results of the Berlin DeWeGE-study." Journal of Clinical Nursing **21**(21-22): 3047-3060.

Wu H, Flaherty J, Dong B, Liu G, Deng J, Zhang Y, Wu J, Zeng G, Ren X, Hu J, Wu W and Malmstrom T (2012). "Impact of geriatric conditions versus medical diagnosis on ADL disability amaong nonagenarians and centenarians." Journal of Aging and Health **24**: 1298-1319.

Yi Z, Yuzhi L and George L (2003). "Gender differentials of the oldest old in China." Research on Aging **25**(1): 65-80.

Zapka J, Carter R, Carter C, Hennessy W, Kurent J and DesHarnais S (2006). "Care at the end of life: focus on communication and race." Journal of Aging and Health **18**(6): 791-813.

Zarit S, Johansson B and Malmberg B (1995). "Changes in functional competency in the oldest old." Journal of Ageing and Health **7**(1): 3-23.

Zermansky A, Alldred D, Petty D and Raynor D (2007). "Striving to recruit: the difficulties of conducting research on elderly care home residents." Journal of the Royal Society of Medicine **100**(6): 258-261.

Zerzan J (2000). "Access to palliative care and hospice in nursing homes." **284**(19): 2489-2494.

Zimmer Z, Martin L, Nagin D and Jones B (2012) "Modelling disability trajectories and mortality of the oldest-old in China" Demography **49**: 291-314

Chapter 7 Appendices

7.0   Appendix 1 Medical Certificate of Cause of Death

Medical Certificate of Cause of Death	Office use Only

Date received........../........./.........   Death Reg. No. ....

Details of Deceased

Surname

First names *(in full)*

Sex	☐ Male	☐ Female	**Date of death**	/ /

Place of death

Age at death   (show age in completed units—years (y) or months (m) or days (d) or hours (h) or minutes (min))

Was the deceased of Aboriginal or Torres Strait Islander origin? (if both, tick both "Yes" boxes)

☐ No   ☐ Yes, Aboriginal origin   ☐ Yes, Torres Strait Islander origin

Date last seen alive by me

Coroner   Is this death being, or has it been reported to the Coroner?   ☐ No   ☐ Yes

Post mortem status   ☐ Not to be conducted   ☐ Has been conducted   ☐ Yet to be conducted

Cause of Death Details	Part I	Cause	Approximate interval between onset and death
Disease or condition *(a)* **directly leading to death**			due to

This means the disease, injury or complication which caused death—**not only** the mode of dying, such as heart failure, respiratory failure, etc.

Antecedent causes *(b)* **(b) – (e)**		due to
Morbid conditions, if any, giving rise to the above cause, **stating the underlying condition last** *(c)*		due to
(d)		due to
(e)		due to

Part II
Other significant conditions contributing
to the death but not related to the disease or condition causing it

Other Details

Operations Was an operation performed on the deceased within 4 weeks before death?   ☐ No   ☐ Yes (If "Yes" specify below)

Type of operation

Disease/condition

Pregnancy Was the deceased pregnant within 6 weeks of death?   ☐ No   ☐ Yes

Was the deceased pregnant between 6 weeks and 12 months of death?   ☐ No   ☐ Yes

Injury   Was an injury/external cause involved in the death?   ☐ No   ☐ Yes (If "Yes" specify below)

Manner of death (tick one box only) ☐ Natural ☐ Accident ☐ Suicide ☐ Homicide ☐ Pending Investigation ☐ Could not be determined

Certification

I hereby certify that I attended the abovenamed deceased during the last illness and that the particulars and cause of death written above are true to the best of my knowledge and belief. (Please print name and address)

Name		Phone	
Address			
Signature		Date	/ /

Form CODMP (Medical Practitioner)   Form CODFD (Funeral Director)   Form CODR (Registry of Births, Deaths and Marriages)

7.1   Appendix 2 The Data Dictionary

Dataset for Phase 2/3

Source	Dataname number (or text)	format or code
RAC File	**Participant ID** (PID)	ddmmyyNNN

Generated by researcher at start of file

RAC File	**Facility ID** (FID)	N

Generated by researcher at start of file

RAC File	**Date of Birth** (DoB)	ddmmyyyy

RAC File	**Date of Admission to RAC** (DoA)	ddmmyy

RAC File	**Date of Death** (DoD)	ddmmyy

RAC File	**Sex**	N	Male=1 Female=2

ACCR4   **Postcode**   NNNN

▦ ▦ ▦ ▦

RAC File   **Place of Death (PoD)**   N

▦ ▦

| RAC=1 |
| Hospital=2 |
| Unknown=99 |

Name of Place of Death   text

ACCR 9   Marital status at admission to RAC?

N   ▦ ▦

| Never married=1 |
| Widowed=2 |
| Divorced=3 |
| Separated=4 |

ACCR 14   What type of accommodation setting did the resident live in prior to admission to RAC?

NN   ▦ ▦

| Owns=1 |
| Family owns=14 |
| Private residence-rental=2 |
| Public rental=3 |
| Independent living within a retirement village=4 |
| Boarding house=5 |
| Short term crisis accommodation=6 |
| Supported community accommodation=7 |
| Low level RAC=8 |
| High level RAC=9 |

If 'other'=13   text

_____

ACCR 15   Did the resident live with family or other prior to
admission?

N

| Not applicable=0 |
| Lived alone=1 |
| Lived with family=2 |
| Lived with other=3 |

ACCR 20   Did the client have a carer prior to admission to RAC?

N

| Not applicable=0 |
| Had one or more carers=1 |
| Had no carers=2 |

ACCR 21   Did the carer live with them?

N

| Not applicable=0 |
| Co-resident carer=1 |
| Non-resident carer=2 |

ACCR 22   What was the relationship of the carer to the resident?

N   ▦ ▦

Not applicable=0
Wife=1
Husband=2
Mother=3
Father=4
Daughter=5
Son=6
Daughter-in-law=7
Son-in-law=8
Other female relative=9

ACCR 23   Prior to entry to RAC, did the resident n<u>eed</u> help with?:

Multiple responses possible

N+   ▦ ▦ +

Self care=1
Movement activities=2
Moving around places at or away from home=3
Communication=4
Health care tasks=5
Transport=6
Activities involved in social and community participation=7

If 'other'=11   text

ACCR 24   Prior to entry to RAC, did the resident <u>get</u> help with?:

                           Multiple responses possible

Not applicable=0
Self care=1
Movement activities=2
Moving around places at or away from home=3
Communication=4
Health care tasks=5
Transport=6
Activities involved in social and community participation=7
Domestic assistance=8

N+   ▨▨+

If 'other'=11   text

ACCR 26   Prior to entry to RAC, did the resident support or assistance

from?:

                           Multiple responses possible

Not applicable=0
CACP=1
EACH=2
HACC=3
Veterans home care=4
Day centre=5
Carer respite Centre=6
Other community program=7
None=8

N+   ▨▨+

If 'other'=7   text

                    *See item 24 on ACCR

ACCR 27   Prior to entry to RAC, did the resident or their carer use

respite care?

Not applicable=0
Residential respite=1
Non-residential respite=2
None=3
Unknown=99

N   ▦ ▦

ACCR 28   Diagnosed diseases/disorders at assessment by ACAT

Use ACAT diagnosis codes

1 _____   Code ▦ ▦ ▦ ▦
2 _____   Code ▦ ▦ ▦ ▦
3 _____   Code ▦ ▦ ▦ ▦
4 _____   Code ▦ ▦ ▦ ▦
5 _____   Code ▦ ▦ ▦ ▦

ACCR pg7   RAC entry level of care recommended by ACAT

High=1
Low=2

N   ▦

BDM   Direct Cause of Death a (DCoD)   text

Antecedent b

Antecedent c …e

Other significant

comments

RAC   RCS at admission

8=lowest
1=highest

N   ▦

RAC   Date of admission assessment (DoRCSi)   ddmmyy

▨ ▨ ▨ ▨ ▨ ▨

RAC   RCS baseline (RCSa) =an RCS assessment done in the interval A=12mths

from death to 9mths

N   ▨

| 8=lowest |
| 1=highest |

RAC   **Date of assessment/s (DoRCSa - ∞)**   ddmmyy

▨ ▨ ▨ ▨ ▨ ▨

| Yes=1 |
| No=2 |
| No admission=9 |

RAC   GP notes

(1) Admission < 2weeks   N   ▨

,, ,,   2 – 12 weeks   N   ▨

(2) Number of visits by GP   ddmmyy   ▨ ▨ ▨ ▨ ▨ ▨

RAC   Presence of Death Certificate in notes   N   ▨

| Yes=1 |
| No=2 |

RAC   Seen by GP – notes on death   N   ▨

RAC   RCS (numerical) rating per item (x=20 items) per assessment RCS

Use an MS Excel table

1. Communication   ▨ ▨ ▨ ▨   0.00 0.28 0.36 0.83
2. Mobility   ▨ ▨ ▨ ▨   0.00 1.19 1.54 1.82
3. Meals and Drinks   ▨ ▨ ▨ ▨   0.00 0.67 0.75 2.65
4. Personal Hygiene   ▨ ▨ ▨ ▨   0.00 5.34 14.17 14.61
5. Toileting   ▨ ▨ ▨ ▨   0.00 5.98 10.65 13.70
6. Bladder Management ▨ ▨ ▨ ▨   0.00 2.22 3.82 4.19
7. Bowel Management   ▨ ▨ ▨ ▨   0.00 3.32 5.72 6.30
8. Understanding and Undertaking Living Activities
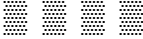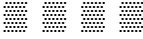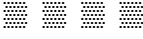
▨ ▨ ▨ ▨   0.00 0.79 1.11 3.40

9. Problem Wandering or Intrusive Behaviour

▦ ▦ ▦ ▦   0.00 0.80 1.58 4.00

10. Verbally Disruptive or Noisy

▦ ▦ ▦ ▦   0.00 1.19 1.75 4.60

11. Physically Aggressive

▦ ▦ ▦ ▦   0.00 2.34 2.69 3.05

12. Emotional Dependence

▦ ▦ ▦ ▦   0.00 0.28 1.50 3.84

13. Danger to Self or Others

▦ ▦ ▦ ▦   0.00 1.11 1.54 1.98

14. Other Behaviour

▦ ▦ ▦ ▦   0.00 0.91 1.82 2.61

15. Social and Human Needs — Resident

▦ ▦ ▦ ▦   0.00 0.95 1.98 3.01

16. Social and Human Needs — Families and Friends

▦ ▦ ▦ ▦   0.00 0.28 0.55 0.91

17. Medication

▦ ▦ ▦ ▦   0.00 0.79 8.55 11.40

18. Technical and Complex Nursing Procedures

▦ ▦ ▦ ▦   0.00 1.54 5.54 11.16

19. Therapy

▦ ▦ ▦ ▦   0.00 3.64 6.10 7.01

20. Other Services

▦ ▦ ▦ ▦   0.00 0.71 1.46 2.93