MODELLING TRAJECTORIES OF AGED CARE USE AMONG OLDER AUSTRALIAN WOMEN

MD MIJANUR RAHMAN

(MSc Statistics and MSc Gerontology)

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School of Medicine and Public Health

The University of Newcastle

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Statement of Originality

I hereby certify that the work embodied in the thesis is my own work, conducted under normal supervision. The thesis contains no material which has been accepted, or is being examined, for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made. I give consent to the final version of my thesis being made available worldwide when deposited in the University's Digital Repository, subject to the provisions of the Copyright Act 1968 and any approved embargo.

Md Mijanur Rahman

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Statement of Thesis by Publication

I hereby certify that this thesis is in the form of a series of five papers of which I am the first author. I have included as part of the thesis a written statement from each co-author, endorsed in writing by the Faculty Assistant Dean (Research Training), attesting to my contribution to any jointly authored papers.

Statement of the co-authors' with the endorsement by the Assistant Dean)Research Training(, is provided in Appendix 2.

10.10.2019

Md Mijanur Rahman　　　　　**Date**

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Contents

List of Publications

1. **Rahman, M**., Efird, J. T., Kendig, H., & Byles, J. E.)2019(. Patterns of home and community care use among older participants in the Australian Longitudinal Study of Women's Health. *European Journal of Ageing*, 16 (3), 293-303.

2. **Rahman, M**., Efird, J. T., & Byles, J. E.)2019(. Patterns of aged care use among older Australian women: A prospective cohort study using linked data. *Archives of Gerontology and Geriatrics*, *81*, 39-47.

3. **Rahman, M.** & Byles J. E.)2019(. Older women's patterns of home and community care use and residential transition: An Australian cohort study, in Press, *Maturitas* journal.

4. **Rahman, M.** & Byles J. E.)2019(. Trajectories of older Australian woman in the residential settings: A multi-trajectories modelling approach, in Press, *Journal of the American Medical Directors Association*.

5. **Rahman, M.,** Efird J. T. & Byles J. E. (2019). Predicting Transition of older women into and through the aged care system over time: A Multi-state Modelling Approach Using Aged Care Linked Data, in Press, *BMC Geriatrics*.

Presentations in Conferences

1. **Rahman, M.** & Byles J. E.)2019). Modelling association between patterns of home and community care use and time to entering residential aged care, accepted for oral presentation at the *Australian Association of Gerontology Conference*, November 6-8, 2019, Sydney, Australia.

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3. **Rahman, M. &** Byles J. E.)2018(. Statistical Modelling Techniques for recurrent event analysis, Oral presentation at the *19th J. B. Douglas Postgraduate Award 2018*, University of Technology Sydney, Australia.

4. **Rahman, M.,** Efird T.J. & Byles J. E.)2018(. Predicting Transition of Older Women into and Through the Aged Care System Over Time: A Multi-state Modelling Approach Using Aged Care Linked Data, oral presentation at the *The Joint International Society for Clinical Biostatistics and Australian Statistical Conference 2018* Melbourne, Australia.

5. **Rahman, M**., Efird T.J. & Byles J. E.)2018(. Transition of Older Women into and Through the Aged Care System Over Time, An oral presentation at the *4th International Conference on Long-term Care Directors & Administrators*, Australian Research Council Centre for Excellence in Population Ageing Research, University of New South Wales, 2-3 August 2018, Sydney, Australia.

6. **Rahman, M.,** Efird T.J. & Byles J. E.)2018(. Trajectories to Aged Care Service use among Older Australian Women: A repeated event latent class analysis, oral presentation at *47th Annual Meeting of the British Society of Gerontology*, 4-6 July 2018, Manchester, United Kingdom.

7. **Rahman, M.,** Efird T.J. & Byles J. E.)2017(. Repeated time to admission and length of stay in residential aged care: A recurrent event analysis using counting process model, Oral presentation at *Young Statistician Conference-2017*, Gold coast Australia,

8. **Rahman, M.,** Efird T. J. & Byles E.J.)2016(. The Types and Patterns of Home and Community Care)HACC(Service Use Among a Large Cohort of Australian Women as They Age from 75-80 To 85-90, Oral presentation at the *Emerging Research on Ageing Conference*, Australian National University, Canberra.

Abbreviations

ACAT	Aged Care Assessment Team
ACFI	Aged Care Funding Institute
ADL	Activity of Daily Living
AHSRI	Australian Health Service Research Institute
AIC	Akaike Information Criterion
AIHW	Australian Institute of Health and Welfare
ALSWH	Australian Longitudinal Study on Women's Health
AN-ACC	Australian National Aged Care Classification
BEH	Behavioural
BIC	Bayesian Information Criterion
BMI	Body Mass Index
CACP	Community Aged Care Packages
CDC	Consumer Directed Care
CEPAR	Centre for Excellence in Population Ageing
CHC	Complex Health Care
CHCP	Commonwealth Home Support Programme
CI	Confidence Interval
EACH	Extended Aged Care at Home
GBTM	Group-based Trajectory Modelling
EACH-D	Extended Aged Care at Home-Dementia
HACC	Home and Community Care
HR	Hazard Ratio

KBL   Key-based data linkage

LCA   Latent Class Analysis

LLLB   Living Longer Living Better

MDS   Home and Community Care Miminum Data set

OCED   Organization for Economic Cooperation and Development

OR   Odds Ratio

PC   Productivity Commission

PCC   Population, Concept, Context

RAC   Residential Aged Care

RMLCA   Repeated Measures Latent Class Analysis

sdHR   Subdistribution Hazard Ratio

SF-36   Short Form-36

TCP   Transition Care Program

WHO   World Health Organization

Abstract

Background: A substantial growth in the number of older people needing care has raised enormous challenges to the health and social care system in many countries including Australia. The structure and dynamics of the Australian aged care system are not yet able to develop a sustainable system for delivering an appropriate model of care. The current aged care system is complex and older Australians experience multifaceted journeys through the fragmented systems to meet their care needs. Research evidence is limited about how different parts of the system intersect and how an individual transitions from one level of care to another in accordance with changing needs over time. There is also a lack of understanding of how individual and social circumstances and supports might predispose older people to use care, or enable them to use appropriate care when they need it. To fill these knowledge gaps, this study aims to assess patterns and trajectories of different types of aged care use over time and to examine the movements of older women between different levels of aged care use according to their changing needs and circumstances throughout later life.

Methods: This study utilised data from the older cohort)born between 1921-26(of the Australian Longitudinal Study on Women's Health and linked aged care and National Death Index data from 2001 to 2014. The sample consisted of 11,245 women who survived to 2001 and did not opted out of linkage of survey data to aged care information. To address the research objectives, we applied the following statistical methods: 1(k-median cluster analysis to assess patterns of home and community care use; 2(repeated measures latent class analysis to identify latent patterns of aged care use over time; 3(competing risk survival analysis to identify risk factors for the time from first home and community care (HACC) use to

residential aged care)RAC(admission; 4(multi-trajectory modelling to assess the trajectories of care need in RAC; and 5(Markov multi-state modelling to estimate the transition rates and probabilities, and length of stay at each level of aged care use.

Results: The results reveal a significant diversity in the patterns of HACC use, with a majority of older women living at home independently, requiring only low-level use of a few basic services, while one quarter have complex care needs requiring greater use of multiple services. Women were most likely to enter aged care by first using HACC. Significant variation in the latent patterns of aged care use was also observed, with around two-thirds of women not using any services or using a limited basic community care services until age 85-90. Only a small proportion of women were increasingly dependent on RAC as they age. Having complex use of HACC was associated with delayed admission to RAC, after adjusting for individual characteristics. Substantial variation was observed among residents in RAC in terms of the trajectories of care needs over time across three domains of the Aged Care Funding Instrument including activities of daily living, behaviour, and complex healthcare needs. Multiple morbidities were associated with membership of an increased complex healthcare needs group. Transition to either HACC or RAC was associated with several demographic and health-related factors including living in regional/remote areas, having difficulties in managing income, having low scores in physical functioning, and having falls with injury.

Conclusion and Implication: Women spend a substantial period of their later life with care and support from either HACC or RAC. Our findings highlight the importance of providing a range of services to meet the diverse care needs of older women, especially in the community setting. Our findings can facilitate appropriate care planning, service delivery, and future capacity design of the aged care system in Australia.

CHAPTER 1: Introduction

1.1 Definitions of Aged Care

Aged care refers to the delivery of a range of services to address healthcare and personal care needs of older people)aged 65 and over(with declining intrinsic capacity. The primary objective of aged care is to support older people to live independently and in the best health they can be)Cubit & Meyer, 2011; Jeon & Kendig, 2017(. Aged care offers a wide variety of care interventions in the absence of cure or rehabilitation for underlying diseases or disability (Centre of Excellence in Population Ageing Research, 2014). While the vast majority of care is informally provided by unpaid family members and friends, aged care in Australia is usually defined as a formal system for supporting older people with activities of daily living)e.g., bathing, dressing, grooming, using the toilet and moving around(alongside nursing care and allied health services over a short or long period of time. Care is usually provided in people's homes in the community or in residential facilities, delivered by a wide variety of providers.

The Australian Productivity Commission has defined aged care as:

"Covering a range of services provided to older people who have diminished capacity to care for themselves because of physical/mental disability or frailty which can include one or more of the following: i(assistance with everyday living activities, such as cleaning, laundry, shopping, meals and social participation, ii(help with personal care, such as help with dressing, eating and toileting, iii(health care, such as medical, nursing, physiotherapy, dietetics and dentistry, and iv(accommodation" (Royal Commission into Aged Care Quality and Safety, 2019a, p. 7).

Outside of Australia, aged care is mostly known as long-term care or social care. Internationally, there is considerable variation in the terminology used for different types of care)Roberts, 2017(. The variation of the terminology between countries is dependent on local culture, capacity, and resources, resulting in a variety of definitions being used across different countries and international organizations. The National Institute on Aging in the United States declares that:

> "Long-term care involves a variety of services designed to meet a person's health or personal care needs during a short or long period of time. These services help people to live as independently and safely as possible when they can no longer perform everyday activities on their own")National Institute of Aging, 2019(.

The above definition is similar to concepts of aged care in Australia and social care in the United Kingdom. Adding to this definition, it is noted that most long-term care is provided by unpaid family members and friends, but depending on people's care needs, can also be delivered in a nursing home, adult day care centre, or in the community.

The World Health Organization has defined aged care as:

> "the activities undertaken by others to ensure that those with a significant ongoing loss of physical or mental capacity can maintain a level of ability to be and to do what they have reason to value; consistent with their basic rights, fundamental freedoms and human dignity")WHO, 2015, p. 140(.

With increasing age, many people experience a significant loss of mental or physical capacity. However, it is widely accepted that even with ageing, people will continue to aspire to optimise their well-being through maintaining the best manageable health and living a life

of meaning and dignity. The availability of care and support services to ageing people is crucial to their maintaining a level of ability, regardless of the significant loss of their intrinsic capacity (Pot, Briggs, & Beard). The ultimate goal of long-term care is maintenance of functional ability rather than simply meeting the basic needs for survival. Long-term care includes efforts to help people)those with significant loss of intrinsic capacity(to regain their productive life and well-being through putting them at the centre of the effort. To achieve this goal, the WHO's definition highlights long-term care as a system comprising multiple components that:

> "Spans family members, friends, volunteers who provide care and support, the workforce of paid and unpaid caregivers, care coordination, community-based services, and institutional care, as well as services that support caregivers and ensure the quality of the care they provide:)WHO, 2015, p. 141(.

The Organisation for Economic Co-operation and Development has defined long-term care as "care for people needing daily living support in many facets of living over a prolonged period of time")Organization for Economic Co-operation and Development, 2011, p. 39(. They are multifaceted systems that are linked to the social, moral and ethical norms, policies, and contexts of individual countries)Ngai & Pissarides, 2009(. While some consider long-term care as a part of the private sphere)informal(, it is a collective responsibility for all stakeholders, including family, friends, community, providers, and governments. Particularly, it is important to be embedded within a system with government oversight, which works alongside informal care provision. The recipients of long-term care can include young people living with a disability or older people living with declining intrinsic capacity. Women and people aged 80 and over have the highest probability of needing long-term care services. A

substantial proportion of recipients suffer from dementia-related problems (Organization for Economic Co-operation and Development, 2011).

Despite the fact that different definitions are in use across different countries or research contexts, the key components of long-term care remain unchanged in most definitions. These components include: delivery of a variety of services; people with declining intrinsic capacity; unpaid or paid caregivers; which can be provided a range of settings; over time; and the promotion of dignity and well-being. The current Ph.D. project focuses on the government subsidized formal long-term care services used by older Australian women. Hereafter, we will use the terminology 'aged care' throughout this thesis.

1.2 Aged Care Services in Australia and Recent Transitions

The Australian aged care system provides a range of services to meet the care needs of every Australian aged 65 and over)50 and over for Aboriginal and Torres Strait Islanders(. The formal aged care system is primarily funded and regulated by the Australian Federal Government)Grove, 2016(. Care services which are provided outside of the formal system such as care provided by family members/friends or accommodation in a retirement village[1] are not within the scope of this Ph.D. study. There are three main service streams under the government subsidized aged care system: community aged care, residential aged care, and flexible care. The following sub-sections contain a brief discussion of these different types of

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[1] Retirement village in Australia is a housing options designed exclusive for people age 55 and over or who have retired from full-time employment but generally not provide aged care services.

aged care programs to provide preliminary background to the research, but a comprehensive discussion is provided in Chapter 2.

1.2.1 Community Aged Care

Following the recommendations of the Productivity Commission (2011), the community aged care system has undergone significant structural reform under the 10-year aged care reform package "Living Longer, Living Better" launched in 2013)Australian Government Department of Health, 2012(. The current study focuses on government subsidized aged care services, which were provided between 2001 and 2014. Before the recent reforms, a range of community aged care programs were available, with Home and Community Care)HACC(being the largest or most commonly used community aged care program. HACC)established in 1985(provided a range of services to allow older people to remain in their home as long as possible rather than entering Residential Aged Care)RAC((Department of Health and Ageing, 2008; Jorm et al., 2010). Services included domestic assistance with meals and personal care, home maintenance and medication, transport, social care, respite care, as well as nursing and allied health services (Department of Health and Ageing, 2012b). Approximately 20% of people aged 65 and over receive support from HACC, which constitutes the largest aged care program in the country (Australian Institute of Health and Welfare, 2015b). Between 2013-14, more than 775,000 older Australians received HACC, with the majority being women)>65%( )Department of Social Services, 2014(. HACC, along with three other minor community aged care programs,)the National Respite for Carers Program, the Day Therapy Centres Program, and the Assistance with Care and Housing for the Aged Program(, merged into the Commonwealth Home Support Program)CHSP(in July 1, 2015.

Other previous community aged care programs were Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH), and Extended Aged Care at Home, Dementia (EACH-D). These programs were alternatives to residential aged care and designed to deliver a choice of care tailored to individuals)Australian institute of Health and Welfare, 2012a(. Community Aged Care Packages)introduced in 1992-93(were equivalent to a low-care level of residential aged care while Extended Aged Care at Home)introduced in 2002-03(and Extended Aged Care at Home, Dementia)introduced in 2005-06(were equivalent to a high-care level of residential aged care. A recommendation from an Aged Care Assessment Team was required to access these services. However, provision of these services were relatively low before the recent reform. These three programs were merged into the Home Care Program)HCP(, which had four levels in 2013. With increased consumer choice and government focus, the provision of HCP services has been sharply increasing in recent years.

1.2.2 Residential Aged Care

Residential Aged Care)RAC(is one of the most substantial components of the Australian aged care system. It offers long- or short-term stays in a residential aged care facility. The Australian Institute of Health and Welfare (2007, p. 101) has defined RAC as "providing accommodation and care services to aged people who are no longer able to support themselves or be supported by others in their own homes". Entering residential aged care requires the older person to first be assessed by an Aged Care Assessment Team (ACAT). Residential aged care provides two streams of care: respite residential aged care)short-term(and permanent residential aged care)long-term(.

Respite residential care is available on a planned or emergency basis to older people who intend to use residential care on a temporary basis. The aim is to support those who are in a transitional stage of health as well as to provide the carer a break from their care-giving role)Australian Institute of Health and Welfare, 2012b(. Respite care can be provided either on a low-care or high-care basis on aged care facility. Most older people who enter permanent RAC have prior records of using respite RAC on one or more instances.

Permanent RAC is offered to older people whose care needs are no longer able to be fulfilled and/or supported at home or in the community. Permanent RAC previously had two levels of care: low-level care and high-level care. From July 2014, this distinction was removed to make permanent RAC a more flexible, simple and transparent arrangement. This reduces red tape for residents and providers without compromising levels of care (Australian Institute of Health and Welfare, 2015b). Currently, the needs-based Aged Care Funding Instrument)ACFI(is applied to determine the level of care needs and appropriate funding support for each resident (Australian Government Department of Health, 2017a). The ACFI assesses care needs and funding based on a series of questions across three domains: activities of daily living (ADL), behaviour, and complex health care (Australian Government Department of Health, 2017a). The more assessed needs for a particular resident, the higher the amount of care subsidy they receive. Residents also pay a basic daily fee, which is capped at 85% of the single basic pension)around AU $ 678.21 fortnightly( )Grove, 2016(. Also, a means-tested)based on income and assets(care fee is applied to some residents, but with annual and lifetime caps. Those with higher means are required to pay part or full accommodation costs. The ACFI has currently undergone extensive review and is expected to be replaced by the Australian National Aged Care Classification)AN-ACC((Australian Goverment Department of Health, 2019a). Details of this review will be discussed in Chapter 2.

1.2.3 Flexible Care

Flexible care offers services to older people who may need a different approach to care other than that provided by mainstream home care and RAC)Grove, 2016(. There are currently four different types of flexible care: Transition Care Program (TCP), Short-Term Restorative Care, Multi-Purpose Services Program, and Innovative Care Program. Besides these, the National Aboriginal and Torres Strait Islander Flexible Aged Care Programme funds services to provide culturally appropriate residential and home care services to Indigenous Australians living in rural and remote areas. As the provision of these services was very low among the participants of the current study cohort, these are not included in the analysis of this Ph.D. project.

1.3 Motivation of the Research

With the continued gain in life expectancy, most people today can expect to live into older age (United Nations, 2016; WHO, 2015). Globally, older people will constitute an increasingly significant proportion of the total population. The demographic shift of the age structure has recently been accelerated as the baby boomers have begun to enter later life paired with increased longevity at older ages (O'Loughlin, Browning, & Kendig, 2016). Particularly, the proportion of very old)aged 85 and over(people, who are increasingly dependent on formal aged care services, has been rapidly increasing. Ageing of the population has wide-reaching effects on numerous systems, structures, and processes including economic growth and the ability of countries and societies to provide for care needs (Bittman, Hill, & Thomson, 2007). This demographic change has raised unprecedented

challenges to policy-makers (Kendig, McDonald, & Piggott, 2016). Governments worldwide are working with great urgency to formulate policy to address these challenges.

Most older Australians need some level of support at some point in later life (Centre of Excellence in Population Ageing Research, 2014; Kendig & Duckett, 2001). The vast majority of this support usually comes from informal carers, including family and friends, who are often female. However, the availability of informal carers has been declining in recent years owing to changes in the family structure through single parenting, divorce, and geographical separation. Specifically, the generation born during the post-war baby-boom are expected to receive significantly less informal care than those of previous generations (Ryan et al., 2012). Given the demographic transitions and other societal changes, there is an increasing gap between the number of older people needing care and the availability of informal caregivers. Consequently, dependency on formal aged care services has been increasing in recent years, and is projected to further rise with the ageing of baby boomers.

Aged care has become a significant component of the Australian health care system incurring $18 billion annual government expenditure in 2017-18 (Australian Institute of Health and Welfare, 2019). Over the last three decades, there has been an increasing focus in government policies to provide care and support services in the community setting to reduce admission to high-cost residential facilities. In addition, most older Australians prefer to remain connected to their families and communities. Strengths and limitations of the current aged care system have been identified)Australian Government Department of Health, 2012; Productivity Commission, 2011(. Significant reforms are currently being implemented, and another major enquiry)Royal Commission on Aged Care Quality and Safety(is currently underway. However, these enquires reforms have not been informed by a comprehensive analysis of

how people use different types of care over the course of their later years, and how this reflects their changing needs and circumstances. Older people may use different types/levels of care and allied health services according to changes in their needs, precipitated by predisposing and enabling factors)e.g., living alone, lower socioeconomic status, inadequate social support(as well as their declining physical functioning, mental health, and social engagement.

Analogous to Australia's general population, older Australians are a diverse group in terms of sociodemographic, cultural, and linguistic backgrounds, leading to wide variation in their expectations and preferences for care. Furthermore, younger cohorts)baby boomers born 1945-1964(are now entering the 'above 65' age bracket with an added burden of life-style related diseases)e.g., obesity, diabetes, and arthritis(and age-associated conditions. In the context of significant social changes, new entrants to the older population tend to have higher education, greater awareness and understanding of health issues, and greater expectations of healthcare services than the current older population. These characteristics pose additional challenges, which may influence future models of aged care provision. Therefore, understanding the patterns of different types of aged care service use across later life among older Australians and their chances of transitioning to different levels of aged services over time according to their changing circumstances and needs, are important for planning service delivery, forecasting future demand, and building workforce capacity for the aged care system in Australia.

1.4 Reasoning behind Modelling Trajectories of Aged Care Use

Many older Australians, at some stage of later life, use different types of aged care services. This ranges from low-level care and support at home or in the community to high-level/complex care in RAC, particularly in the last few years before death. Trajectories of aged care needs and use of different types of services over time across later life are not often linear. People's aged care needs are driven by their inability to self-care and live independently, because of declining functional and intrinsic capacity. According to the WHO Health Ageing model "functional capacity enables people to be and to do what they have reason to value. It is made up of the intrinsic capacity of the individual, relevant environmental characteristics and the interactions between the individual and these characteristics")WHO, 2015, p. 28(. Furthermore, Andersen's Behavioural Model of health services use suggests that an individual's health service utilization is not only driven by the need factors, but also by predisposing characteristics, enabling factors and psychosocial factors (Andersen & Newman, 1973). This model is widely used in examining older people's actual or intended use of health and aged care services (Chen & Berkowitz, 2012; Fu et al., 2017; Hsu, 2013). It is pivotal to understand how people's aged care use is influenced by their predisposing characteristics and health-related needs factors, or how they are mitigated by available enabling factors.

Not all older people necessarily use all types of services, and some may never use any services. Characteristics of those who use services, how long they use them for, and the specific services they use, can be measured using descriptive statistics. This information is available in the standardised reports or statistical overviews that are periodically published by the Australian Institute of Health and Welfare and the Department of Health. While these

reports provide valuable insights about different segments of the system, they cannot reveal contextual driving forces or latent patterns and relationships. Most of these reports are of a cross-sectional nature, and usually reveal specific circumstances or individual parts of the system, rather than examining the trajectories, patterns or pathways into and through the system over time.

Furthermore, the complexity of the Australian aged care system is well documented)Productivity Commission, 2011(. Reforms over the last 30 years often address different ongoing issues in isolation rather than the system as a whole. Older people, their family members and carers have expressed their concern at the overly complex system)that includes a variety of stakeholders, funding and care models, complex regulatory frameworks and changing multi-stage processes(, particularly in the RAC system. To understand the dynamics and structure of these complex systems, researchers need to utilize the power of extensive data sources including routinely collected administrative data, national death index data, and linked longitudinal survey data. Given the recent availability of such datasets, trajectories into and through the aged care system can be statistically modelled which can help us to understand the underlying dynamics and driving forces of the system. For example, estimates from such models)including the chances of using different types of aged care, service use according to participant characteristics, length of stay, and survival probabilities at each progression level(can be used to better understand the pathways of care trajectories, facilitate proper service delivery, and provide a realistic projection for the future demand for different types of services in the aged care system.

Statistical modelling can replicate decision-making, taking into account the viewpoints of all relevant stakeholders)including individual characteristics, family and community support,

caregivers and providers(and allow us to extend such explanation with some predictive power. Providing an explanation through replicating a complex system is often the main reason behind building a model (Miller & Page, 2009). However, the use of conventional statistical models is sometimes not feasible, such as in the case of understanding the complex system and trajectories of older people within each segment of the aged care system and throughout the system over time. Applications of advanced statistical models are required to assess the patterns or latent trajectories of different types of aged care use and to estimate the predicted probabilities for transitioning between different types and levels of care, length of stay, and survival probabilities at each level of aged care use over time. [1]

1.5 Research Objectives

Given the above, we come closer to the nature of the problem that we would like to address in this thesis. Currently, there is a lack of understanding about how older people use different types of aged care services over time, according to their changing needs and circumstances and which factors influence them to transition to complex or high-level service use. This study examines the trajectories of older women into and through the aged care system, to understand their patterns of aged care service use over time and how their movement between different levels of aged care are influenced by their changing needs and circumstances throughout later life. Using survey data from the 1921-26 cohort of the Australian Longitudinal Study on Women's Health)ALSWH(, linked aged care data, and national death index data, we have examined the following research objectives.

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[1] Details regarding the advanced statistical modelling techniques are discussed in the method section (Chapter 3)

- To identify the predictors of using HACC services; to assess the patterns of home and community care use; and to examine the factors associated with each pattern of service use.

- To evaluate latent patterns of aged care use across later life; and to examine whether participants' characteristics are associated with membership of different latent groups.

- To estimate probabilities of transitioning between different types of aged care services over time; and to identify factors associated with each level of transition.

- To identify distinct groups of women living in RAC who had a similar trajectory of care needs over time; and to examine the trajectory group according to participants' characteristics and their survival pattern.

- To evaluate whether home and community care service use and participants' characteristics are associated with admission to RAC.

- To prepare an evidence-based policy brief for the stakeholders and government policy-makers.

1.6 Research Questions

In accordance with the aforementioned research objectives, the current thesis addresses the following research questions.

1. a(What factors are associated with age at first HACC service use?

   b(What are the patterns of HACC use among older Australian women across later life?

   c) How are the participants' characteristics associated with different patterns of service use?

2. a) What are the latent patterns of aged care service use among older Australian women across later life?

   b) What are the participants characteristics associated with membership of different latent groups?

3. Are the patterns of HACC service use and participants' profile (socio-demographic and health) associated with time from first HACC service use to residential aged care admission?

4. a) What are the distinct trajectories of care needs among older women living in RAC?

   b) Are the residents' characteristics associated with being a member of different trajectories groups?

   c) What are the survival outcomes of the different trajectory groups?

5. a) What are the probabilities of using different types of aged care services over time according to participants' characteristics?

   b) What are the predictors of transitioning into different levels of aged care service use across later life?

   c) What are the survival probabilities for the participants at each level of service use?

1.7 Significance and Implication of the Research

The current Ph.D. project takes advantage of over 15 years of prospective longitudinal survey data from a large representative older cohort (born between 1921-26) of the Australian Longitudinal Study on Women's Health. The survey datasets are linked with comprehensive aged care datasets and National Death Index datasets from 2001 to 2014 when the participants were aged 75-80 and 88-93 years, respectively. The longitudinal survey data comprise of information on changes in health, function, activities and supports available to

the participants over time, and the aged care datasets provide detailed information on the different government-supplied aged care service types and use over the study period. Together, the combined linked datasets provide a broad informative platform to follow up the participants' patterns of aged care use over time according to changes in their needs and circumstances throughout later life. Furthermore, it allows us to examine the latent patterns of service use and contextual population and inter-sectoral factors that drive demand for different levels of care, and affect transitions between levels of care services over time. Overall, the opportunities associated with data linkage in ageing, health, and aged care research are immense.

The first study assessed the patterns of HACC service use and identified associated risk factors of using this service. The findings highlight the importance of providing a range of services in community settings to meet the diverse care needs of older women, and also have potential to facilitate service delivery with targeting women with similar patterns of service use.

The second study identified four different latent patterns of aged care service use over time across later life. Women in the four different patterns differed with respect to the timing of their entry into aged care, type and combination of service use, and their survival patterns. These findings will help guide policy-makers in their efforts to improve service delivery and to optimize future capacity planning in the aged care system.

The third study reveals that patterns of HACC use and consumer characteristics were associated with time from first HACC use to RAC admission. The findings highlight the

importance of providing more community care services, age-friendly housing, and fall prevention and physical enabling programs to reduce inappropriate admission to RAC.

The fourth study identified five distinct trajectory groups among older women living in RAC. The trajectory groups differ in terms of levels of care needs across three ACFI domains over time, and there were significant survival differences among women in the different trajectory groups. These findings will help to better understand the changing care needs of older women in RAC over time and facilitate appropriate care planning and service delivery for them.

The fifth study estimated the probabilities of transitioning between different levels of aged care use over time, length of stay at each level and survival. Participants' baseline)demographic and health(characteristics were associated with transitioning into different levels and aged care use. Understanding these characteristics and the probabilities of transitioning between different levels of service use have important implications for better planning and capacity design of the aged care system in Australia.

Overall, the findings from this project are essential for effective planning of aged care services, particularly for understanding the capacities required for different elements in the aged care system. Importantly, the project addresses a key finding of the Productivity Commission Inquiry into Aged Care, which called for the use of data in rigorous analysis to test and evaluate policies, programs, and reforms and to allow for planning, policy development and service provision. In the face of recent significant reforms to the aged care system and potential future reforms arising from the Royal Commission into Aged Care Quality and Safety, this sort of detailed and comprehensive information on trajectories of aged care

service use over time is important to assess whether the reforms have been appropriately targeted and to inform further adjustments and ongoing evaluation.

1.8 Organization of the Thesis

The current thesis follows the format that is usually used for a quantitative research paper)Figure 1(.

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                        ┌─────────────────────────┐
                        │        Abstract         │
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                    ┌───────────────────────────────────┐
                    │ Chapter 1: Introduction and        │
                    │ Research Questions                 │
                    └───────────────────────────────────┘
                    ┌───────────────────────────────────┐
                    │ Chapter 2: Background and          │
                    │ Literature Review                  │
                    └───────────────────────────────────┘
                        ┌─────────────────────────┐
                        │ Chapter 3: Data and      │
                        │ Methods                  │
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Chapter 5 (Sub-study 2): Latent Patterns of Aged Care Use Over Time

Results

Chapter 8 (Sub-study 5): Transition into and Through the Aged Care System

Chapter 4 (Sub-study 1): Assessing the Patterns of Home and Community Care Use

Chapter 6 (Sub-study 3): Patterns of Home and Community Care Use and RAC Transition

Chapter 7 (Sub-study 4): Trajectories of Care Needs in Residential Aged Care

Chapter 9: Discussion

Chapter 10: Policy Brief

Figure 1: Organization of the thesis)Chapters and Titles(

This thesis begins with an abstract summarizing the research objectives, design, key findings, and a conclusion. The results section consists of five chapters)Chapters 4 to 8(with each chapter containing the completed five sub-studies designed to address the five different objectives. Each of these sub-studies have already been published or in press or are currently under review in peer-reviewed international journals. The main chapters are listed below:

Chapter 1: The current chapter aimed to introduce the readers about the aged care system in Australia, the motivation of the research, research questions, significance, and implications of the research.

Chapter 2: This chapter focused on background and literature review which included a literature search strategy, a glimpse of ageing and aged care both international and Australian context, history of aged care reforms and description of aged care service provision in Australia, patterns of aged care use over time, predictors of aged care use, and gaps in the current literature.

Chapter 3: Included the data and methods section with a detailed description of the data sources, study designs to address the proposed research questions, key outcome variables, predictor variables, review of statistical techniques that are applied in the different sub-studies, and a detailed analytical approach for each sub-study.

Chapter 4: Addressed the first research question, with a major focus on patterns of HACC service use. A peer-reviewed article titled "Patterns of home and community care use among older participants in the Australian Longitudinal Study on Women's Health" which has been

published in the *European Journal of Ageing*)2019(is included in this chapter. The findings of this article has also been published in the Australian Community Care Review magazine.

Chapter 5: With addressing the second research question, latent patterns of aged care use across later life were identified and examined in this chapter. The findings have been published as a peer-reviewed article titled "Patterns of aged care use among older Australian women: A prospective cohort study using linked data" in the *Archive of Gerontology and Geriatrics* (2019). The Australian Ageing Agenda magazine has also covered the findings of this article.

Chapter 6: Addressed the third research question with a focus on association between patterns of HACC service use and time to entering RAC. Based on the findings of this study, a manuscript titled "Older women's patterns of home and community care use and residential transition: An Australian cohort study" is currently in Press, the *Maturitas* journal.

Chapter 7: Discussed the trajectories of care needs among the older women in RAC over and address the research question four. A manuscript titled "Trajectories of long-term residential care needs among older Australian women: A cohort study using linked data" is currently in Press, the *Journal of the American Medical Directors Association*.

Chapter 8: Based on the research question five, and included a manuscript titled "Transitioning of older Australian women into and through the long-term care system: A cohort study using linked data", currently in Press, the *BMC Geriatrics* journal.

Chapter 9: Included the discussion section, which draws together the findings from the different results chapters and discusses how these findings answer the research questions. Particularly, how the findings contribute to and improve on previous/existing knowledge of the topic. Limitations of the findings are also clearly stated. Finally, a conclusion sub-section highlights the implications and future directions of the research.

Chapter 10: Consisted of a policy brief, which translated the findings to draw the attention of the policy-makers, highlighting the potential implications of the findings from current and future policy perspectives.

CHAPTER 2: Background and Literature Review

2.1 Introduction

The goal of this Ph.D. project was to assess the patterns of aged care service use and to estimate the predicted probabilities of transitioning into and through the aged care system over time, according to participants' characteristics. This will allow us to understand how older people use different types of aged care services according to their changing needs and circumstances throughout later life. A comprehensive literature review has been completed to develop a background to the study. This chapter includes: i(scope and search strategy; ii(a glimpse into global ageing and aged care; iii(ageing and aged care challenges in Australia; iv(a brief history of aged care reforms in Australia; v(provision of aged care services; vi) patterns of aged care use vii(predictors of aged care use; and viii(gaps in the current literature. In accordance with the objectives of the current study, the literature review mainly focuses on the context of the aged care system in Australia. Nonetheless, evidence from outside Australia has also been cited when found to be relevant to the objectives.

2.2 Scope and Search Strategy

Examining trajectories of aged care service use throughout later life using linked administrative records with longitudinal survey data is a relatively new field of inquiry in Australia and even across the world. Taking this recentness into consideration, this study initially searched relevant resources across the world for the period 1990-2018 using the databases Medline, Web of Science, Google Scholar, and CINAHL Complete to investigate what is available in the existing literature. We searched for relevant reports and working

papers from government organizations)e.g., AIHW, Australian Bureau of Statistics, Department of Health, and Department of Social Services(and non-government national and international organizations)e.g., World Health Organization, International Longevity Centre, Australian Research Council Centre for Excellence in Population Ageing (CEPAR), and Council on the Ageing(. The mnemonic PCC)Population, Concept, Context(which is recommended by The Joanna Briggs Institute)2015, p. 18(for scoping reviews has been employed in the current study. Table 1 shows the PCC search terms and Boolean phrases incorporated in the search strategy.

Using all the databases, a total of 925 records were identified from the search results, and 27 of these studies were conducted in the context of Australia. The titles and abstracts of these 27 studies were read, and only seven studies met the search criteria (Australian Institute of Health and Welfare, 2011a, 2014b; Joenpera et al., 2016; Jorgensen et al., 2018; Karmel & Gibson, 2007; Karmel et al., 2009; Kendig et al., 2012). Among these seven studies, two studies by Karmel and colleagues (Karmel & Gibson, 2007; Karmel et al., 2009) focused on the methodological innovation of data linkage between hospital episode and residential aged care services, and transition from hospital to residential facilities. The remaining five studies focused on aged care service episodes using administrative data linkage. These five studies and relevant international studies are critically discussed in the different sub-sections of the current chapter. To date, no study has been identified that uses linked administrative aged care and longitudinal survey data to identify patterns and predictors for a particular cohort of older people, and to examine trajectories of aged care use across later life.

Table 1: The PCC mnemonic)Population, Concept, Context(search terms and Boolean phrases incorporated in the search strategy

Population)AND(	Concept)AND(	Context)AND(
Older People)or(	Aged care)or(	Linked data)or(
Old People)or(	Residential aged care)or(	Data linking)or(
Elderly)or(	Long-term care)or(	Data linkage)or(
Ageing)or(	Elderly care)or(	Administrative data)or(
Aging)or(	Home and Community Care)or(	Longitudinal data)or(
Aged)or(	Home care)or(	Longitudinal survey data)or(
Frail elderly)or(	Community care)or(	Panel data)or(
Elder)or(	Community aged care)or(	Health records)or(
Over 65)or(	Domiciliary care)or(	Time series data)or(
Over 65 years)or(	Assisted or supported living)or(	
65 and over)or(	Individual support)or(	
65 years and over)or(	Social care)or(	
Aged 65 years and over	Dementia care)or(	

Beyond these few studies, a wide range of relevant literature has been discussed to develop a comprehensive background to this study. Our review includes journal articles, books, reports, working papers, and policy briefs of government institutions, and national and international organizations. The reference lists of the key articles/chapters/reports were also reviewed to find additional relevant resources. Overall, 255 relevant articles/reports/working papers/books were identified and exported into EndNote X9 database, and cited in this thesis.

2.3 A Glimpse into Global Ageing and Aged Care

The world population is ageing faster than ever before due to the combined effect of increasing longevity and declining fertility. The number of people aged 80 and over)the fastest growing age group(is projected to triple)426 million(by 2050, from 143 million in 2019)United Nations, 2019(. Around 10% of the total population in the OECD countries will be very old by 2050, when it was only 1% in 1950. (Organization for Economic Co-operation and Development, 2011). Although having started later, the pace of demographic transition is faster in developing countries than developed countries. It is projected that, in 2050, two out of three people aged 80 or over will be living in developing countries (United Nations Department of Economic and Social Affairs, 2015). This rapid shift in the age structure raises unprecedented challenges to policy-makers across the world. With a wide-ranging effect on numerous systems)including health and social care systems as well as economic growth(, ageing of the population is perceived as one of the main forces that has been transforming societies both in developing and developed countries (Bittman, Hill, & Thomson, 2007; Bloom, Canning, & Fink, 2010).

There has been a growing debate around whether increased longevity is an opportunity or a threat to the stability of societies. This is largely dependent on one key factor: whether it accompanies negative health effects such as multiple morbidities and progressive loss of physical, mental and cognitive capacity which leads to impairment or disability (Chang et al., 2019). While we often assume that increasing longevity comes with extra years of good health, there is limited evidence to suggest that older people today experience a better health trajectory than their parents did at the same age. Research evidence is mixed around whether the impacts of population ageing can be mitigated by decreasing in disability among older

people)Robine & Saito 2009(and altering the severity of a disability by transforming it to dependency or a range of care needs (Jagger et al., 2007; Majer et al., 2013). Researchers in the United Kingdom and Japan report increased longevity has been accompanied by a reduction in dependency in early old age)65-74 years(but increases in dependency among people in the very old group (85 and over))Kingston et al., 2017; Seko et al., 2012(.

Demand for long-term care use is highly age-related, with over half of all users aged 80 and over (Organization for Economic Co-operation and Development, 2011). While most people in their sixties or seventies continue to live independently, they are likely to become frail and experience multiple morbidities and disabilities in their eighties)Austad, 2009; Stones & Gullifer, 2016(. With increased age-related disabling chronic conditions, many people of this age group experience a significant loss of mental or physical capacity and are dependent on available long-term care and support services (Pot, Briggs, & Beard, 2017; United Nations, 2016). Consequently, ageing of the global population will increase the absolute number of older people who will be dependent on long-term care services. Growth in the number of the very old population will mean an increased demand for long-term care services.

Furthermore, in accordance with the rise in life expectancy)Figure 2.1(and the growing number of older people, the incidence of cognitive diseases including dementia continue to increase. Globally, the incidence of dementia is projected to increase fom 44 million in 2015 to 75 million by 2030)WHO, 2015(. Approximately two-fifths of people aged 85 and over suffer from dementia, primarily Alzheimer's disease in the United States. In Australia, three out ten people aged 85 and over have been diagnosed with dementia)Dementia Australia, 2018(. The majority of people with dementia need a greater level of care and support, leading to a further increase in the demand for long-term care services. However, researchers in a

recent Australian study reports that the prevalence of dementia among people accessing aged care has declined from 50.0% in 2008 to 46.6% in 2014 (Harrison et al., 2019).
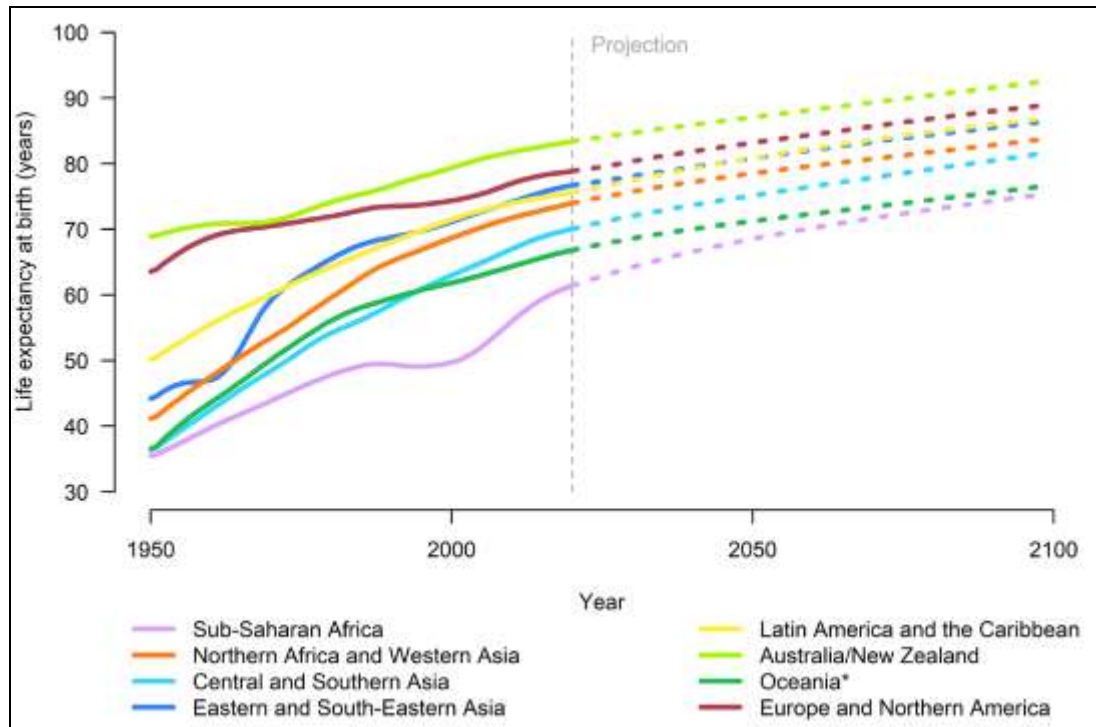
Source: United Nations)2019(

*Excluding Australia and Newzealand

Figure 2.1: Estimated and projected life expectancy at birth by different region across world for 1950-2100 according to median-variant projection

Long-term care for older people is predominantly known as social care in the United Kingdom, and aged care in Australia. There is a wide international variation in the terminology used for different types of care)Roberts, 2017(, and the general definitions of long-term care have been presented in Chapter One. Care systems differ greatly between countries depending on local culture, capacity and resources, and long-term care is delivered in many different ways across countries. There is also significant variation between countries

in terms of the funding mechanisms and the level of public support for long-term care)or social protection(. For example, the funding models in the OECD countries fall into four broad categories: social insurance)e.g., Germany(, taxation and means-tested charges)e.g., United States(, taxation without means-tested charges)e.g., Denmark, Austria(, and social insurance and taxation)e.g., Japan.(. Taxation means-tested charges may also be the best category to describe the funding of the Australian aged care system. Another defining characteristic of aged care in Australia is that most)80%(of aged care is delivered in the community.

Many low-income countries including Bangladesh, Nepal, Ghana and Kenya have very limited formal long-term care services (Darkwa, 2000; Lloyd-Sherlock, 2014; Shetty, 2012). Residential aged care is usually non-existent in these countries, but limited in-home services are available. A study based in Nepal, which included in-depth interviews with 18 decision makers reported that the majority of decision makers do not believe long-term care is an important role for the government and most are not aware of the problems associated with long-term care services)Basnyat, 2010(.

2.4 Ageing and Aged Care Challenges in Australia

Australia is one of the countries that are at the forefront of global ageing. While, ageing of the Australian population has been shaped by falling fertility and mortality for the past 150 years, it has been included as a policy priority since the 1980s, following the Borrie Report on indicative population projections from 1970 to 2070)National Population Inquiry, 1975(. The dramatic increase in the aged population is evident considering that in 1870, only 2% of the total population of Australia was aged 65 and over. Less than 150 years later, the share of

this population will increase to 15%)in 2017(and the projected proportion increases to 22% by 2057)Figure 2.2(. One of the key forces that is accelerating population ageing, making population ageing a pressing issue, is the ageing of the baby boomer generation. Consequently the Australian government has a policy focus on related policy challenges including health and aged care, retirement support, and managing intergenerational relationships)Piggott, 2016(.
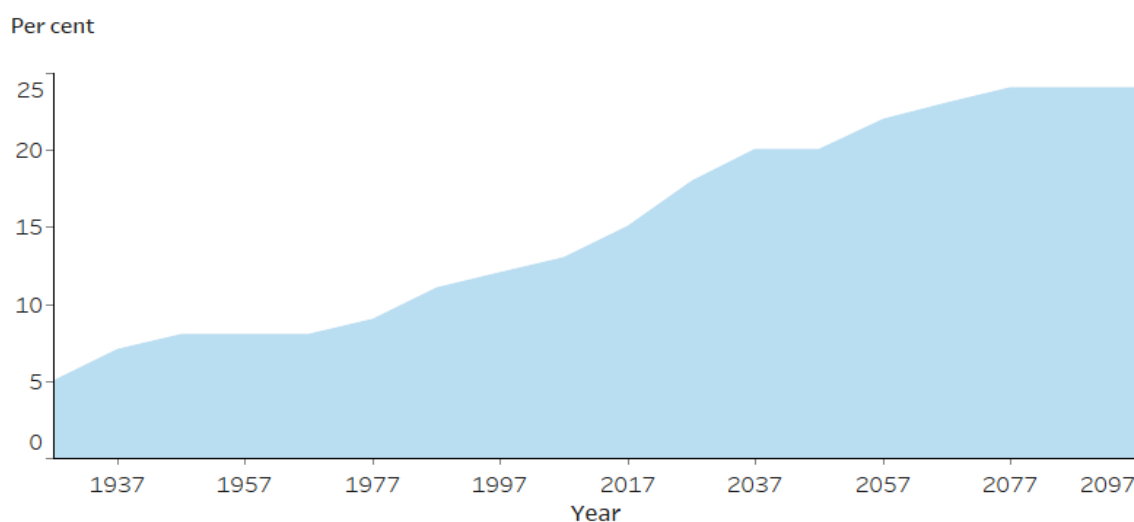
Source: Australian Bureau of Statistics (2016)

Figure 2.**2**: Proportion of older Australians)aged 65 and over(in the total population over time

Demographic ageing has accelerated in recent years as the post war large baby boomers generation)born between 1946 and 1964(begin entering the agegroup of 65 years and over)McDonald, 2014(. People born at the leading edge of this boom are currently aged in their 70s, and will soon enter their 80s. With their increased longevity at older ages, the proportion of people aged 85 and over)the fastest growing age group(is expected to increase more rapidly over the next few decades, reaching approximately two million)over 5% of the total

population(by 2055, which is from 0.4 million in 2010. The centenarians age group is also projected to increase to reach over 40,000 by 2055)Australian Treasury, 2015(. Most of these older people are women as they have a longer lifespan than men, but men's longevity is catching up and the life expectancy gap between men and women is diminishing.

Today Australians live longer than ever before, with life expectancy being one of the highest in the world)80.5 years for men and 84.5 years for women(. However, increased life expectancy at 65 has also been accompanied by increases in years with both mild and severe disability, with a significant impact on demand for health and aged care services (Freedman, Wolf, & Spillman, 2016). Between the period of 1998 and 2012, the expected gain in longevity has been accompanied by an increase in the expected years of life with disability, in particular severe or profound limitations in core activities)Australian Institute of Health and Welfare, 2014a(. In 2012, a 65 year old man could expect to live 19.1 additional years of which 10.4 years were with disability including 3.7 years of profound disability; whereas, for an older woman the expected additional number of surviving years was 22 years of which 12.5 years were with disability, including 5.8 years with severe disability)Australian Institute of Health and Welfare, 2014a(.

As the population ages, and with increasing life expectancy, a growing number of older Australians will mean a greater demand for formal aged care services. Many older people are dependent on formal aged care services because of disabling chronic-conditions and lack of informal support including loss of a spouse)Austad, 2009; Stones & Gullifer, 2016(, and these needs generally increase with age. The Aged Care Financing Authority)2019(reports that three times the number of people who aged 85 years and over use home care and RAC than people aged 70 and over. With population ageing, the number of Australians needing

aged care is projected to increase from 1.3 million in 2018 to 3.5 million by 2050)Royal Commission into Aged Care Quality and Safety, 2019a). Total government expenditure on aged care in 2017-2018 was around AU $ 18 billion, with over two-thirds)AU $ 12.4 billion(spent on RAC. Moreover, government expenditure on aged care is expected to increase from 1% of Gross Domestic Production)GDP(in 2017 to 1.8% of GDP by 2050)Aged Care Financing Authority, 2019; Productivity Commission, 2011(. Despite considerable attention over the last few decades, Australia's ability to afford this increasing demand has been an issue of pressing national concern.

The growing number of older people, especially the very old, presents several challenges to the welfare system, including growing expectations and need for aged care services)Borowski & MacDonald, 2007(. In terms of the ratio of working age people to other people, each person aged 65 or over is currently supported by five working age people)age 15-65 years(. This ratio is projected to reduce to 2.7 working age people by 2050)Productivity Commission, 2011(. Furthermore, the relative availability of informal carers has been declining in recent years, due to smaller family sizes and women's greater workforce participation, and this is expected to continue to decline in coming years as the baby boomer generation who have been providing major informal care for many years to date, increasingly need care themselves)Productivity Commission, 2011(. It is apparent that a growing number of older people in the coming years will receive care from a shrinking number of informal carers, and consequently, they will be more dependent on the formal care system to meet their care needs than the current generation of older people.

Furthermore, younger cohorts)the baby boomer generation(are now entering the 'above 65' age bracket with an added burden of life-style related diseases)e.g., obesity, diabetes, and

arthritis(. In the context of significant social changes, new entrants to the older population tend to have higher education, greater awareness and understanding of health issues, and greater expectations of healthcare services than the current older population. These changes will pose additional challenges, which may influence future models of aged care provision. There is increasing diversity in their expectations and preference of care choices)which will continue to increase(. In addition, older Australians include very diverse groups)like the Australian population as a whole(in terms of socio-demographic, cultural and linguistic backgrounds. Consequently, their care needs, and preference of how and where they intend to use care services are also equally diverse (Australian institute of Health and Welfare, 2012a). However, a common preference of older Australians is to receive culturally relevant care that supports them living independently in the community within their own home)Productivity Commission, 2011(.

2.5. A Brief History of Aged Care Reforms in Australia

Australia's formal aged care system has developed through a series of '*ad hoc reform*' over time)Figure 2.3; (Kendig & Duckett, 2001). We have discussed this in the following four subsections:

2.5.1 Aged Care Reforms until the 1970s

The first aged care policy was initiated by Governor Macquarie in 1821 through approval of funding)to a non-profit organization(for the building of the Benevolent Society Asylum to provide services to people who were aged and indigent (Braithwaite, Makkai, & Braithwaite, 2007; Browning, 2000). In the late 1850s, the New South Wales)NSW(Colonial government established the state hospital system, and took over the administration of the facilities

operated by the Benevolent Society)NSW Department of Health, 2003(. Until World War II, the state government was the largest provider of aged care through the state hospital system. Between 1909 and 1954, the Australian government provided maintenance subsidies)or a payment substitute for the Age Pension(to the pensioners in the Benevolent Asylums. Very similar historyies of development unfolded in other states, with state government having the ownership and control over the size and location of facilities and state hospitals being responsible for their operation.

The first public innovation in aged care was related to capital funding for building new homes for people with low-level care needs under the *Aged Persons Home Act 1954*)Cullen, 2003(. This funding policy was restricted to not for-profit organizations only, and excluded the state government and for-profit organizations. Under the *Home Nursing Subsidy Act 1956*, the provision of professional services at home was launched, with nurse' visiting people in their own homes or other places of residence)Le Guen, 1993(. In 1963, the Menzies Government introduced subsidies for nursing home residents who were chronically ill, to assist with their daily fees. Both not for-profit and for-profit providers were eligible to provide services through these subsidies, but state government aged care providers were excluded)Gray, 2001(. With the introduction of the daily care subsidy, there was a substantial growth in the sector throughout the 1960s, particularly among nursing homes operated by for-profit providers. By 1983, the number of aged care places eligible for the daily subsidy had increased by 282%. Over the 15 years from 1965 to 1980, the number of for-profit nursing homes increased by 62% compared to 26% not for-profit nursing homes)Cullen, 2003; Le Guen, 1993(.
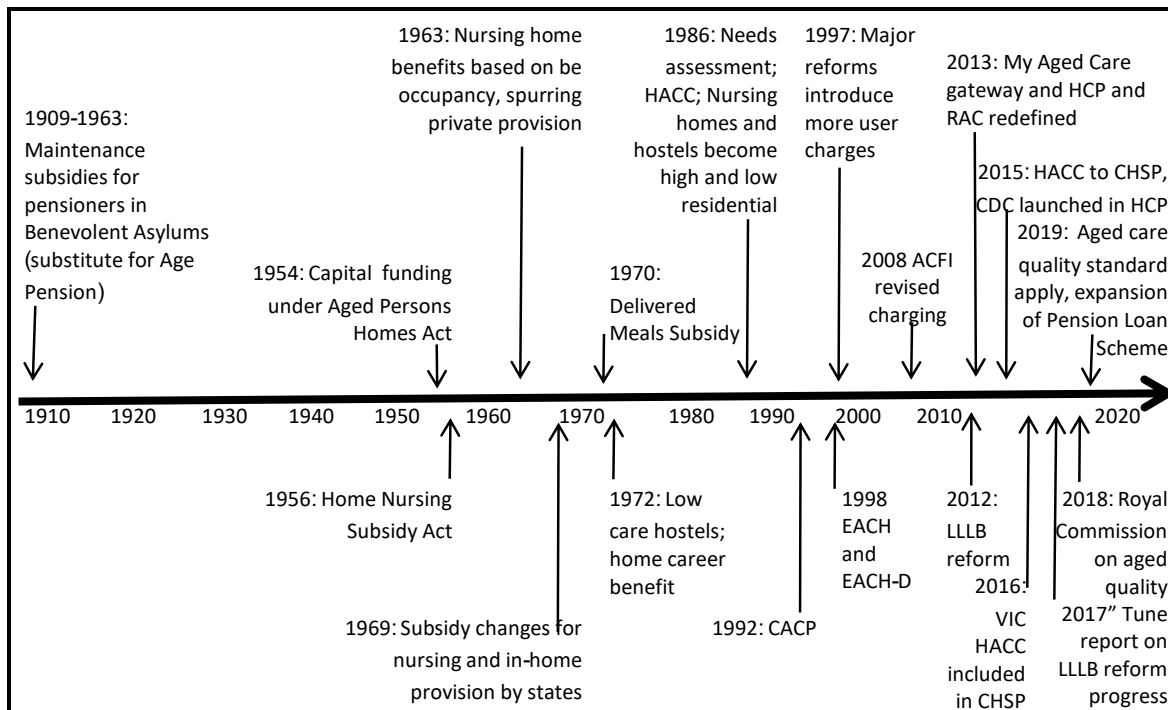
Source: Adapted from CEPAR (2019; 2014)

Figure 4: Trend of aged care reforms in Australia

2.5.2 Aged Care Reforms 1980-2012

With the significant growth in the number of nursing home beds between 1962-1972, successive federal governments have taken the view to slow down the growth in nursing homes, and focused on meeting care needs)Le Guen, 1993(. Since then the Australian Federal Government policy response has been aiming to expand progressive funding, assessment, and service options in the community to support older people to remain in their home as long as possible with greater emphasis on home-based support (Gibson, 1998; Jacobs et al., 2015). In the early 1980s, the Australian House of Representatives Standing Committee on Expenditure introduced a robust set of reforms, which had a strong influence on the government aged care policies in later years (McIntosh & Phillips, 2001; McLeay, 1982). For example, the population based funding model, which provided a formula to

determine the number of aged care beds to be funded for each 1000 people aged over 70. Other key reforms included coordinated assessment services to admission into RAC (undertaken by an ACAT), emphasis on quality, funding for meeting care needs of specific groups, and separating care and non-care cost. The reforms also included the introduction of Home and Community Care)HACC(services in 1986, which provided an extensive range of in home services to meet needs for domestic assistance, transport, meals, nursing, and other health and social needs. Later, in the 1990s, the provision of care in the home evolved further to include Community Aged Care Packages)CACP(in 1992 and extended aged care services at home)EACH and EACH-D(in 1998.

In the early 1990s, the 'mid-term review of the government reform strategy' by Professor Bob Gregory was concerned with "the sustainability of funding arrangement, the lack of choice for residents in the current arrangement, inequalities and gaps between the nursing home and hostel schemes, problem with the quality of care and building and complex and unwieldy regulation")Cullen, 2003, p. 73(. In response to the Gregory report, the Australian Government introduced the 'Aged Care Act 1997', which emphasized increased capital contribution by consumers and provided the current framework of the residential aged care sector. From 1998 to 2011, two major independent reviews)Gray, 2001; Hogan, 2004(and several reports by the Productivity Commission)Productivity Commission, 1999, 2008, 2011(focused on different aspects of the aged care system including future demands and challenges, financial viability and stability under the current regulations and subsidies, the supply of services and consumer choices, and the level of government regulations. A major reform in 2008 was the replacement of the previous Resident Classification Scheme with the Aged Care Funding Instrument which provides a basis for funding allocation for aged care

places based on a resident's assessed needs (Australian Government Department of Health, 2019a).

2.5.3 Productivity Commission Report 2011

In 2009, the National Health and Hospital Reforms Commission reported that a significant reform in the aged care system is essential to meet the challenges of caring for the growing and increasingly diverse older population)National Health Hospitals Reform Commission, 2009(. In April 2010, the Australian Government Treasury requested the Productivity Commission)PC(to develop detailed options for redesigning the aged care system to meet the challenges in coming decades)Productivity Commission, 2011(. A range of challenges were acknowledged in the background of the inquiry, including increasing demand due to a growing ageing population; a declining number of informal carers and skilled care workers; increasing age-related chronic conditions)such as dementia(; increasing preferences and choices in aged care service options; growing community concerns about the access and equity of services; and an increasingly diverse older population in terms of their geography, culture, linguistic background, and sexuality. After reviewing around 900 submissions from different organisations and individuals, the PC presented a landmark report 'Caring for Older Australians' in 2011)Productivity Commission, 2011(.This report focused on the weaknesses of the existing aged care system, key drivers and future challenges of aged care, and provided a detailed and extensive set of recommendations for reform strategy to restructure the entire system.

One of the key findings, noted throughout the report, is the 'significant lack of publicly available data and policy relevant evidence in the area of aged care' *(*Productivity

Commission, 2011*, p.* 463(. Specifically, data on consumers' outcomes, their experience of service use, and movements between different services is very limited. While aged care data has been regularly collected, many participants in the inquiry complained that these data are difficult to access with limited public availability for analysis. This finding is reflected in the position statement of the Australian Association of Gerontology, the peak body for aged care research and advocacy in Australia (Howe et al., 2010). The PC argued that more could be done to inform improvements in aged care using currently available data through coordination across multiple datasets, increasing accessibility of data to researchers, and dissemination of reliable evidence. Rigorous analysis of aged care data is essential for effective planning, policy development and service provision, particularly to understand the capacities required for the different elements in the aged care system as well as to evaluate policies, programs, and reforms over time. A strong evidence base is increasingly seen as an important stepping-stone to develop a more convincing case for reform, to increase the likelihood of the proposed reform to be accepted, and to enable evaluation of the post-reform impacts.

The PC report stated that 'Throughout this inquiry it became apparent that a better evidence base is needed to answer basic questions about many aspects of aged care. Several submissions also indicated a need for an improved evidence base to address various other research gaps')Productivity Commission, 2011*, p.* 472(. With regard to access to quality aged care data and subsequent research and evaluation, the PC proposed the establishment of a national 'clearinghouse' for aged care data with the Australian Aged Care Commission playing a central role in collecting, coordinating and disseminating aged care data. As a national repository for aged care data, the clearinghouse would collect and coordinate data directly from the agencies and departments, and make it publicly available while maintaining

data security and confidentiality. This data clearinghouse has now been established (http://www.aihw.gov.au/national-aged-care-data-clearinghouse/).

In addition to the lack of aged care data and gaps in ageing research, the PC has identified a set of weaknesses in the current aged care system, including its difficulty to navigate, its provision of limited consumer choice and control over care arrangements, its lack of continuous care options across community-based care, its faces workforce shortage, its confusing pricing arrangements including complex user contributions, and the uncertainty around the availability of services in particular community care packages.

The PC proposed a range of recommendations to overcome the above weaknesses. One of the key recommendations was to develop a simplified national gateway the "Australian Senior Gateway Agency)The Gateway(that would be responsible for maintaining the national aged care database")Productivity Commission, 2011, p. 490(and deliver the assessment of care needs and financial capacity to contribute care coordination and carer referral services. By accessing the Gateway, older Australians would be able to exercise choices relevant to their care needs by being informed about what services are available, how to access services and the cost for a particular care service. Furthermore, the PC recommended that the government policy should aim to ensure older people receive care with dignity and respect, have access to person-centred care services; receive consumer directed care provision; have access to affordable services; and informal carers receive support to enable them to continue their caring role.

2.5.4 Aged Care Reforms from 2012 onward

The Australian Government's response to the PC report and recommendations was the introduction of a 10-year reform package called Living Longer Living Better)LLLB(, which has three phases; 2012-2014, 2014-2016 and 2016-2022)Australian Government Department of Health and Ageing, 2012(. This reform was undertaken with the aim of providing comsumers more choice, easier access, better care, and financial stability. The Government has implemented the first two-phases of the progressive reforms and the implementation of the third phase is currently on going. The key reforms, which were undertaken until 2019 are briefly discussed in subsequent sub-sections.

2.5.4.1 My Aged Care

One of the key reforms implemented under the LLLB reforms was the creation of a single entry point for all government subsidised aged care services. That entry point is 'My Aged Care' through which older Australians, their families, and carers obtain aged care information about access services, assessing their needs, and finding Commonwealth funded services in their local area. My Aged Care was initially launched in 2013, and it has fully been functional since early 2016. It includes a website)www.myagedcare.gov.au(, a contact centre, central client records, online referral management, a web-based portal for consumers, holistic need assessment, assessors and service providers. My Aged Care contact centre is the first place of contact for older people who are currently seeking government funded aged care services. After the initial screening by the contact centre staff, consumers may either be referred to Regional Assessment Services)for entry-level support from CHSP(or an assessment by ACAT for more complex aged care needs)to receive services from HCP or enter RAC(. The

assessment determines the eligibility of an individual for a particular level of care and support.

2.5.4.2 Consolidation of Aged Care Programs

The proliferation of community-based aged care programs in the 1990s and 2000s rendered the aged care system increasingly complex, and older Australians found it difficult to navigate)Productivity Commission, 2011(. In order to make the system easier for older people, and to increase the flexibility of care provision, LLLB reforms has moved to amalgamate all the community-based care programs under a single program)Australian Government Department of Health, 2012(. As part of this reform, the CHSP was launched in 1 July 2015 by combining the former Commonwealth-State HACC and three other minor community aged care programs,)the National Respite for Carers Program, the Day Therapy Centres Program, and the Assistance with Care and Housing for the Aged Program(. This excluded Victoria and West Australia where the transitions occurred on 1 July 2016 and on 1 July 2018, respectively.

All community care packages programs)CACP, EACH, EACH-D(merged into HCP in 2013, which has four levels ranging from basic care needs)level 1(to high care needs)level-4(. In addition, the distinction between low- and high- level care in RAC has been removed; funding is now based on a four level rating across three ACFI domains as of 1 July 2014.

2.5.4.3 Means Testing Consumer Contribution

Home Care Packages: A means-tested consumer contribution for care fee was introduced in HCP on 1 July 2014. In addition to a basic daily fee, HCP consumers may be asked to pay an

income tested care fee based on an assessment of the consumers' financial information, which does not include the value of their home and other assets. There are annual and lifetime caps that apply for this fee. Once the consumers reach these caps, they will not be asked to pay the income-tested fee over the period. HCP providers have been required to publish their maximum pricing information on the My Aged Care portal since 30 November 2018.

Residential Aged Care: A more comprehensive income testing arrangement based on assessment of combined income and assets was launched in RAC on 1 July 2014. This means-tested care fee included an annual cap of $27,532.59)March 2019 rate(and a lifetime cap of $66,078.27. These fees are different for everyone as they are based on an individual income. All consumers are required to pay a basic daily fee)85% of single aged pension(but accommodation and care fees are dependent on their means-tested income. For example, consumers of low means are not required to contribute to accommodation cost and care as they are subsidised by the Australian Government. Consumers who have a moderate means-tested income are required to make a capped contribution to their accommodation costs, and those with greater means must contribute to their accommodation and care cost. Furthermore, a new accommodation arrangement is currently allowing a market-based accommodation price for non-supported residents.

2.5.4.4 Consumer Directed Care

It became mandatory for all levels of HCP packages to deliver Consumer Directed Care (CDC) on 1 July 2015. CDC is a new way of providing care that gives consumers more control and greater choices over the types of care and services they intend to purchase, and how, when and by whom those services are delivered. From February 2017, packages have

been directly assigned to the consumers rather than allocated to the providers. This arrangment puts control of the care into consumers' hands. Consumers have options to choose a provider to deliver their desired services and they can opt to change providers at any time. CDC is currently only available for the HCP program. The government has plans to start CDC in RAC in future; although no date has been set yet.

2.5.4.5 Legislative Review of Aged Care 2017

When the LLLB reform package was announced in 2012, the government declared that an independent review would be undertaken by 1 July 2017 to assess progress/implementation of the first phase of reform and the ways forward (Australian Government Department of Health, 2012). This review is known as the "Aged Care Legislative Review")The Review or Tune Review(. The Review considered a range of issues relevant to the LLLB reform, including control of the number and mix of places for RAC and home care packages, a consumer driven model of care instead of a supply driven model model of care, and effectiveness of the means-testing arrangement, workforce strategies and arrangement of access to aged care services (Australian Government Department of Health, 2017b).

The Review highlights four key points -for removing the regulatory control to uncap supply-which must be met before developing and delivering a consumer demand-driven system.

- An accurate understanding of the demand of aged care services

- Equitable and sufficient consumer contributions to their cost must be ensured

- A robust assessment process for eligibility of government funded services must be developed

- A policy to ensure equitable supply of services across settings and different population groups must be developed.

In terms of demand and supply of aged care services, The Review found that while several sources of information are available to determine whether the government is offering appropriate number and mix of aged care places, these are unable to accurately measure demand, for a number of reasons. Using the available evidence and advice from sector stakeholders, it was found that there is increased demand for high-level care at home, and additional investment beyond the current plan of government is needed to meet the projected future demand of aged care. The provision of respite care will need to be increased to support the carer. While it is assumed that an increased proportion of care at home is the key reason of the increased need for respite care, it is not clear what forces are driving this increased demand. Furthermore, the Tune Review proposed to use the population aged 75 and over instead of 70 and over for determining the ratio of number of aged care places. The shift of age (for determining the number of aged care places) is needed based on the current average age for entry to aged care services and the 'demographic bulge of baby boomers' who are expected to enter aged care within the next decade.

The LLLB reform package introduced a new income-tested arrangement for home care packages and a combined income and assets consumer contribution in residential RAC, with annual and life caps in both settings. With these changes, the government's contribution to care cost has dropped from 98% to 94% of the total cost, which is a modest change. To make the aged care system resilient in the face of future challenges, the Tune Review proposed further changes to LLLB to ensure that consumers provide an equitable and sufficient contribution to the cost of their care. For example, it proposed that annual and lifetime caps

on consumers' contributions to their care costs should be abolished. This would ensure equitable contributions by those of high-wealth as well as those who remain in care for a longer period of time.

The Review also provided several recommendations for further improvement of My Aged Care to make it a better pathway to aged care as well as an effective system for most older people. For example, the Review recommended improvement of My Aged Care's ICT platform)with particular focus on information sharing between sector stakeholders and other government organizations(and assessment system)e.g., combining the RAS and ACAT workforce(

In terms of workforce strategy, while the LLLB package allocated AU $ 1.2 billion over four years to increasing wages in the sector, this fund was utilized more generally rather than with the specifi for wage growth. The Review stated that

> "Wages in the sector have been, and remain, relatively low and are an ongoing source of concern for both employees and the sector more broadly. Other workforce issues include the need for stronger education and training"(Australian Government Department of Health, 2017b, p. 12).

Overall, The Review found that "The LLLB reforms have been successful in taking Australian aged care further along the road towards a consumer demand-driven and sustainable system that will meet both current and future aged care needs" (Australian Government Department of Health, 2017b, p. 12). There is a broad consensus among the government and stakeholders that the aged care sector requires further reform in order to move towards a consumer demand-driven system. Particularly, reforms are needed to

improve information, assessment, consumer preference, means-tested contributions, and equity of access to services

2.5.4.6 Royal Commission into Aged Care Quality and Safety

On 8 October 2018, the Royal Commission on Aged Care Quality and Safety was established by the Governor-General of the Commonwealth of Australia, which followed high profile national media criticism of aged care and reports of abuse and neglect, particularly in RAC settings. Two commissioners (The Honourable Richard Tracey AM RFD QC and Ms Lynelle Briggs) were appointed, with terms of reference announced by the Australian Government (Royal Commission into Aged Care Quality and Safety, 2019b). The commission is currently looking at the quality of aged care services, how best to deliver aged care services in a sustainable way, and the future challenges and opportunities of delivering high quality, affordable, and accessible care that is consumer-centred and gives older Australians more control and greater choices about the services they use.

In December 2018, the commission invited interested members of the public and institutions to make submissions. The commission will accept submissions until the end of April 2020. Hearings of the Royal Commission in all the capital cities and a number of regional cities are taking place from January 2019 to December 2019. An interim report of the Commission is due by 31 October 2019 and a final report is due by 30 April 2020.

2.5.4.7 Residential Aged Care Funding Reforms

Current RAC funding is determined by ACFI, which was launched on 20 March 2008 and replaced the Residential Classification System. Since the inception of ACFI, there has been a substantial increase in ACFI claims. While providers argue that these increased claims reflect

the increasing care needs and frailty of residents, the government's view is that this reflect providers 'claiming behaviour' rather than a growth in acuity levels of residents. The reasoning behind the government's view is that the increase in classifying the residents' needs as high in a certain ACFI domain (i.e., complex health care needs) has not been consistently accompanied by increases in other domains (ADL and behaviour). Consequently, it has caused funding instability for governments, providers and residents. In addition, due to some issues with ACFI (including a lack of focus on what drives cost, a lack of individual variations in care cost, inequitable outcomes in terms of geographic and socioeconomic status) and policy changes over the last decade, ACFI is no longer fit for purpose (Eagar et al., 2019). In 2017, the Australian government commissioned the Australian Health Service Research Institute (AHSRI) of the University of Wollongong to develop a funding model for meeting the following aims (Australian Goverment Department of Health, 2019c):

- To make RAC funding fairer and more stable

- To improve the assessment process for more accurate funding

- To free up resources for aged care worker so that they can spend more time delivering safe and effective care

- To enhance innovation in RAC

The proposed new funding model is called the "Australian National Aged Care Classification (AN-ACC(". To develop the new funding model, AHSRI conducted the 'Resource Utilisation and Classification Study' throughout 2018. Another study of the fixed cost of providing care in regional and remote areas is currently underway to accurately reflect the cost of service provision in those areas.

In 2018, AHSRI conducted four closely related Resource Utilisation and Classification Studies, and produced six reports, with Report 6 providing a consolidated set of recommendations. The findings revealed that the cost of residential aged care service use is driven by the care burden which stems from end of life needs, functional decline, cognition, behaviour and complex nursing care needs. In terms of staff hours in RAC, the study found that 50% of total time was spent on providing care tailored to the specific needs of residents, while the rest was spent on delivering care shared across all residents. As part of the Resource Utilisation and Classification Study, a new funding assessment tool "AN-ACC Version 1" has been developed. The AN-ACC Version 1 consists of 13 classes that explain about half of the variation in the individual residential care costs. Care costs for individuals in the most expensive AN-ACC class are almost five times higher than those in the least expensive AN-ACC class. This model introduces a fixed price for the cost of daily shared care and a variable price per day for the cost of individual care needs. The trial of the AN-ACC is expected to start late this year and concludes mid-2020.

2.6 Provision of Aged Care Services in Australia

The Australian aged care system is highly regulated and complex. It provides a range of services which aim to deliver the best possible care to every older Australian according to their assessed needs. The services range from supportive care in the community to high-level care in the residential setting, with emphasis on retaining people in the community)Productivity Commission, 2011(. An overview of the current provision of the government subsidised aged care services is depicted in Figure 2.5.

| Entry and Screening	Assessment		Services		
	Eligibility and Needs	Fees	Short term and Episodic Care	Ongoing Care	
My Aged Care Information Screening Referral	**Home Support Assessment** For Commonwealth Home Support Programme by the My Age Care Regional Assessment Service	**Client Contribution Assessment** For Commonwealth Home Support Programme by service provider		Entry-level support at home **Commonwealth Home Support Programme** **)Formerly HACC(**	
				Nursing — Meals — Social Support-Individual Allied Health and Therapy Services — Other Food Services — Social Support-Group Goods Equipment and Assistive Technology — Transport — Specialised Support Services Home Modifications — Domestic Assistances — Personal Care Home Maintenance **Care Relationships and Carer Support - Respite** **Assistance with Care and Housing** **Service System Development**	
	Comprehensive Assessment For Home Care Packages, Transition Care, Short-term Restorative Care and Residential Aged Care by Aged Care Assessment Team	**Income Assessment** For Home Care Packages by the Department of Human Services or Department of Veterans Affairs	**Short-Term Restorative Care and Transition Care** Short-Term care services in the home or residential care setting s for situations such as restorative care)transition to independence(return to independence from an accidental illness	More complex support for older people who are able to continue living independently in their own homes with assistance	
				Home Care Packages Four levels of coordinated packages of care and services to meet a person's specific care needs, including personal care, support services and nursing, allied health and clinical services. Packages are consumer directed and assigned through the national prioritisation process	
		Combined Assets and Income Assessment For Residential Aged Care by the Department of Human Services or Department of Veterans' Affairs		A range of care options and accommodation for older people who are unable to continue living independently in their own home	
				Residential Respite Care Short term planner or emergency residential age care	**Residential Aged Care** Care and support to people who can no longer remain living independently at home
			The aged care quality and regulatory framework ensures older people receive safe care		

Source: Aged Care Financing Authority)2019(

Figure 2.5: Provision of government subsidised aged care services as at February 2019

)Note: In addition to the aged programs listed in the figure, Veteran Home Care is a subsidised program, provided by the Department of Veteran Affairs).

Access to each type of care program is controlled by the government through the Aged Care Assessment Program. The process is started by a phone call to My Aged Care that initiates screening, which may be followed by a face-to-face assessment with either an Aged Care Assessment Team)ACAT(or a Regional Assessment Service (Australian Government Department of Health, 2019b). The Regional Assessment Service is provided for people with lower level needs that can be met under the CHSP. Those who are likely to require CACP, RAC, or short-term care programs (including respite care and transitional care arrangements) are assessed through their local ACAT which consists of medical, nursing and allied health professionals. The ACAT assessors determine the eligibility of older people based on comprehensive assessment of care needs)according to the Aged Care Act 1997 and 2013(and make a referral to an appropriate aged care program. Around 1 in 6 older people do not get approval for admission into RAC, HCP or transitional care at their first ACAT assessment. However, the majority of these people)over two-thirds(accessed HACC or Veteran Home Care within 12 months of the first ACAT assessment)Australian Institute of Health and Welfare, 2014b(.

After the ACAT assessment, older people who have been approved for care often wait for a significant amount of time to access their approved programs. The waiting time depends on a range of factors including availability of places in residential facilities or in a particular level of home care, organization of the sale of assets, and availability of informal care that may be important for the person. The median wait time to enter RAC is around four months)121 days(from the approval date)Productivity Commission, 2019b(. With the high demand on HCP services currently, there is over a 3-month wait time to access HCP Level 1 and more than 12 months for other levels of HCP)Level 2 - Level 4((Australian Goverment Department of Health, 2019c; Yu & Byles, 2019).
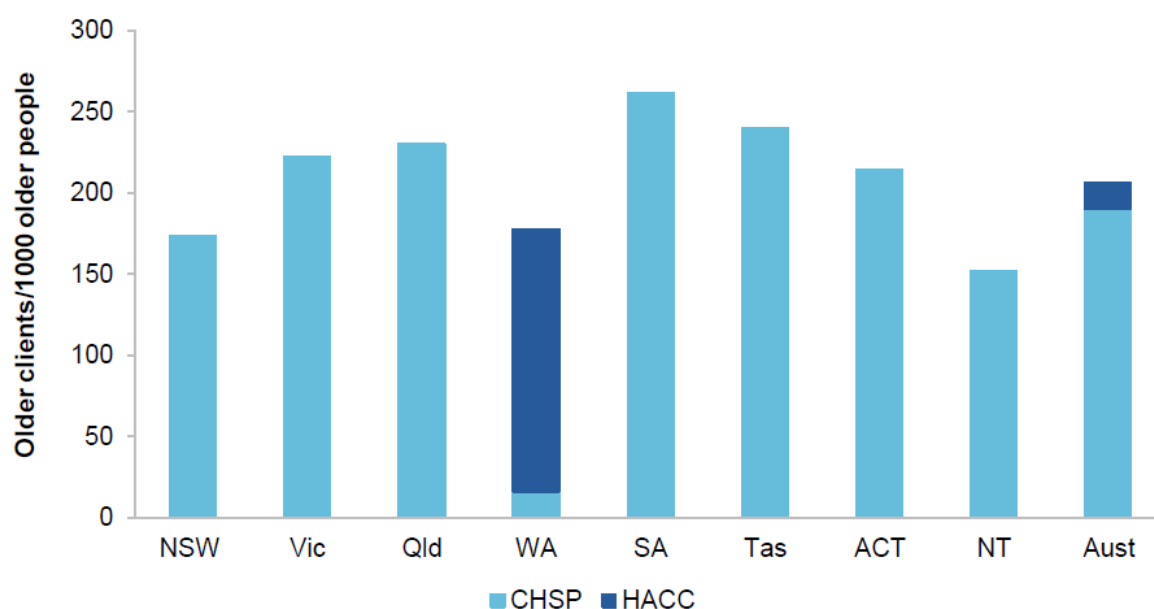
Source: Productivity Commission)2019a(

Figure 2.7: Number of older consumers who used home support programs)CHSP and HACC in West Australia(per 1000 older people by state/territory in 2017-18

Nationally, 830,272 older people used CHSP/HACC services in 2017-18. This is equivalent to an average of 206 consumers per thousand older people. However, there was a substantial difference across the states/territories, with South Australia having the highest number of consumers per thousand older people)approximately 260(and the Northern Territory having the lowest number of consumers)nearly 150(. Furthermore, 128,580 older people used Home Care Packages and 234,789 were in Permanent RAC in 2017-18. Nationally, the combined number of consumers who used RAC and HCP services is approximately 108 per thousand older people aged 70 and over including people aged 50-69 for Aboriginal and Torres Strait Islander people)Figure 2.8(. The Northern Territory had the lowest provision of RAC per 1000 older people but the highest provision of HCP services.

Source: Productivity Commission)2019a(

Figure 2.8: Number of operational places per 1000 older people aged 70 and over and Aboriginal and Torres Strait Islanders aged 50-69 by different states.

2.7 Patterns of Aged Care Use

In accordance with the pace of population ageing, the number of people receiving aged care services has been steadily increasing over the last few decades. For instance, the number of people who receive aged care services in a particular year has almost doubled from around 642,000 in 2002-2003 to around 1.3 million in 2017-2018. However, most people aged 65 and over do not use any aged care services in any given a year. Using the Pathways in Aged Care database, the Australian Institute of Health and Welfare)2014b(report that almost 71% of people aged 65 and over did not use any aged care services in 2010-2011. In that year, nearly 20% of older people used HACC/Veteran Home Care services, approximately 7% used permanent RAC and another 2% used other services including community care packages and respite RAC with a combination of mainstream HACC and permanent RAC)Figure 2.6(. The common pattern of aged care service use was HACC only followed by a combination of HACC and permanent RAC, and then permanent RAC only.

Per cent of population aged 65+

PRAC only 5.6%

PRAC + community care (& perhaps RRC) 1.2%

RRC + community care 0.6%

RRC only 0.1%

PRAC + RRC 0.2%

HACC/VHC only 19.7%

Packages only 0.8%

HACC/VHC + packages 0.8%

Service use 29.2%

No service use 70.8%

Notes

1. PRAC = permanent residential aged care; RRC = respite residential aged care.

2. Figure does not include TCP and ACAP.

3. Service use includes people aged 65 and over on 1 July 2010.

Source: Australian Institute of Health and Welfare (2015b)

Figure 2.6: Percentage of people aged 65 and over who used community and residential aged care use in 2010-2011

People's aged care use significantly increases with age, particularly in the last few years before death. Based on the Pathways in Aged Care database, Joenpera et al. (2016) reported that three out of four older people who died in 2010-2011 at the age of 65 or over used an aged care service at some time during their lifespan. The older a person is at the time of death, the more likely it is that he/she will have accessed at least one aged care program during their life. For example, 91% of people who died after the age of 85 accessed one or more aged care program before their death versus 57% of people aged 65-74 at death. Nearly 80% of people aged 65 and over who died in 2010-2011 used one or more aged care services within eight years prior to death. Most)84%(enter into the aged care system through first

using community aged care services and only 10% directly enter permanent RAC. Over three-quarters of older people who entered permanent RAC, first used HACC services (Australian Institute of Health and Welfare, 2017a).

Using the linked HACC Minimum Data Set (MDS) data for the participants of the Sax Institute's 45 and Up Study, Kendig et al. (2012) identified nine distinct groups of consumers based on their types and volume of HACC service use over the period 2006-2008. Their study demonstrates a great diversity among consumers in terms of patterns of service use, with 75% of consumers using a low volume of services compared with only 8% of consumers who used a higher volume of service with a complex pattern. Only a small proportion of older people received an intensive amount of community-based health and social care services as also reported in other studies (Australian Institute of Health and Welfare, 2007; Choi, Morrow-Howell, & Proctor, 2006).

Research shows that in many developed countries including Australia only 4-6% of people aged 65 and over used residential aged care at any one time (Australian Bureau of Statistics, 2009; Broad et al., 2013; OECD, 2015). However, this evidence is mostly derived from studies that used cross-sectional methods and thus do not reflect the lifetime risk of using permanent RAC. Instead, this method sometimes leads to an incorrect conclusion that only a small proportion of people use RAC (Broad et al., 2015; Holm, 2011) during their lifespan (Broad et al., 2015; Holm, 2011). A substantial proportion of people aged 65 and over enter RAC at any time before dying in many developed countries including USA)41%(, Finland)41%(, UK)28%(, and Germany)26%((Friedberg et al., 2014; Martikainen et al., 2013). According to a technical report by the Australian Government Department of Health)2011(, the likelihood of a woman aged 65 or over entering Permanent RAC at any point during the

rest of her life is 54% while for a man of the same age the corresponding likelihood is 37%. Using death information in RAC, Broad et al. (2015) report that 47% of people aged 65 and over used RAC for later life care in New Zealand.

Residents in RAC are increasingly older, frailer, and have disabilities and complex health care needs on admission and throughout their stay)Theou et al., 2017(. The Australian Institute of Health and Welfare (2018c) reported that in 2018, the majority of older people in RAC were classified as needing high care based on behavioural problems)64%(, activity of daily living limitations)59%(, and complex health care need)55%(, with 31% having high care needs in all three domains. However, it is also documented that a significant proportion of older people enter RAC with low dependency)Challis et al., 2000(. For example, approximately one-fifth of nursing home residents in the USA are high-functioning)0-2 ADL limitations(, but require rehabilitation services or chronic care for mobility or sensory impairment, incontinence, or medical conditions (McNabney et al., 2007). The proportion of low dependency residents in RAC has been declining over the last few decades. Higher proportions of residents have been classified in the high dependency category in Australian and New Zealand (Andrews-Hall, Howe, & Robinson, 2007). However, most studies that focused on care needs in RAC have been cross-sectional in nature and include descriptive or trend analysis.

Furthermore, there is scant information available about the accurate length of stay within different aged care programs. Particularly, most reports on the length of stay in RAC are based on discharge records which is problematic for several reasons; for example, it ignores residents who have been newly admitted, those who are still in care, or those who move between facilities)Australian Government Department of Health, 2011(. Understanding of

the LOS within the different types of aged care is crucial for service utilization and delivery planning across the aged care system. Recently, the Department of Health funded the AIHW to develop dynamic data display tools for exploring length of stay in the aged care system (Australian Institute of Health and Welfare, 2016b). The average length of stay in RAC for people who left in 2015-2016 was 2 years 11 months, with women's stay)3 years 3 months(being almost 1.5 times longer than men's)2 years 3 months( )Aged Care Financing Authority, 2019(. The average tenure of Home Care Packages was 2 years 5 months and nearly 5 years for CHSP/HACC.

2.8 Predictors of Aged Care Use

Previous research on the predictors of aged care use were mostly based on Andersen's behavioural model of health service utilization (Chen & Berkowitz, 2012; Luo et al., 2018; Slobbe et al., 2017; Steinbeisser et al., 2018). While the model was originally introduced in 1968, it has evolved over time (Andersen, 1968; Andersen & Newman, 1973, 2005; Andersen, 1995; Andersen, Rice, & Kominski, 2011). With this model, the author and his colleagues confirmed that health service utilization is a function of a person's predisposing, enabling and health need factors. The predisposing factors include demographic and social structure variables, and individual health beliefs. Enabling factors include family)i.e., income, health insurance, and access to regular source(, community-level variables)area of residence, price of health services, ratio of health service personnel(and other factors relevant to accessing health services. The need factors relate to varing functional and health problems)i.e., physical, psychological and functional health status including illness and disability(that result in a need for health care services.

While this model is commonly use, not all researchers have applied the model in a consistent way (Thygesen et al., 2009). Different predictors have been operationalized in several studies to examine health and aged care service utilization (Harris & Cooper, 2006; Kendig et al., 2010; Miller & Weissert, 2000). This variation is understandable, considering the differences in the context of the enabling factors for using health and aged care services. Particularly, this set of predictors greatly depends on the context of socio-economic circumstances of a region, including national legislation and provision of health services.

It is well documented that older age and female gender are two strong predictors of long-term care use. Older women are more likely to use aged care services as they live longer and have a shorter disability-free life than men (Laditka & Laditka, 2001; Murtaugh, Kemper, & Spillman, 1990). The Australian Institute of Health and Welfare (2018d) reported that two out of three people in aged care are women, and over half of people in RAC are aged 85 and over. Research in the USA and Canada found that age is the most significant risk factor for nursing home admission (Andel, Hyer, & Slack, 2007; Tomiak et al., 2000).

In general, women are more likely to report a greater degree of disability)in particular, difficulties with instrumental activities of daily living(originating from health conditions in later life)Murtagh & Hubert, 2004(. Furthermore, older women are more likely than men to live alone and without a spouse, resulting in an increased need for aged care services (McCann, Donnelly, & O'Reilly, 2012). Living alone is associated with an increased risk of dependence on formal long-term care services; this is attributed to a lack of informal care support)Slobbe et al., 2017; Steinbeisser et al., 2018(. At the time of admission to RAC almost 65% of women reported their marital status as widowed compared with only 26% of men. In addition, prior to admission to RAC, men are more likely than women to have been

living with family while women are more likely than men to have been living alone)Australian Institute of Health and Welfare, 2011b(.

A substantial body of research has identified demographic (predisposing and enabling) and health-related need factors as predictors of admission into RAC (Forder et al., 2017; Fu et al., 2017; Kendig et al., 2010; Miller & Weissert, 2000; Temple, Jukic, & Dow, 2017). Older age, widowed, living alone, low independence of activities in ADL, living in a flat or retirement village, falls, and cognitive impairment are significantly associated with increased risk of admission to RAC (Cumming et al., 2000; Forder et al., 2017; Smith, Kokmen, & O'Brien, 2000). Other risk factors for admission to RAC are social isolation, burden of ill-health and personal safety concerns (Kendig et al., 2010), cognitive impairment (Andel, Hyer, & Slack, 2007; Gaugler et al., 2007; McCann, Donnelly, & O'Reilly, 2012) and physical decline (Latham, 2011). John McCallum and colleagues (McCallum et al., 2007) demonstrate that diagnosis of dementia is a significant influencing factor for entering RAC in Australia. Their studies found that 44% of nursing home (or RAC) admissions are due to dementia.

Besides individual factors, a recent Australian study demonstrated that each hour per week of HCP service use is associated with a 6% decreased risk of entering RAC)Jorgensen et al., 2018(. Although this study provides significant insights into service outcomes of HCP, the participants were from only one HCP provider in New South Wales and Canberra, and were studied for a relatively small observation period. A number of US-based studies have reported that a greater volume of home- and community-based care use is associated with a reduced risk of subsequent nursing home admission)Chen & Berkowitz, 2012; Greiner et al.,

2014; Sands et al., 2012(. Research is yet to explore whether high usage of HACC/CHSP reduces the risk of entering RAC.

As with RAC, demographic vulnerability factors and health-related need factors including cardiovascular illness, diabetes, and other chronic conditions, physical functioning, dependence for ADLs and IADLs are associated with the use of home and community aged care services (Calsyn & Winter, 2000; Calver, Holman, & Lewin, 2004; Jorm et al., 2010; Rochat et al., 2010; Wang et al., 1999). Several researchers reported that the demographic characteristics of older people are associated with their use of particular community services, for example, in the UK gender is significantly associated with using domestic assistance)Boniface & Denham, 1997(, while in the USA living alone is associated with use of transportation services (Alkema, Reyes, & Wilber, 2006), and in Canada, individuals with cognitive impairment are more likely to receive home and social care services (Lafortune et al., 2009).

2.9 Gaps in the Current Literature

Over the course of their later life, many older Australians use different types and levels of care from different parts of the aged care system, according to changes in their needs. There are a range of factors that might predispose them to needing care or enable easier access to and uptake of services over time. A continuum of care is essential to meet their diverse care needs across later life. However, several reviews have identified that the current Australian aged care system is complex and older people experience multifaceted journeys through the fragmented systems to meet their care needs. Our review has identified the following gaps in the literature.

- While the pivotal role of the HACC services)now CHSP(for caring and supporting older Australian has been acknowledged, limited research evidence is available about the consumers who use these services, their patterns of using these services and whether the patterns are associated with the consumer characteristics and needs.

- Longitudinal evidence on how older Australians use different types of aged care services and their latent patterns of service use across later life are not available.

- Evidence relating to the movement of older people between different levels of age care service use over time, the chances of transitioning between different levels of care use, and how these transitions vary according to participant characteristics.

- How management of health conditions or provision of low-level community care at earlier stages in a person's home or in the community might predispose them to using high-level residential care, or enable them to stay longer in the community are not well understood.

- A substantial proportion of older Australians enter RAC at some point in later life and stay an average of 3 years. However, how their trajectories of care needs change over time throughout their stay is not yet explored, nor whether their survival patterns are associated with the trajectories of their care needs.

- In Australia and even across the world, there is little information about how older people use different types of aged care services with very limited population level research on community-based aged care, and even less longitudinal information on changes in service use

CHAPTER 3: Data and Methods

3.1 Introduction

The current PhD project comprises five different sub-studies based on the proposed research objectives aiming to fill gaps in the current literature. We have an opportunity to use 20 years of longitudinal survey data and linked administrative aged care and National Death Index data to address the research questions. This chapter includes a detailed description of data sources, data linkage, study variables, and statistical techniques.

3.2 Data Source

This research utilized survey data from the older cohort)born between 1921-26(of the Australian Longitudinal Study on Women's Health)ALSWH(, linked to administrative aged care data, and the National Death Index. The aged care administrative data for the participants of the older cohort of ALSWH were linked to identifiers of ALSWH's participants by the AIHW with approval granted by the Australian Government Department of Health. A description of the ALSWH highlighting the older cohort and the linked administrative aged care data is provided in the subsequent sub-sections.

3.2.1 Australian Longitudinal Study on Women's Health

The ALSWH is designed to investigate factors associated with the physical and emotional health of Australian women across their lifespan, aiming to provide scientifically valid information for the development of health policy and practices in women's health. The ALSHW has been funded by the Australian Government Department of Health since the inception of the study in 1996. The study was jointly implemented by researchers and staff

from the University of Newcastle and the University of Queensland through a collaboration. Participants were randomly sampled from the Medicare Australia database)the national universal health insurance database(with an oversampling of women from remote and rural areas, with a two-fold higher probability of selection of women living in urban areas)Brown et al., 1999(. The Australian Medicare database includes the name and address of every Australian citizen and permanent resident. ALSWH samples are broadly representative of the national female population of the respective age groups with a slight over-representation of women who are married, Australian born and women with a university, college or trade qualification)Dobson et al., 2015(.

Over 40,000 women were recruited at baseline)1996(from three different birth cohorts: aged 18-23 years)born in 1973-78(, 45-50 years)born in 1946-51(, and 70-75 years)born in 1921-26(, using a self-reported postal questionnaire. The cohorts were selected to represent critical stages of women's health across the life-course. A new young cohort of women aged 18-23 years)born in 1989-1990(was recruited in 2013 via social media to provide data on the next generation of Australian women. Each cohort is roughly representative of women of similar ages in the Australian population. Many aspects of women's health during their life course have been examined, and the study has an international reputation for its multidisciplinary methodology. Details about survey design, questionnaires, and each of the cohorts have been published elsewhere)Dobson et al., 2015; Lee et al., 2005(, Questionnaires, reports and other research outcomes are available on the ALSWH website)http://www.alswh.org.au(.

ALSWH survey data has been linked to a number of State, Territory, and national datasets. National databases that are linked with ALSWH data include the Medical Benefits Schedule, the Pharmaceutical Benefits Scheme, aged care, and cancer collections. State-based Admitted

Patient Data and Perinatal databases have also been linked to ALSWH participant data. Linkage of the Medical Benefits Schedule, the Pharmaceutical Benefits Scheme for all cohorts and administrative aged care data for the oldest cohort provide detailed and comprehensive sources of information regarding the health, medication use, and aged care services use by these participants. Death records are also available via linkage with the National Death Index (Powers et al., 2000). Due to linkage of longitudinal survey data from representative cohorts and to multiple national and state databases, ALSWH provides a national resource for women's health research. The study provides an evidence base for the government, all relevant stakeholders, and policy-makers within Australia to evaluate policies and practices that may affect women's lives and to enhance national and international knowledge through collaboration with national and international research teams.

3.2.1.1 ALSWH Older Cohort (1921-26)

The older cohort comprises 12,432 women who completed a postal questionnaire at baseline)1996(when they were aged 70-75. These women were then surveyed every three years until 2011 and on a six-monthly rolling basis thereafter. A brief description of the different waves/follow-ups of this cohort is depicted in Figure 3.1. The characteristics of women who participated in Survey 1 were similar to those of similarly aged women in the 1996 Australian National Census except for a slight over-representation of married women and women with a higher qualification and an under representation of women of Aboriginal or Torres Strait Islander descent)0.4%( )Dobson et al., 2015(. With respect to Medicare funded service utilization, non-respondents were less likely than respondents to have visited a medical specialist in the previous two years)65% versus 72%(.
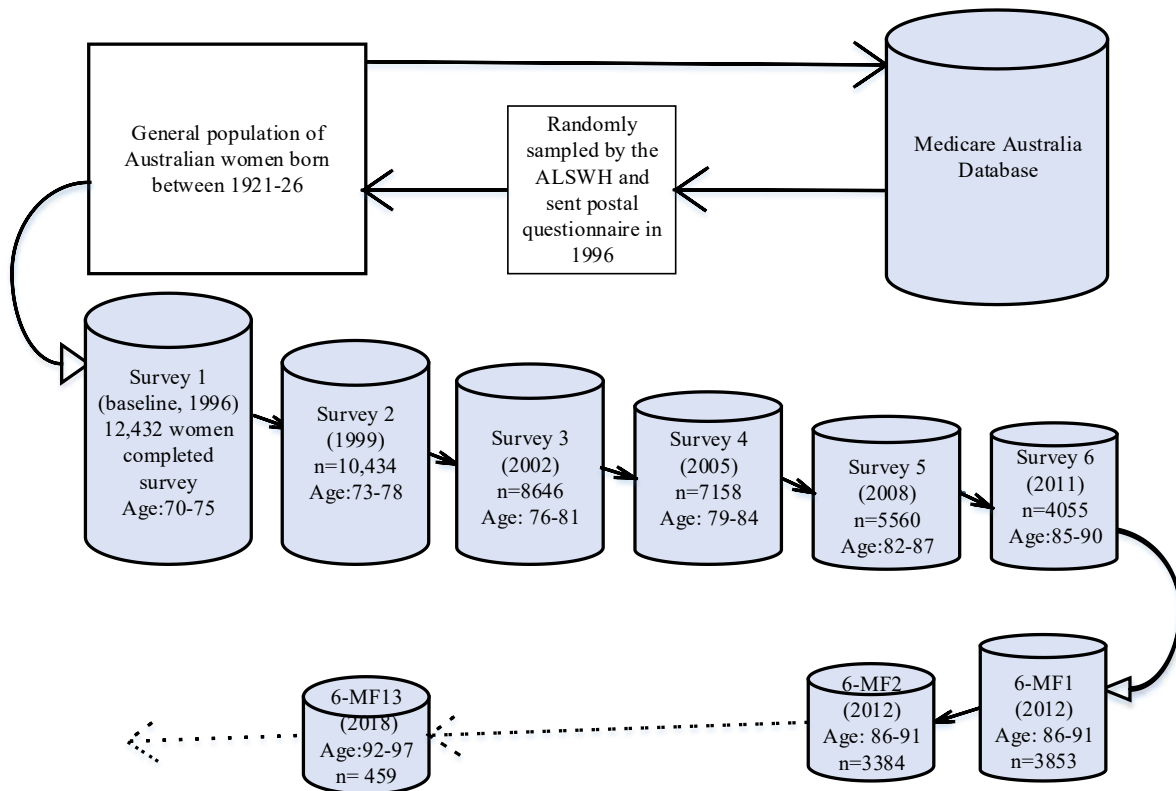
Source: The author with evidence from the ALSWH website)www.alswh.org.au(

Figure 3.1: The survey waves of the older cohort of the ALSWH from 1996 to 2018

Almost 59% of women in the older cohort died between 1996 and 2014, and 20% requested

no more surveys (mainly due to frailty). However, women of the ALSWH older cohort have

a 9.5%)8.3-10.7% at 95% confidence interval(relative survival advantage compared to the

national population of women born between 1921-26. This is partly attributable to better

demographic and health behaviours among ALSWH women, as found in the baseline survey,

compared with the general population. Over the course of the study, under-representation of

women from a non-English speaking country of birth and underweight women grew from

3.9% to 7.2% and 1.3% to 3.8%, respectively. Regardless of such small differences from

women of a similar age in the national population, the diversity of women in the cohort has

been well preserved and suggests that findings from this study are largely generalizable to

Australian women of the same age group)Byles & Dobson, 2011(. Moreover, linkage to aged care and death index data provides opportunities for follow-up of outcomes even when women do not return a survey at a particular data point.

3.2.2 Aged Care Linked Data

The process of data linkage between the ALSWH survey and aged care use datasets was undertaken by the AIHW with approval from the Australian Government Department of Health. Details about the data linkage process have been discussed in a separate sub-section of this chapter. While the residential aged care admission records are available for all years, administrative data from other aged care programs including HACC, CACP, HCP, EACH, EACHD, and TCP have been available only since 2001. A total of 11,245 women were eligible for linkage of survey data to their aged care data, excluding 847 women who died before 2001 and 357 women who opted out of linking their aged care information with survey data. The potential pathways of older women between the two mainstream aged care programs (HACC and RAC) and relevant administrative datasets are depicted in Figure 3.2.

The linked administrative aged care and national death index datasets can broadly be categorized into three parts:

- **Program-specific National Minimum Data Sets**: Data on the quarterly usage of the 28 types of HACC)currently CHSP(services, and the date of entry to and exit from HACC services are included in the HACC MDS. A detailed description of the HACC MDS is provided in a separate sub-section of this chapter. Data from ACAT assessments, which are carried out under ACAP, are recorded in the ACAP MDS. Data are collected through a minimum reporting requirement for ACAP as part of a

condition of grants between the Commonwealth and State or Territory governments. The ACAP MDS includes the date of assessment, identified needs, current assistance, and service recommendations and approvals.
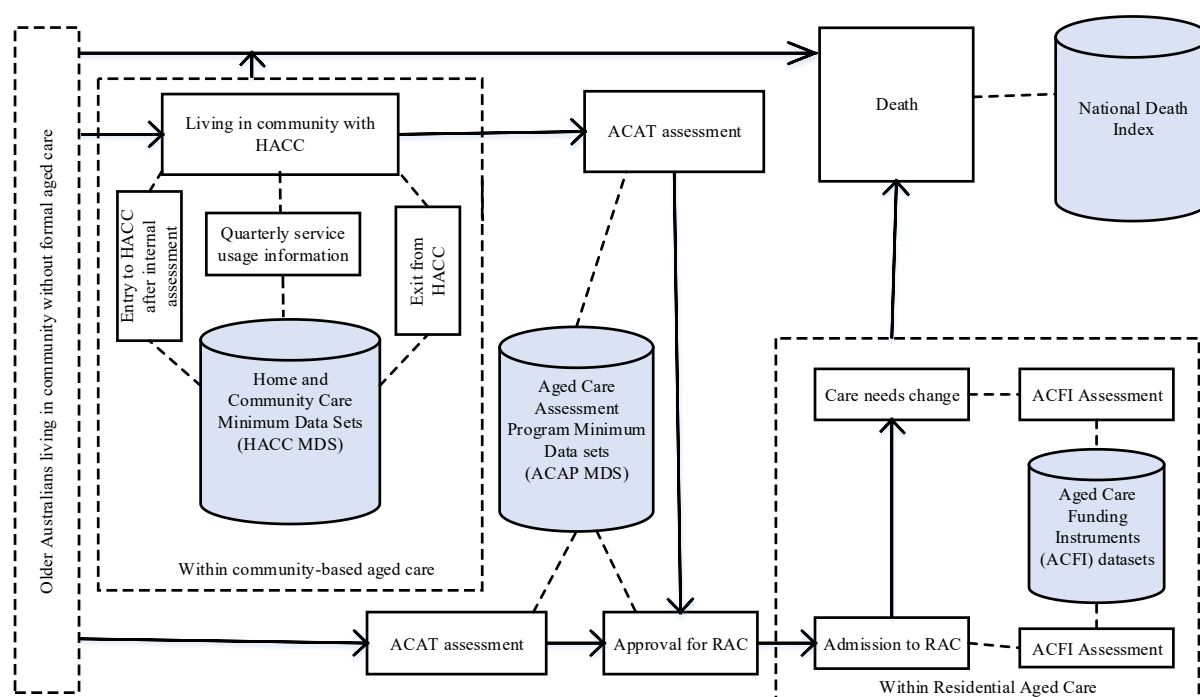
Source: The Author, August 2019

Figure 3.2: An overview of the linked aged care datasets produced throughout the aged care system in Australia

- **Program administrative data**: Data from permanent RAC, respite RAC, CACP, EACH, EACHD, and TCP programs come from the Aged and Community Care Management Information System. The Australian Government maintains this database as part of paying subsidies to the service providers of these programs. According to the objectives of the current study and due to the low prevalence rate for the use of EACH, EACHD, and TCP services among our study cohort, the data for these programs were not included in the analyses of the current study. The RAC

database includes information on admissions and transfers, appraisal level, Resident Classification Scale or ACFI checklist, ratings, and results. A detailed description of the ACFI dataset is provided in a separate sub-section of this chapter.

- **National Death Index**: In this database, death information for all Australians has been recorded since 1980. To help preserve confidentiality, dates of death are recorded in calendar months only.

3.2.2.1 Home and Community Care Minimum Data Sets

Although the HACC program commenced in 1985, the collection of HACC MDS data began in January 2001. This was undertaken by the state and territory governments until 2009-2010 and thereafter the Australian Government collated State databases into a national database (Australian Institute of Health and Welfare, 2014b). HACC providers across all states and territories were required to report minimum data every three months to the National Data Repository. The minimum data within the HACC program are defined in the HACC National MDS User Guide Dictionary Versions 1 and 2)Australian Institute of Health and Welfare, 2009; Department of Health and Ageing, 2006(.

This study utilized the HACC MDS data from 2001 to 2014 (the latest available data), with information regarding the service episode, date of entry, date of exit, and amount and types of services provided by the HACC program)e.g., volume, number, and types of service(. HACC services received by the consumers are measured in terms of time)hours(, quantity)number or frequency(and cost)AU $(. The total number of services delivered under the Commonwealth HACC program are categorised into 19 types after merging a range of minor services under 'goods and equipment' (Department of Health and Ageing, 2012a). HACC

services that are measured by time)hours(include allied health services at home or within a care centre, assessment service, centre-based day care, care coordination, domestic assistance, counselling and advocacy, nursing care at home or within a care centre, home maintenance, personal care, respite care, social support, and other food services)excluding meals(. Services of transport, meals at home or within a care centre, and a range of minor services grouped into 'goods and equipment' are quantified using number or frequency. Only home modification services are measured using currency)AU $(.

3.2.2.2 Residential Aged Care Funding Instrument Datasets

The ACFI was introduced on 20 March 2008, replacing the former Residential Classification Scale. It assesses the relative care needs of residents to inform the allocation of resources)government subsidies(to care providers. It is mandatory to complete an ACFI assessment within two months of admission to RAC. Subsequent ACFI assessments are undertaken whenever a resident's care needs substantially change, which may suggest a different level of government subsidy.

Care needs are assessed using ratings of 'high', 'medium', 'low', or 'nil' for 12 questions, which are contextually positioned in three ACFI domains, namely activity of daily living)ADL(, behavioural problems)BEH(, and complex health care)CHC(. The ADL domain includes measures of nutrition, mobility, personal hygiene, toileting, and continence, while the BEH domain measures cognitive skills, wandering, verbal behaviour, physical behaviour, and depression. Need for assistance with medications and one or more ongoing complex health care procedures)except nursing interventions(are measured by the CHC domain. Details about the ACFI have previously been published)Australian Government Department of Health, 2017a).

The current study utilized ACFI data from 2008 to 2014. The availability of longitudinal data for the broad types of variables under the three domains facilitates assessment of changes in residents' care needs over time, identification of groups of residents sharing similar care needs over time, and comparison of their survival differences. This dataset provides a detailed picture of the dynamics within RAC, given the length of observation is much longer than the average length of stay in RAC. Beyond the data on ADL, BEH and CHC domains, data regarding medical diagnoses can help to identify individual trajectories within RAC (Australian Government Department of Health, 2017a). A range of medical conditions are recorded under two supplementary questions related to diagnosis and documented disease or disorder)excluding mental and behavioural disorders(. A detailed description on how the ACFI data have been used in the current study is discussed in Chapter 7.

3.2.3 Data Linkage

Data linkage is a powerful technique for identifying and integrating consumers' information within and across datasets. Both probabilistic and key-based data linkage)KBL(methodologies were used to produce linkage keys that allow aged care data to be linked to the ALSWH survey data without using participant identifiers. In the probabilistic method, linkage of records between two data files is based on the probabilities of agreement)m probabilities(and probabilities of disagreement)u probabilities(across a range of linkage variables. This method allows for variation in reporting by considering m probabilities as being less than 1 and u probabilities as greater than zero. The probabilistic method is used when information on the consumers' full name and demographic data are available. The linkage of records using the KBL method is based on exact one-to-one character matching of
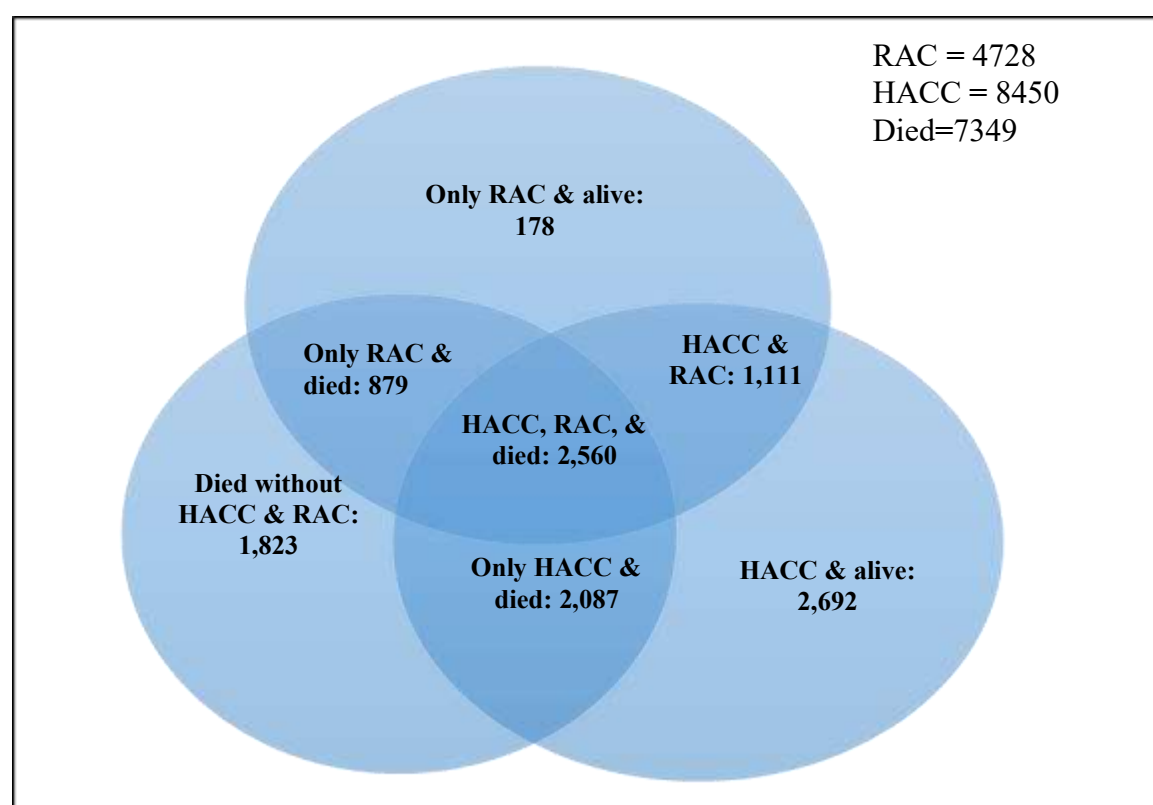
a fixed set of variables. This method is commonly used when a person identifier or full name is not available for linking but other data characteristics are available that can be used to link records of two data files. Details about these data linking processes have been published elsewhere)Australian Government National Statistical Service, 2019(.

Probabilistic linkage of ALSWH participant data to the National Death Index is conducted every six months based on names, dates of birth and addresses)Powers et al., 2000(. Using this linkage, dates of death are obtained with a lag of approximately one year. The records of aged care service use for the 1921-26 cohort of ALSWH were linked to the survey identifier in the following two main stages:

Stage 1: The database containing the aged care service use information between 1 July 2002 and 30 June 2011 were linked in this stage using two approaches. First, the probabilistic name-based linkage method was used where consumers' names were available. This procedure included those women on the linked database who had used community care packages, RAC, TCP, or died. Second, KBL based on SLK-581 and postcodes were used where names were not available, and this procedure included those women on the linked database who had used ACAP and/or HACC.

Stage 2: Databases of earlier aged care program use)before 1 July 2002(and later program use)after 30 June 2011(were linked. For the earlier data, the probabilistic name-based linkage method was used to link the databases of RAC, CACP and a few early EACH packages from 1996 to 30 June 2002, and the KBL method was used to link the databases of HACC MDS from 2001 to 1 July 2002. For later program use, the name-based probabilistic linkage method was used to link RAC and home care packages program use from 30 June

2011 onward. The KBL method using SKL-581 and postcode was used to link HACC MDS and ACAP MDS.

RAC = 4728
HACC = 8450
Died=7349

Only RAC & alive: 178

Only RAC & died: 879

HACC & RAC: 1,111

HACC, RAC, & died: 2,560

Died without HACC & RAC: 1,823

Only HACC & died: 2,087

HACC & alive: 2,692

Source: The author, September 2019

Figure 3.3: Numbers of women across three datasets, namely, HACC MDS, RAC, and the National Death Index until 2014 (Note: cohort size (n) = 12,432 women and 357 opted out to link their aged care data to ALSWH survey data)

Figure 3.3 presents the number of women in the older cohort of the ALSWH who had linked records in HACC MDS, RAC, and the National Death Index and the overlap between these databases up to 2014. Among 7349 women who had died by 2014, 35%)n = 2560(had records of using both HACC and RAC, and 25%)n = 1823(had no records of using HACC or RAC. Of those who entered RAC)n = 4728(, 78%)n = 3671(had used HACC services previously.

3.4 Measurement of Variables

3.4.1 Outcome Variables

The main outcome variable of this study was the use of aged care services which was measured based on the available information from the aged care datasets. However, measures of the outcome variable differed according to the research questions addressed in the different sub-studies. Detailed descriptions of the measurement of outcome variables for each research question are provided in the relevant chapters)from Chapter 4 to Chapter 8(. A list of the outcome variables and the corresponding data sources is presented in Table 3 and a brief discussion are provided below.

In the first sub-study)Chapter 4: 'Assessing patterns of home and community care'(, the outcome of interest for the first stage of analysis was age at first HACC service use from 2001 to 2011 ascertained from the MDS. In the second stage of analysis, the outcome variable was patterns of HACC service use, which is a data driven variable based on the volume of service use between 2001 and 2011.

In the second sub-study)Chapter 5: 'Latent patterns of aged care use over time'(, the aged care status of women in each year from 2001 to 2011 was measured based on the data from HACC MDS and RAC. This was considered as the indicator/outcome variable and was used to identify the latent patterns/classes of service use over this period. Subsequently, the latent pattern was considered as the outcome variable in the analyses performed to identify the factors associated with membership of different classes.

Table 3.1: An overview of the outcome variables used in the different sub-studies and corresponding data sources.

Sub-study (Research objective)	Chapter and title	Outcome variable	Data source
Sub-study 1 (Objective 1)	Chapter 4: Assessing Patterns of Home and Community Care	HACC use and age at first HACC use	HACC MDS
Sub-study 2 (Objective 2)	Chapter 5: Latent Patterns of Aged Care Use Over Time	Types/levels of aged care use over time	HACC MDS, CACP, and RAC admission records
Sub-study 3 (Objective 3)	Chapter 6: Patterns of Home and Community Care and Residential Transition	Time from first HACC use to RAC admission	HACC MDS and RAC admission records
Sub-study 4 (Objective 4)	Chapter 7: Trajectories of Care Needs in Residential Aged Care	Scores of ADL, behavioural, and complex health care	ACFI
Sub-study 5 (Objective 5)	Chapter 8: Transition into and Through the Aged Care System	Types/levels of aged care use over time	HACC MDS and RAC admission records

In the third sub-study)Chapter 6: Patterns of home and community care use and residential transition'(, the outcome variable was the time from the first HACC service use to the date of admission to permanent RAC during the period 2001-2014. Time was measured in months from July 2001 to June 2014 with a maximum observation period of 156 months)13 years(.

In the fourth sub-study)Chapter 7: Trajectories of care needs among women in residential aged care'(, participants' care needs in three ACFI domains including ADL, BEH and CHC

over time up until 60 months from the date of admission to RAC was considered the outcome variable in the first part of the analysis. In the second part, trajectory groups based on patterns of ADL, BEH and CHC was treated as the outcome variable to identify predictors of membership of different trajectory groups.

In the final sub-study)Chapter 8: 'Transition into and through the aged care system')(, levels of maintream aged care service use across later lifew was considered as the outcome of interest. Aged care service use was categorized into four well-defined states including 'not used any aged care services', 'home and community care service use', 'residential aged care service use', and 'death'.

3.4.2 Participants' Characteristics

A range of socio-demographic)predisposing and enabling(and health-related need factors were included in accordance with the Andersen's Behavioral Model for explaining patterns of health service use (Andersen & Newman, 1973). This model has been used in several studies to identify determinants of long-term care in later life (Chen & Berkowitz, 2012; Slobbe et al., 2017; Steinbeisser et al., 2018). In our analyses, individual/societal characteristics were grouped into three categories: predisposing factors)age, area of residence, marital status, and education(, enabling factors)managing with available income, living arrangements, and housing type(, and need factors)physical, psychological and functional health status including illness and disability(.

 With the exception of the highest educational qualification)whch was measured only in Survey 1, 1996(, variables for this research were measured at Survey 3)in 2002(, which was

the nearest ALSWH survey point to the baseline year)2001(. Data from adjacent surveys)Survey 2 in 1999 and Survey 4 in 2005(were used to fill-in missing values)<5%(rather than using model-based imputation techniques. Detailed information about the impact of attrition on the representativeness of the cohort has been published elsewhere (Brilleman, Pachana, & Dobson, 2010)

Participants' area of residence was categorized as 'major city' or 'inner/outer/remote area' based on the Accessibility/Remoteness Index of Australia Plus. This index measures distance to services, including access to tertiary teaching hospitals)Glover & Tennant, 2003(. There was a small proportion of women in the outer and remote categories, and so these categories were combined with the inner region category. The detailed measurement and categorization of other socio-demographic)predisposing and enabling(factors are provided in the respective sub-studies)Chapter 4 to Chapter 8(.

Health-related need factors included being diagnosed with physical conditions, falls with injury in the past 12 months, self-rated health, and the physical, social and mental functioning scores of the health-related quality of life profile. The scores were determined from the Medical Outcomes Short Form-36)SF-36(and raw scores were linearly transformed to produce subscale scores ranging from 0-100)with higher scores indicating better health(. The detailed measurements and categorization of all other health factors are provided in the respective sub-studies)Chapter 4 to Chapter 8(.

3.5 Statistical Methods

A range of statistical techniques were applied to address the research questions in the current study. A brief theoretical discussion of these methods is provided in subsequent sub-sections.

Detailed descriptions of how these methods were applied to address the different research questions are provided in the relevant chapters)Chapter 4 to Chapter 8(.

3.5.1 Kaplan-Meier Survival Function

Survival analysis often begins with a primary summary of overall survival experience using a non-parametric approach, which does not depend on assumptions regarding the distribution of the survival function in the underlying population. Descriptive statistics for survival time)e.g., mean or median(cannot directly be calculated from observed data owing to censoring)subjects with withdrawal or loss of follow-up(, which biases estimates. Non-parametric approaches are usually considered as a first step to estimate descriptive statistics, which are often followed by semi-parametric or parametric approaches.

The Kaplan-Meier)product limit(estimator is the most common non-parametric approach to measuring the survival of subjects over time after treatment onset (Goel, Khanna, & Kishore, 2010). The visual representation of this function is called the Kaplan-Meier curve/plot and shows estimates of the survival function $S)t($ as a series of steps/intervals according to observed event times. In addition to allowing visualization of the survival experience of the study cohort, this plot can also be used to estimate the median survival time)time when $S)t(\leq$ 0.5(or quartiles, deciles or percentiles of survival time.

The estimator of the Kaplan-Meier survival function is calculated as

$$\hat{S}(t) = \prod_{t_i < t} \frac{n_i - d_i}{n_i}$$

where n_i = the number of subjects under at risk at time t_i and d_i = the number of subjects who fail at time t_i. The term $\frac{n_i - d_i}{n_i}$ is the conditional probability of surviving beyond time t_i,

given that the subject has survived up to time t_i. Multiplication of all conditional probabilities up to time t_i produces the survival function $)\hat{S}(t)($ which represents the unconditional probability of surviving beyond time t_i.

The main assumption of this method is non-informative censoring, meaning subjects who were censored owing to withdrawal or loss to follow-up are assumed to have the same distribution of failure times as those who were not censored)Allison, 2010(. When comparing several groups, it is assumed this assumption is satisfied in each group. Furthermore, it is assumed there is no cohort effect on survival and censoring occurs after failure, so that subjects have the same survival probability irrespective of when they arrived in the study.

3.5.2 Cox Proportional Hazards Model

The seminal work by D.R. Cox "Regression Models and Life-Tables" published in 1972, is one of the most frequently cited articles in statistics and medical research)Cox, 1972; Fox, 2002; Lin & Wei, 1989(. The Cox proportional hazards regression models the association between the hazard of the event and a set of covariates. Estimation is performed using partial or marginal likelihood methods)Kalbfleisch & Ross, 1980(. The Cox model is defined as

$$h_i(t) = h_0(t) \exp\big(\beta_1 X_1 + \beta_2 X_2 + \cdots + \beta_p X_p\big)$$

where $h_i(t)$ is the hazard at time t for the ith subject and $h_0(t)$ is the baseline hazard at time t, i.e., the value of the hazard when all covariates are set to zero

Takeing the natural logarithm)In(of both sides of the above model yields,

$$In \left(\frac{h_i(t)}{h_0(t)} \right) = \beta_1 X_1 + \beta_2 X_2 + \cdots + \beta_p X_p$$

That is, log of the relative hazards as a linear function of the predictors. The Cox model is a semi-parametric approach as the model consists of a non-parametric component and a parametric component. The non-parametric component $h_0(t)$ does not need to be estimated in order to conduct inferences regarding covariate effects and has no assumed distributional form. For this reason, the Cox model is robust to misspecification of the baseline hazard function. The parametric component contains the covariate vectors, which are multiplied by the baseline hazard. Consequently, the effect of the covariates is assumed to be constant throughout the observation period, and this is the foundation of the proportional hazard assumption. Under this assumption, the hazard function for two subjects are proportional at any time over the study period, and the hazard ratio does not change with time (Allison, 2010). Satisfying this assumption is pivotal to the use and interpretation of a Cox model. A number of techniques both graph-based and test-based are available to assess the violation of the proportional hazard assumption.

1) Plotting the Kaplan-Meier curve. If the predictor satisfies the assumption, the graph of the survival function produces a graph with parallel curve.

2) Plotting the graphs of the log)-log)survival((versus log of the survival time. This will also result in parallel lines if the predictor satisfies the proportional hazard assumption.

3) Including time dependent covariates in the model by interaction of predictor and a function of the survival time. Evidence of significant time interaction indicates a predictor may not satisfy the proportional hazard assumption.

4) Tests based on Schoenfeld Residuals: A non-zero slope of the scaled Schoenfeld Residuals on a function of time suggests a violation of the proportional hazard assumption)Grambsch & Therneau, 1994(. Furthermore, graphing the residuals against functions of time can help to identify non-linearity or influential variables.

3.5.3 Competing Risk Analysis

The competing risk theory was first proposed by Swiss mathematician and physicist Daniel Bernoulli in 1766 to demonstrate the benefit of smallpox inoculation)Dietz & Heesterbeek, 2002(. The objective of Bernoulli was to estimate the gain in life expectancy at birth, resulting from eliminating smallpox as a cause of death. Competing risks occur naturally in epidemiological research when subjects under study are at risk of more than one event; for example, if the event of interest is admission to RAC, then death is considered a competing event as those who die are no longer at risk for the event of interest)Figure 3.4(. Competing events can preclude observation of the event of interest in epidemiological data)Noordzij et al., 2013(. The analysis of time to event data with competing risks is an extension of traditional survival analysis methods, which aim to correctly estimate the marginal probability of an event in the presence of competing events)Austin & Fine, 2017(.
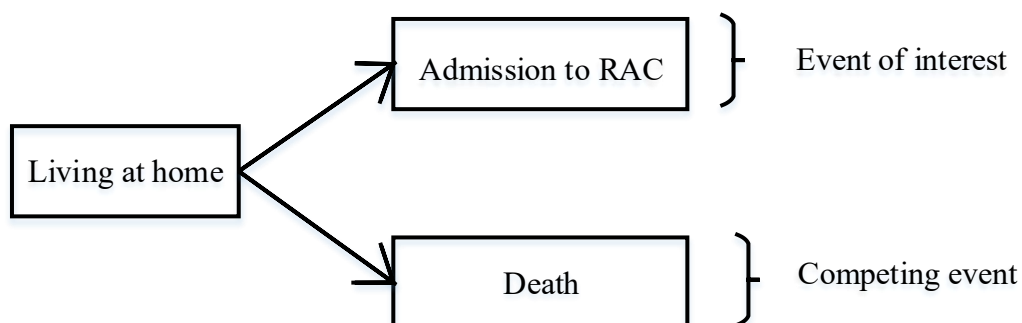

Figure 3.4: Example of competing risks.

In the presence of a competing event, a common analytical approach in standard survival analysis is to estimate the probability of only the event of interest over time, allowing the subjects to fail from competing events but assuming they are censored at this time (Lau, Cole, & Gange, 2009). In relating to this study, we might be interested in estimating the RAC admission rate over time and evaluating whether this admission differs for different groups (Figure 3.4). This can be addressed by applying the Kaplan Meier product limit method, calculating the event probability over time by group and by using the Cox proportional hazard model to estimate the relative hazard. However, the assumption of independent censoring)i.e., subjects with censored survival times are assumed to have the same survival prognosis as those still in the study(is invalid because subjects who die have no possibility)probability of zero(of experiencing the event of interest. Consequently, the estimated survival probabilities from the Kaplan Meier method are biased. Competing risk analysis extends the scope of standard survival analysis methods to deal with time to event data that have more than one cause of failure. Two widely used approaches are: 1(modelling the cause-specific hazard function; and 2(modelling the cumulative incidence function)sub-distributional hazard function(.

3.5.3.1 Cause-Specific Hazard Function:

The cause-specific hazard $h_k(t)$ is the instantaneous risk of an event of interest occurring from a particular cause k given that the subject has not experienced the event by time t)Prentice et al., 1978(.

It is defined as

$$h_k(t) = \lim_{\Delta t \to 0} \{(P(t \leq T < t + \Delta t, K = k | T \geq t)/\Delta t\}$$

where T denotes the time to failure from the kth event type $)K = 1, 2, 3,\ldots\ldots.k($.

This method estimates the probability for each type of event, treating the other event types)competing events(as censored, which is similar to those who are censored owing to withdrawal or loss to follow-up)Guo & So, 2018(. For example, when admission to RAC is the event of interest, deaths are censoring events in addition to conventional censored observations. The cause-specific hazard model)based on the Cox proportional hazard model(can be applied to analyse the cause-specific hazard functions from different event types. For each cause, a separate proportional hazard model can be assumed. The proportional hazard model for cause k can be expressed as:

$$h_k(t, X) = h_{0k}(t) \exp\left(\sum_{i=1}^{p} \beta_{ik} X_i\right)$$

where $h_{0k}(t)$ is the baseline hazard of the cause-specific hazard function, and β_{ik} is the effect of covariates which differed by event type)or cause(at time t.

While the cause-specific hazard function offers a more natural interpretation than Fine and Grey sub-distributional hazard function)which will be discussed in the next section(, one major caveat is the assumption of independent censoring for subjects who actually failed due to other causes)de Glas et al., 2015(. Under this assumption, it is considered that those who were censored owing to death would have the same hazard of admission to RAC as subjects censored for adminstrative reasons. This is the standard assumption for usual time to event

analysis)Allison, 2010(. However, we cannot test whether this assumption is valid for a given dataset with competing risks as those who die are no longer at risk for admission to RAC. Consequently, estimates from cause-specific hazard function do not have an informative interpretation)de Glas et al., 2015(. For example, a hazard ratio above 1 for subjects with a particular risk factor no longer implies that they are more likely to specifically experience the event of interest)admission to RAC(. This is because they can die from other causes before reaching the event of interest.

3.5.3.2 Modelling Cumulative Incidence Function

The cumulative incidence function)CIF(is the probability of failure from a specific cause k prior to time t. Alternatively, it is the instantaneous risk of dying from a specific cause k given that the subject has not previously died from cause k. The CIF is also referred to as the sub-distributional hazard function as it is not a true probability distribution. Mathematically, it is defined as

$$F_k(t) = P(T \leq t, K = k), K=1, 2, 3, \ldots\ldots.k$$

$$= \lim_{\Delta t \to 0} \left\{ \frac{P(t \leq T < t + \Delta t, K = k | T \geq t) \, or \, (T \leq t \, \& \, T \neq t)}{\Delta t} \right\}$$

This can also be expressed via the integral of all the cause-specific hazard functions

$$F_k(t) = \int_0^t h_k(u|X) \, S(u) \, du$$

where h_k is the cause-specific hazard function and $S(u)$ is the overall survival function

Fine and Gray)1999(defined the sub-distributional hazard function as the hazard of the CIF, i.e., $h_{ks}(t) = \frac{d}{dt} \log(1 - F_t(t))$. Based on the Cox proportional hazard model, they provided

a new way of modelling the CIF by proposing the proportional hazard assumption on the sub-distributional hazards as

$$h_{ks}(t, X) = h_{0ks}(t) \exp \left(\sum_{i=1}^{p} \beta_{iks} X_i \right)$$

where $h_{0ks}(t)$ is the baseline sub-distributional hazard of cause k. This model directly links the CIF to the covariates and is based on a relationship between the hazard and survival function (Putter, Fiocco, & Geskus, 2007). The hazard ratio denotes the relative change in the occurrence of the event of interest among subjects who have not experienced that event but who may have experienced a competing event. As the subjects who failed due to competing events are still in the risk set, this may be a potential source of 'immortal time' bias in the result; therefore, some investigators may not find this interpretation appealing. A recent study by Austin and Fine)2017(reported that except for a setting where an event of interest is rare, there is not an exact association between the subdistribution hazard ratio and relative changes in the cumulative incidence function. While the direction of the subdistribution hazard ratio denotes the direction, it does not directly provide the magnitude of the effect of the covariate on the CIF. Therefore, care is needed while interpreting hazard ratio from the subdistributional hazard model regarding the magnitude of covariate effects on the CIF.

3.5.4 K-medians Cluster Analysis

K-medians clustering is an alternative to k-means clustering where instead of the mean, the median is used to determine the centroid of each cluster. K-medians clustering is an important clustering tool as it is more robust to the effects of outliers)Anderson et al., 2006(.

This method works by using the Manhattan distance)1-norm distance(instead of the squared Euclidean distance used in k-means clustering. The criterion function of the k-medians clustering algorithm is

$$S = \sum_{j=1}^{K} \sum_{x \in \pi_j} |x - c_j|$$

where c_j is the median of each individual feature, and the function operates in the following four steps:

Step 1: Select k-points)i.e., k-medians(as the initial representative of the data

Step 2: Assign every data point to its nearest median

Step 3: Re-compute the median using the median of each individual feature; and

Step 4: Repeat steps two and three until the convergence criterion is satisfied

Clusters are formed by minimizing the distances within cluster and maximizing the differences between clusters. In this work, participants were assigned into mutually exclusive clusters based on the closeness)or similarity(of volume of service use. However, it is an important decision to choose the right number of clusters; statistical techniques)e.g., distortion technique(may not always provide a meaningful number of clusters where units of distinct characteristics group together (Sugar et al., 2004). Traditionally, the approach has been to increase the number of clusters until an optimum number of distinct groups has been generated. In this study, the Pseudo F Statistics)PFS(value was used to decide the number of clusters, with a large value of the PFS indicating the optimal cluster number had been reached)SAS Institute Inc., 1999(.

In sub-study 1 (Chapter 4) and sub-study 3 (Chapter 6), the k-medians cluster analysis technique was used to identify the distinct groups of women based on their similarity with regard to volume of HACC service use (Kendig et al., 2012; Mark & Blashfield, 1984; Sugar et al., 1998; Sugar et al., 2004).

3.5.5 Latent Class Analysis

Latent class analysis)LCA(is a finite mixture model that is used to identify latent sub-groups)sub-population(within a population based on individual responses for the observed variables)Collins & Lanza, 2010(. Alternatively, LCA is a multivariate classification technique that illustrates the relationship between observed variables)e.g., aged care service use status at different time points(and unobserved latent variables)e.g., service use pattern over time(. The LCA technique classifies the data into mutually exclusive classes based on item response probabilities of class membership. This method also provides the prevalence of each latent pattern and error associated with observed variables for measuring the patterns.

LCA is a person-centred rather than variable-centred analysis technique. The emphasis is on the subjects as a whole (Bergman & Magnusson, 1997; Bergman, Magnusson, & El Khouri, 2003). Alternatively, in a variable-centred approach, for example factor analysis, the emphasis is usually on identifying relationships between variables and then assessing how these relationships apply across subjects.

The estimation of the model is based on the Expectation Maximization)EM(algorithm, which starts with random allocation of individuals into different latent classes and reclassifies them based on an improvement criterion, which continues until the best classification has

been found)Collins & Lanza, 2010(. Figure 3.5 presents a typical conditional latent class model, where Y's are observed categorical variables, C's are latent categorical variables, and X is a covariate vector. More detail about LCA and its extensions have been documented elsewhere)Collins & Lanza, 2010(.
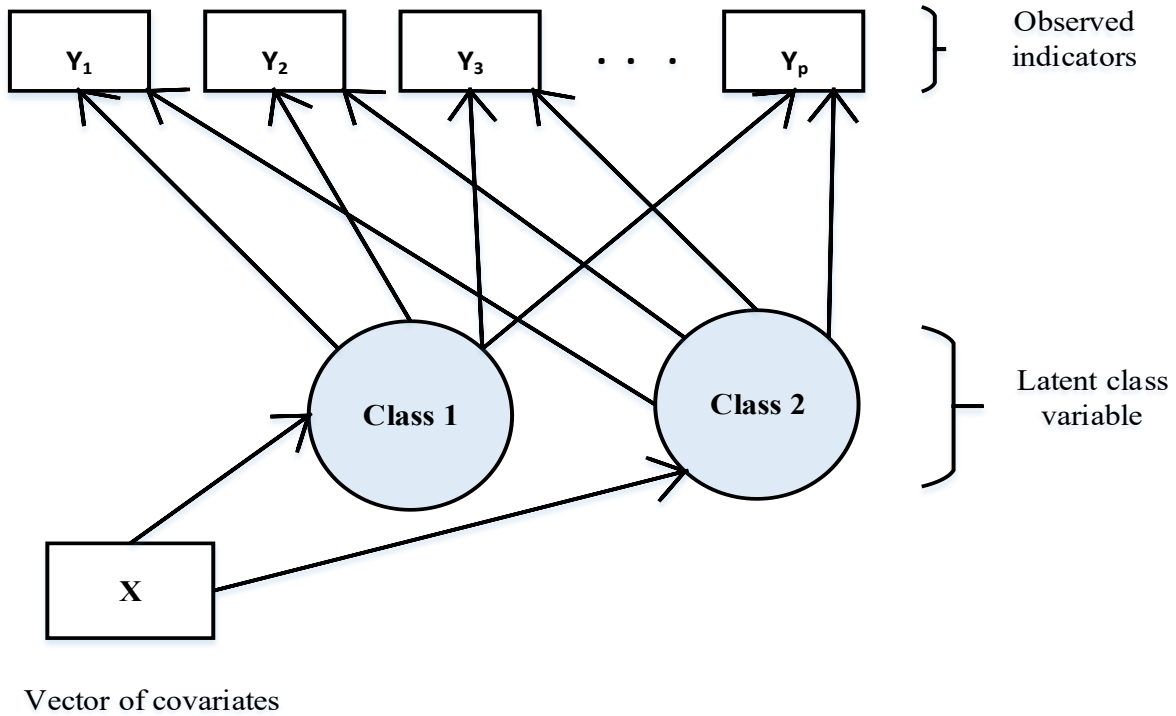

Figure 3.5: A typical conditional latent class model.

The latent class model can be defined as

$$P[Y_i = y_i | X_i = x_i] = \sum_{c=1}^{K} \gamma_{c_i}(X_i) \prod_{m=1}^{M} \prod_{r_m=1}^{R_m} \rho_{m r_m c}^{I(y_m - r_m)}$$

Where Y = vector of all observed response patterns

X = vector of all covariates

γ_c = Probability of membership of latent class c

ρ = Relationship between discrete latent variable and observed indicator variables

$\rho_{mr_mc}^{I(y_m - r_m)}$ = probability of response r_m to indicator *m*, conditional on being a member of the latent class *c*)or item response probability(.

3.5.6 Repeated Measures Latent Class Analysis

Repeated measures latent class analysis)RMLCA(is a technique for analysing longitudinal data by means of LCA. This method is useful for identifying time-dependent patterns for different sub-groups/populations, without imposing any restrictions. It is a person-centred analytic technique, which is an extension of LCA for analysing longitudinal datasets. In the section on LCA, we discussed how this technique helps identify the latent patterns of response/behaviour existing in the data. LCA also provides estimates of the prevalence of each class and an individual's probability of membership of each class.

In RMLCA, observed indicators of latent classes are the same but fewer in number and measured over three or more times)Collins & Lanza, 2010(. For example, in sub-study 2)Chapter 5(we used a single, five-level indicator)non-user, basic HACC user, moderate-high-level HACC user, RAC user, death(for each year across the 11-year observation period. Examination of item response probabilities within classes facilitated understanding of patterns over time and qualitative description/labelling of the latent classes that emerged. Furthermore, plotting item response probabilities by latent classes over time helps to explain the clinical significance of the classes as well as to differentiate between the classes.

Parameters were estimated from the model using the maximum likelihood method)Collins & Lanza, 2010(. A model with an optimal number of classes was determined by examining various fit criteria, includingAkaike Information Criterion)AIC(, Bayesian Information Criterion)BIC(, likelihood-ratio G^2 diagnostic, and entropy (Celeux & Soromenho, 1996; Nylund, Asparouhov, & Muthén, 2007). The conditional probabilities of responding to an item given membership within a latent class, were graphically presented for interpretability of each of the resultant latent classes. RMLCA can be performed with missing data in the indicator variables, assuming that data are missing at random. Furthermore, this method considers the conditional independence assumption that correlations among the indicator variables are fully accounted for by each latent class. The model is also not subject to assumptions of normality.

3.5.7 Multinomial Logistic Regression

Multinomial logistic regression is used to model nominal outcome variables with more than two categories. It is a simple extension of binary logistics regression. In this model, log odds of the outcome variable is modelled as a linear combination of the predictor variables and maximum likelihood method is used to estimate the parameters. The regression method does not consider the normality and linear assumption. However, one of the major assumptions of this technique is that the outcome responses are independent; the membership of one category is not related to membership of another category)Hilbe, 2009(.

The binary logistic regression model is defined as

$$ln\left(\frac{p}{1-p}\right) = X\beta$$

where $ln\left(\frac{p}{1-p}\right)$ is the log odds ratio of reporting a favourable outcome, and it is linear in the explanatory variables as well as parameters.

Suppose there are a total of j categories of the outcome variable, then the total number of comparison is *j*-1. The equation for the model can be written in terms of the logit of the outcome; a comparison of a particular category with the referent category, both denoted p_j here

$$ln\left(\frac{p_j}{p_j}\right) = X\beta_j$$

The log odds ratio of the two is the same as the binary logistic regression where $ln\left(\frac{p_j}{p_j}\right)$ replaces $ln\left(\frac{p}{1-p}\right)$, and this is sometimes referred to as a generalized logit)Long, 2014(. Therefore, a binary logistic regression model is a special case of the multinomial logistic regression.

3.5.8 Group-Based Multi-Trajectory Modelling

Group-based multi-trajectory (GBMT) modelling is an extention of the univariate group-based trajectory (GBT) modelling which is a specialized application of finite mixture Modelling. GBT is designed to analyze development trajectories of an outcome)progression of disease or behaviour(over age or time)Nagin & Odgers, 2010(. As developed by Nagin)1999, 2005(, the method has increasingly been applied in clinical research to identify clusters of subjects following a similar symptoms patterns or progression of disease over time and to assess responses to clinical interventions.

With the increased availability of longitudinal multivariate datasets in medical and health sciences, identification and monitoring of multiple diseases and their relationships with other clinically important factors have been reported in recent years. However, conventional statistical approaches often handle indicators of interest in sequence or separately rather than

jointly. As discussed above, the GBT model is designed to model the longitudinal pattern of a single outcome or behaviour. Group-based dual or joint trajectory modelling, a specific form of GBT, is disigned to measure the linkage between the trajectories of two distinct but related outcomes. However, the concern is a proliferation of probability matrices linking the trajectories of various outcomes of interest. For example, a joint model with three outcomes requires three tables of conditional probabilities)for outcome 1 to 2, 2 to 3, and 1 to 3(to link trajectories of all outcomes. An extension of four outcomes will require six tables of joint probabilites.

The GBMT is designed to identify and examine the developmental trajectories across multiple indicators/outcomes of interest over time, without proliferation in the number of joint probabilities tables (Nagin et al., 2018). Within the GBMT model, multiple regression models are estimated simultaneously through maximization of a combined likelihood, which collects information from all sub-models. Model parameters are estimated by the maximum likelihood method.

The distribution of the outcomes conditional on time $P(Y_i \mid tme_i($, and the model assumes that the population is composed of a finite number of distinct trajectory groups)J(. The likelihood of the *ith* individual, conditional on J number of groups is given by:

$$P(Y_i|time_i) = \sum_{j=1}^{J} \pi_j \cdot P\left(Y_i \mid time_i, j, \beta_j\right)$$

Where Y_i: a vector of longitudinal sequence of measurement for the *ith* individual

$time_i$: vector of time when each of the longitudinal measurement was recorded

π_j: probability of being a member of group j.

β_j: conditional distribution of Y_i given membership in group j which also contributes to the shape of the group-specific trajectory.

With the assumption of conditional independence within the trajectory groups, we can write,

$$P\left(Y_i \middle| time_i, j;\; \beta_j\right) = \prod_{t=i}^{T} p\left(y_{it} \mid time_{it}, j \;;\; \beta_j\right)$$

where $p\left(y_{it} \mid time_{it}, j \;;\; \beta_j\right)$ is the distribution of the y_{it}, which is conditional on being a member of group j and longitudinal measurement of individual i at time t. The assumed distribution of the response may be normal, Poisson, binomial or any other form of distribution.

As part of an optimal multi-trajectory model selection process, initially GBT models for each of the outcome variables are estimated separately with a combination of linear and quadratic polynomials.)Niyonkuru et al., 2013(For each outcome variable, a model with an optimal number of trajectory groups was selected based on AIC, BIC and average posterior probability of group membership for the participants assigned to each trajectory group.)Akaike, 1974; Nagin & Odgers, 2010; Schwarz, 1978(. GBMT models were performed using all three outcome variables together. A model with an optimal number of groups was chosen based on fit indices of the models)AIC and BIC(and consideration of the optimal model for each of the outcome variables separately. Furthermore, the trajectory groups were plotted over time in terms of the indicator variables to check the shape of the trajectory groups over time. Selection of the best fitting model involves a combination of formal statistical criteria, explanatory power, and clinical relevance of the obtained groups)Nagin & Odgers, 2010(.

3.5.9 Multi-State Markov Models

A multi-state Markov model describes a stochastic process in which subjects under study move through a finite number of well-defined states in continuous time (Abner, Charnigo, & Kryscio, 2013; Jackson, 2016). A sequence of trials of a clinical experiment is a Markov chain if the outcome of interest is one of a set discrete states and depends on only the present state not on any previous states)'memoryless property'(. The Markov process consists of a series of transient states and an absorbing state)i.e., once individuals enter the absorbing state, they have no chance of leaving this state(. Death is a commonly used absorbing state in clinical research but it is also a potentially competing event for many clinical outcomes of interest, particularly among older people.

A multi-state model is a generalization of a standard survival model, which includes at least one transient state)living at home(and an absorbing state)death( )Figure 3.6a(. This model is suitable for the analysis of clinical data in the presence of competing events. Transition between states accounts for competing events at each transition level (Figure 3.6b(. A widely used multi-state model in medical research is the illness-death model (Xu, Kalbfleisch, & Tai, 2010). This model includes three states, including two transient states)e.g., living at home and admission to RAC(and an absorbing state)death(. Transitions are allowed from living at home to admission to RAC, exit from RAC to living at home)recovery(, living at home to death, and RAC to death)Figure 3.6c(. However, in some clinical states, the chances of recovery are low, for example, improving functional status for cancer or dementia patients or permanent RAC to returning back to living at home. In such circumstances, a state progression model is applied treating the different stages of the event of interest)in terms of

severity(as different progressive states from which reverse transition is not allowed)Figure 3.6d(.
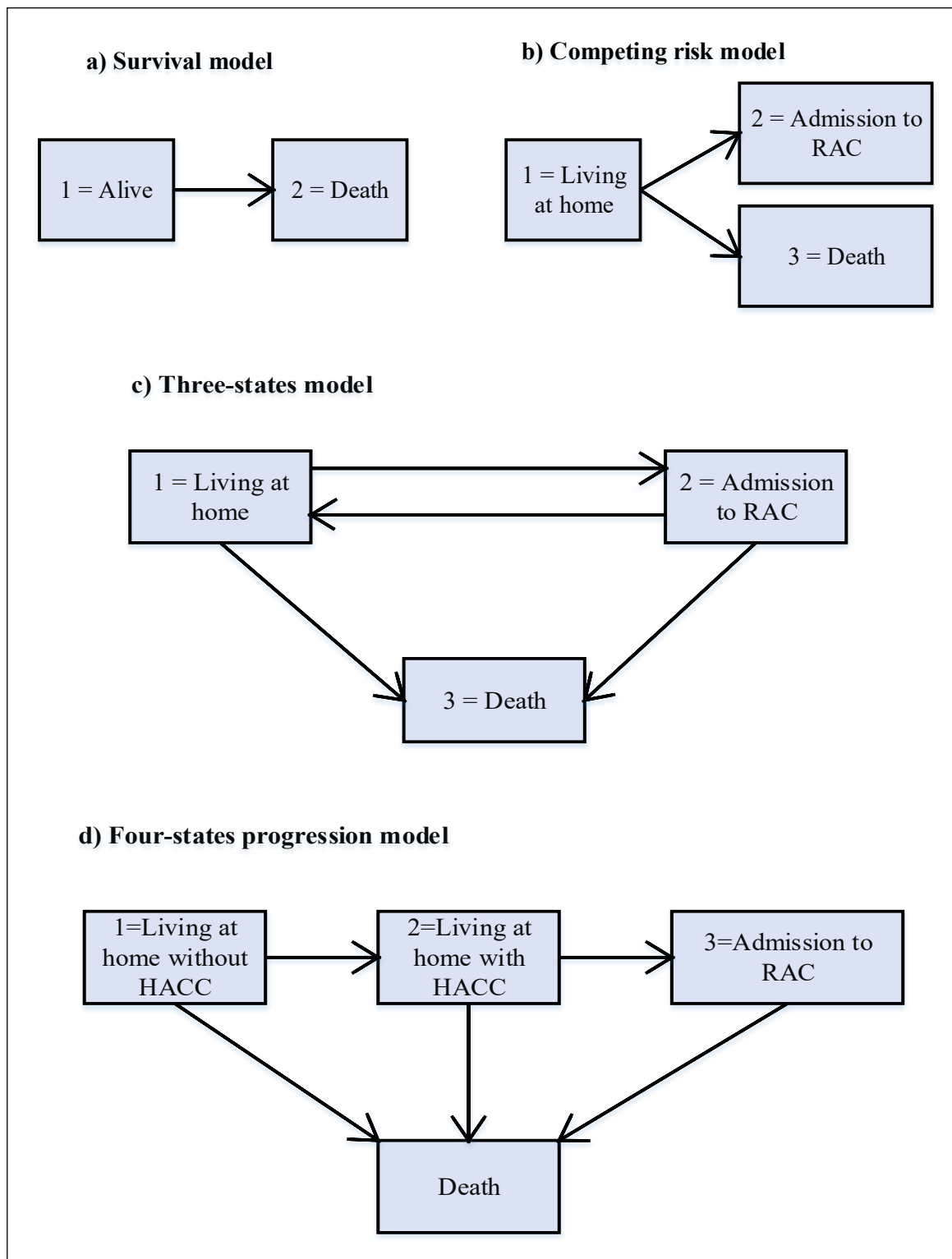
Figure 3.6: Different types of multi-state models

The current study employed a four-state Markov multi-state model)Chapter 8(to examine the movements of older women into and through the mainstream aged care programs across later life. A woman's level of aged care use was categorized into four hierarchical states: 1(not use any aged care; 2(home and community care use; 3(residential age care use; and 4(: death)Figure 3.7(. The first three states denote transitional states, while the fourth is an absorbing state. As the level of aged care needs increase with age among older people, we did not consider any reverse transition)e.g., transition from permanent residential care to home and community care(as per a state progression model. We used a covariate-adjusted Markov model to estimate transition probabilities through these four states (Islam, Chowdhury, & Huda, 2013; Jackson, 2011; Xie, Chaussalet, & Millard, 2005).
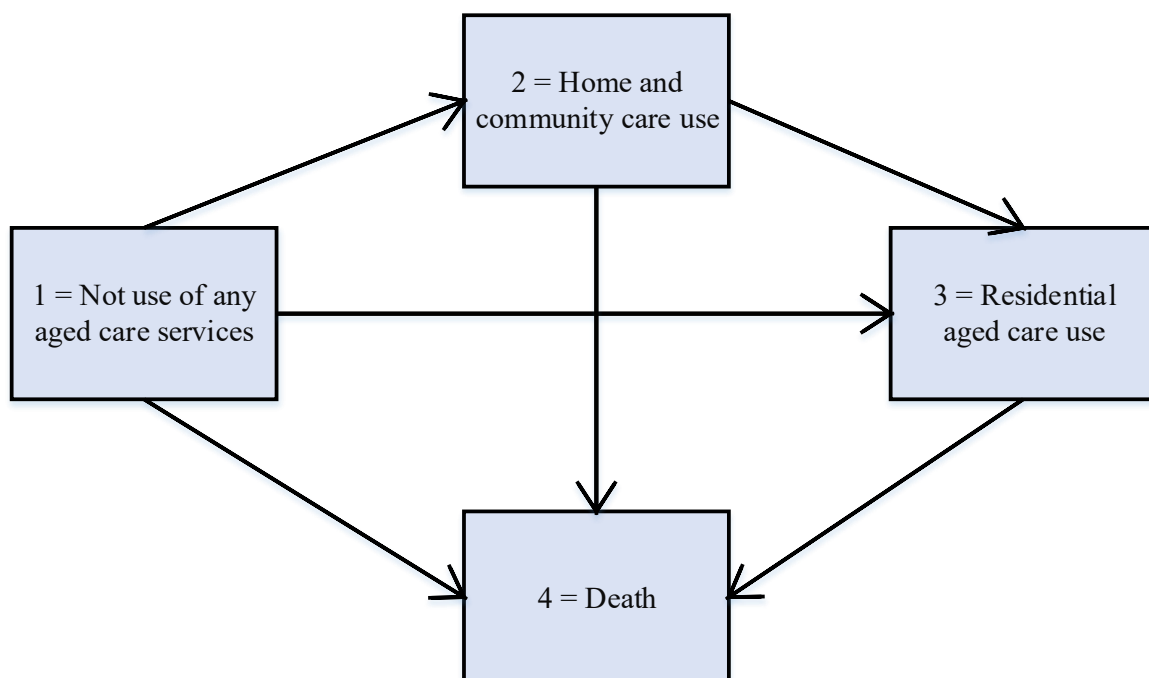
Figure 3.7: A four-state multi-state model for aged care use among older women across later life.

Transition intensity rates are the key quantities estimated by the Markov multi-state model. The movements of individuals between states and the time of movements are governed by transition intensities $q_{ij}(t\,|F_t)$. It is the instantaneous rate of transitioning from state i to state j within the interval t and $t+dt$, which is conditional on the history of process at time t. Mathematically,

$$q_{ij}(t\,|F_t) = \lim_{dt \to 0} \frac{P(X(t+dt) = j\,|\,X(t) = i,\ F_t)}{dt}$$

The transition intensities constitute a matrix Q, with row sum equal to zero so that the diagonal elements are $q_{ii} = -\sum_{i \neq j} q_{ij}$

The effects of covariates on a particular transition intensity were modelled as

$$q_{ij}(z(t)) = q_{ij}^{(0)} \exp\left(\beta_{ij}^T z(t)\right),$$

where $z(t)$ represents the column vector predisposing, enabling and health-related need factors in the current study)Marshall & Jones, 1995(. The transition probability $P)t($ of being in state j at time $)t+u($, given the state at time t)i.e., $i($ are computed as $P(t) = Exp(tQ)$, where Q denotes the state transition intensity matrix.

CHAPTER 4: Assessing Patterns of Home and Community Care

Peer Reviewed Published Paper

Key Findings

- Six distinct clusters were identified. The majority of consumers belonged to a cluster who used low volume of few basic home and community care (HACC) services with a wide range of service options from their age late 70s to until late 80s. Nearly one-quarter belonging to three complex clusters who had complex use with high volume of many services.

- An increased risk of HACC use was associated with a) living in remote/inner/regional areas; b) being a widowed or divorced, c) having difficulty in managing income; d) having chronic conditions; and e) reporting lower scores in physical functioning.

4.1 Introduction

In accordance with the objectives of this Ph.D. project, our analysis began by focusing on the most commonly used aged care service 'home and community care')HACC(, which is currently known as Commonwealth Home Support Programme. The HACC provides a range of entry-level care services to support the independence and wellbeing of older people and help them to remain at home for as long as possible, rather than entering residential aged care. This study aimed to address the first research question, which included the following specific objectives:

- To identify the factors associated with age at first home and community care service use

- To assess the patterns of home and community care use among older Australian women across later life

- To identify the participants' characteristics that are associated with different patterns of service use

4.2 Peer reviewed Published Paper

Details about the study bacground, data and analytical methods, and the findings have been published as a peer reviewed paper titled 'Patterns of home and community care use among older participants in the Australian Longitudinal Study of Women's Health' in the *European Journal on Ageing*, and the final published version of this manuscript is presented in this section.

The paper can be assessed at: https://link.springer.com/article/10.1007/s10433-018-0495-y

Patterns of home and community care use among older participants in the Australian Longitudinal Study of Women's Health

Mijanur Rahman, Jimmy T. Efird, Hal Kendig & Julie E. Byles

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Patterns of home and community care use among older participants in the Australian Longitudinal Study of Women's Health

Mijanur Rahman[1,2,3] · Jimmy T. Efird[1,2] · Hal Kendig[4] · Julie E. Byles[1,2]

Abstract

The aims of this study were to investigate patterns of home and community care (HACC) use and to identify factors influencing first HACC use among older Australian women. Our analysis included 11,133 participants from the Australian Longitudinal Study of Women's Health (1921–1926 birth cohort) linked with HACC use and mortality data from 2001 to 2011. Patterns of HACC use were analysed using a k-median cluster approach. A multivariable competing risk analysis was used to estimate the risk of first HACC use. Approximately 54% of clients used a minimum volume and number of HACC services; 25% belonged to three complex care use clusters (referring to higher volume and number of services), while the remainder were intermediate users. The initiation of HACC use was significantly associated with (1) living in remote/inner/regional areas, (2) being widowed or divorced, (3) having difficulty in managing income, (4) not receiving Veterans' Affairs benefits, (5) having chronic conditions, (6) reporting lower scores on the SF-36 health-related quality of life, and (7) poor/fair self-rated health. Our findings highlight the importance of providing a range of services to meet the diverse care needs of older women, especially in the community setting.

Keywords Home and community care · Demographic factors · Health-related needs · Older women · Data linkage · Australia

Introduction

The number of people aged 60 and over is projected to reach over 2 billion worldwide by 2050, which is more than double the 2015 figure (UNDESA 2015). Representing the most rapidly growing age group, individuals in their eighties are increasingly dependent on care from formal sources (Stones and Gullifer 2016). The transition from informal family-based support to institutional and community care services reflects the participation of more women in the labour market and their adoption of a nuclear family structure (Genet et al. 2011; Lowenstein et al. 2001). Adding to an already overburdened healthcare system, the need for formal care is anticipated to increase until the year 2050 (Wouterse et al. 2015). Debate exists on how to best provide long-term care for an ageing population and ways to address this complex policy issue (Francesca et al. 2011; Merlis 2000).

Over the past few decades, increased costs and consumer choices have led to a shift from long-term residential aged care to lower-cost home- and community-based care. Moreover, this trend is expected to continue into the foreseeable future (Australian Institute of Health and Welfare 2008a; Department of Work and Pensions 2007). For instance, older people in Europe, Australia, and the USA prefer to receive aged care in the home and community-based setting (Chen and Berkowitz 2012; EUROBAROMETER 2007; Productivity Commission 2011). Several countries in the Organisation for Economic Co-operation and Development (OECD)

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have been promoting 'Age in Place' policies in recent years (Francesca et al. 2011).

In contrast to many countries, Australia has a well-developed long-term care system (formally known as aged care) for older people aged 65 and over. Beginning in the 1980s, policy-makers have focused on providing aged care in the community setting. This was precipitated by the need to reduce the burgeoning cost of residential aged care and to address the desire of older Australians to remain in their own home (Jeon and Kendig 2017; Keleher 2003; Productivity Commission 2011).

The Commonwealth Home and Community Care (HACC) programme was implemented in 1985 to provide a range of care services for older Australians (including younger people with disabilities) in the community setting (Department of Health and Ageing 2008). Additionally, this programme is important for older Australians who may later require more advanced care (Australian Institute of Health and Welfare 2017; Palmer and Short 2000). Until 2012, HACC was funded by the Commonwealth of Australia and state/territory entities (Australian Institute of Health and Welfare 2014). Thereafter, the Australian Government assumed full responsibility for the financing and management of HACC (except for Victoria and West Australia). Around the same time, the legislature announced the Living Longer Living Better plan to reform aged care services in the community (Department of Health and Ageing 2012). Specifically, HACC and three smaller commonwealth programmes were merged into the Commonwealth Home Support Programme (CHSP) as a means to consolidate and increase the efficiency of aged care to older Australians.

HACC provides a range of services to allow older people to remain in their own home as long as possible, rather than entering residential aged care (RAC) (Department of Health and Ageing 2008; Jorm et al. 2010). Services include domestic assistance with meals and personal care, home maintenance and medication, transportation, social care, respite care, as well as nursing and allied health services (Department of Health and Ageing 2012). Approximately 20% of people aged 65 and over receive support from HACC, constituting the largest aged care programme in the country (Australian Institute of Health and Welfare 2015). From 2013 to 2014, more than 775,000 older Australians received HACC, with the majority being women (> 65%) (Department of Social Services (DSS) 2014).

Although HACC is a pivotal component of the community aged care system in Australia, limited evidence is available regarding client characteristics and their patterns of care needs (Jorm et al. 2010). Nine distinct groups of HACC clients were identified in a recent study, with most (~75%) only using a few of the wide range of available services (Kendig et al. 2012). Demographic vulnerability and health-related needs of older people were associated with the use of

community age care (Lafortune et al. 2009). Women tend to use more aged care than men, as they typically live longer and manifest multiple morbidities and disabilities (Laditka and Laditka 2001). Furthermore, women have a greater likelihood to live alone in later life, increasing their dependence on formal aged care (McCann et al. 2012). Although nearly two-thirds of clients in the Australian aged care system are women, there is a paucity of information pertaining to their patterns of service use and factors influencing the risk of HACC use.

The aim of the present study was to identify the patterns and timing of HACC use among older women in Australia. Specifically, we addressed the following research questions: (1) what are the main combinations of services used by HACC clients aged 75–90 years, from 2001 to 2011, and (2) what are the factors associated with an increased risk of HACC use.

Methods

Study sample and data linkage

The 1921–1926 cohort of the Australian Longitudinal Study on Women's Health (ALSWH) was recruited in 1996 with 12,432 women participating in the baseline survey (aged 70–75 years) (Loxton et al. 2015). ALSWH is a national population-based study of women's health, with participants being randomly sampled from the Medicare Australia database. Data were collected from participants through self-reported postal questionnaires every third year until 2011 (Survey 1: 1996; Survey 2: 1999; Survey 3: 2002) and on a six-month rolling basis thereafter. Linked HACC data were not available before 2001. Consequently, the current study focused on the period from 2001 to 2011, whereby Survey 3 constituted the sample from which the baseline covariate characteristics (except educational qualification, measured only in Survey 1) were obtained. The total attrition by 2002 was $N = 1237$, with a response rate of 88%. Data from adjacent surveys (Survey 2 and Survey 4) were used to fill in missing values rather than using model-based imputation methods. A small proportion of missing values ($\leq 5\%$) was not available in adjacent surveys. A detailed description of the ALSWH survey and its design has been previously published (Brilleman et al. 2010).

Survey data were linked with the administrative HACC Minimum Data Set (MDS) on an opt-out consent basis. In total, 11,133 women (> 95%) in the 1921–1926 cohort were eligible for data linkage, undertaken with the approval of the Australian Government Department of Health (DOH). The Australian Institute of Health and Welfare (AIWH) used a probabilistic algorithm to link the ALSWH and HACC data sets (Karmel et al. 2010; National Statistical Services 2017).

This study was approved by the Human Research and Ethics Committee (HREC) of the University of Newcastle and University of Queensland. Ethical clearance for the linkage of ALSWH survey data with aged care data was approved by the Australian Institute of Health and Welfare Ethics Committee.

HACC use

In total, 7747 women were identified as HACC users from July 2001 to December 2011. This dataset provided information on the quarterly use of HACC services for each client. Among the 28 service types, data on 'HACC assessments' and 'carer services' were not used in the current analysis. These two services were excluded as HACC assessment was related to the determination of eligibility for service provision (not an ongoing care type), while carer services were related to needs of the carers, rather than the care recipients. A range of minor services (including communication aids, self-care aids, support and mobility aids, reading aids, medical care aids, car modification, formal linen service, and other goods and equipment) were grouped under the 'equipment and aids' category. Accordingly, the number of service types included in our analysis was 19. Of these, 14 were characterized by hours of use, 4 by the frequency of use, and 1 by the amount of dollars expended (Department of Health and Ageing 2006) (Table 1).

Andersen–Newman model and participants' baseline characteristics

The Andersen and Newman (2005) behavioural model was used to identify influencing factors associated with HACC use (Chen and Berkowitz 2012; Fu et al. 2017). While the model was originally introduced in 1968, it has evolved over time (Andersen 1968). In our analyses, individual/societal characteristics were grouped into three categories: predisposing factors (age, marital status, and education), enabling factors (income, living arrangements, and area of residence), and need factors (physical, psychological, and functional health status including illness and disability).

Demographic predisposing and enabling factors included area of residence (major cities, remote/inner/regional areas), country of birth (born in Australia, overseas), highest educational qualification (no formal, secondary certificate, high school/trade/diploma/university), marital status (married/de facto, widowed/divorced/never married/separated), living arrangements (living alone, living with partner/others including live with own children/other family members/non-family members), difficulty in managing income (easy/not too bad, difficult some/all the time), and Veterans' Affairs coverage for health service use (yes, no). However, ALSWH did not include individual beliefs and community level enabling factors.

Health factors included diagnosed chronic conditions (e.g., heart problems, diabetes, arthritis, and asthma), falls with injury in the past 12 months, self-rated health (poor/fair, good/very good/excellent). Physical, social, and mental functioning scores were obtained from the SF-36 health-related quality of life, with row scores being computed from ten, two and five items, respectively. Scores were linearly transformed to produce subscale scores ranging from 0 to 100 (with a higher score indicating better health) (Ware et al. 1993). Based on the literature, scores above prescribed cut-off points corresponded to better functional capacity (e.g. physical function > 40, lower mental function > 52, and lower social function > 52) (ALSWH 2018; Stevenson 1996).

Statistical analyses

The data were analysed in two stages: the first was to identify which types of services women used, and the second was to identify factors associated with risk of first HACC use.

Cluster analysis

In the first stage, summary statistics regarding usage were computed for 19 HACC service types from 2001 to 2011. Z-scores were estimated to obtain a standardized metric for each service type. The distribution of usage was skewed for many service types. Accordingly, a robust k-median cluster analysis technique was applied to identify distinct groups of women based on their similarity with respect to the volume of HACC use (Anderson et al. 2006; Kendig et al. 2012; Sugar et al. 1998, 2004).

Clusters were formed by minimizing the Euclidian distance within a cluster and maximizing the differences between clusters (Aldenderfer and Blashfield 1984). Participants were grouped into mutually exclusive clusters based on the closeness (or similarity) of the volume of service use. In the current study, we used the Calinski/Harabasz pseudo-F statistic (PFS) value to determine the number of clusters (Caliński and Harabasz 1974).

Once clusters were identified, descriptive statistics (median with 95% confidence interval (CI) and proportions) were computed to explore service use patterns in each cluster. The clusters were given a descriptive name based on the volume, number, and type of services used. We divided the total participants ($n = 11,133$) into three broad categories: 'HACC non-users', 'basic HACC' users, and 'moderate- to high-level HACC' users (included all distinct groups except Basic HACC). Chi-square tests were performed to explore associations between participants' baseline characteristics and patterns of HACC use from 2001 to 2011.

Table 1 Percentage of women and their volume (median) of different types of HACC use by distinct cluster from 2001 to 2011

HACC services (measurement units)	Cluster						All HACC clients 7747
	Basic HACC (n=4173)	Basic domestic (n=1280)	Home meal (n=398)	Complex nursing care (n=168)	Complex domestic (n=914)	Complex transport (n=814)	
Domestic assistance (hrs)							
% using service	33	99	72	75	100	75	59
Median (CI)	10 (9–11)	57 (55–60)	69 (56–83)	54 (37–71)	201 (193–209)	42 (37–50)	
Meals at home (number)							
% using service	27	39	100	57	59	56	40
Median (CI)	45 (40–49)	57 (51–64)	564 (542–605)	135 (85–221)	72 (66–80)	63 (55–70)	
Nursing care at home (hrs)							
% using service	37	51	62	100	66	60	48
Median (CI)	7 (6–8)	10 (9–11)	16 (12–19)	189 (175–207)	12 (10–14)	13 (11–15)	
Allied health at home (hrs)							
% using service	16	31	34	52	46	40	26
Median (CI)	3 (2–4)	3 (2–4)	3 (2–3)	6 (4–10)	3 (2–4)	3 (2–4)	
Allied health at centre (hrs)							
% using service	15	27	35	46	48	41	26
Median (CI)	3 (2–4)	3 (2–4)	2 (1–3)	5 (4–7)	4 (3–5)	3 (2–4)	
Case management (hrs)							
% using service	10	22	34	41	40	37	20
Median (CI)	2 (1–3)	3 (2–4)	4 (3–5)	4 (3–5)	4 (3–5)	5 (4–6)	
Care coordination(hrs)							
% using service	27	54	62	65	72	71	44
Median (CI)	2 (1–3)	4 (3–5)	5 (4–6)	5 (3–6)	5 (4–6)	6 (5–7)	
Counselling (hrs)							
% using service	9	20	29	31	36	38	19
Median (CI)	1 (0–2)	2 (1–3)	2 (1–3)	2 (1–3)	3 (2–4)	3 (2–4)	
Centre-based day care (hrs)							
% using service	15	27	41	40	47	82	29
Median (CI)	40 (36–44)	46 (40–52)	67 (55–80)	71 (40–151)	60 (53–72)	343 (295–374)	
Other food services (hrs)							
% using service	1	2	6	2	3	5	2
Median (CI)	6 (2–14)	10 (4–13)	9 (5–29)	2 (1–3)	12 (6–27)	7 (2–12)	
Home maintenance (hrs)							
% using service	23	43	52	57	70	49	37
Median (CI)	4 (3–5)	5 (4–6)	6 (5–7)	6 (4–8)	10 (9–11)	7 (6–8)	
Home modification (AUD $)							
% using service	10	12	16	14	19	18	13
Median (CI)	101 (90–120)	100 (74–120)	120 (77–182)	73 (37–170)	100 (85–135)	100 (77–138)	
Meals at centre (number)							
% using service	8	15	29	30	31	63	19
Median (CI)	7 (6–8)	7 (5–10)	11 (8–15)	8 (4–11)	10 (9–11)	43 (36–48)	
Nursing care at centre (hrs)							
% using service	9	12	19	38	24	23	14
Median (CI)	2 (1–3)	2 (1–3)	2 (1–3)	3 (1–5)	2 (1–3)	2 (1–3)	
Personal care(hrs)							
% using service	16	38	49	63	55	46	30
Median (CI)	10 (9–12)	19 (16–23)	28 (20–36)	54 (32–86)	23 (19–29)	17 (14–20)	
Social care(hours)							
% using service	17	34	49	54	52	63	31

Table 1 (continued)

HACC services (measurement units)	Cluster						All HACC clients 7747
	Basic HACC (n=4173)	Basic domestic (n=1280)	Home meal (n=398)	Complex nursing care (n=168)	Complex domestic (n=914)	Complex transport (n=814)	
Median (CI)	12 (10–14)	15 (12–19)	22 (15–29)	16 (9–22)	20 (17-24)	36 (27–43)	
Transport (number)							
%using service	29	39	55	47.6	57	92	42
Median (CI)	10 (8–12)	14 (12–15)	24 (20–29)	19 (10–28)	24 (20–26)	129 (118–144)	
Equipment and aids (number)							
% using service	8	15	22	21	23	25	14
Median (CI)	2 (1–3)	2 (1–3)	4 (3–5)	3 (1–6)	3 (2–4)	3 (2–4)	

The differences in proportions of women using services between the clusters were significant at $P < 0.01$

The Calinski/Harabasz pseudo-F statistic (PFS) value (283) was used to determine the number of clusters. Cluster analysis identified six distinct clusters. Clusters were named according to the number and volume of services used by the women in the respective classes

Detailed description of the different HACC services is available in (access date: 12 October 2018) https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/112014/prov_4b1_hacc_mds_user_guide.pdf

hrs Hours, *AUD* Australian dollar, *CI* confidence interval

Competing risk analysis

Women who were alive during Survey 3 and who had not used HACC before 2002 were included in the analysis ($n = 9203$). Age at first HACC use was measured from the begining of 2002, and if no HACC use was recorded, participants were censored at 31 December 2011 or their date of death. The maximum observation period was 120 months. Competing risk analysis was performed to obtain an accurate incidence of HACC use, wherein age at first HACC use was considered as the target variable with death as the competing event (Berry et al. 2010; Forder et al. 2017). Competing risks occur in a study when participants experience one or more events that compete with the event of interest (Noordzij et al. 2013). This study considered death as the competing event because participants are no longer at risk of using HACC after dying. Initially, crude hazard ratios (HR) and 95% confidence intervals (CI) were estimated using Cox proportional hazard models (Fong et al. 2015). The adjusted model included demographic (predisposing and enabling) and health-related need factors that were significant in the unadjusted model, but excluded the SF-36 subscales and self-rated health. This was owing to a probable causal relationship with other health indicators included in the model. Four separate multivariable models were performed on self-rated health, physical, social, and mental functioning, adjusting for demographic variables. All the statistical tests were two-sided, and the level of significance was set at $P < 0.05$. Analyses were conducted using STATA/IC 15.0 (StataCorp LP, College Station, Texas, United States of America) and SAS 9.4 (SAS Institute, Cary, NC, USA).

Results

Distinct groups of HACC users

Approximately 70% ($n = 7747$) of women used HACC at some point during the study period. Six distinct groups of women were identified in our cluster analysis, where the number of groups was determined based on the PFS value of 283 and interpretability of the groups. The distinct groups were accordingly named based on the proportion of women using different HACC services and their median volume of service use (Table 1). While 'basic HACC' constituted the largest cluster of women (54%), this group had the lowest use of the 19 HACC services (shown in Column 1), compared with other clusters ($P < 0.01$). The median volume of each service use was lower than other groups. Approximately 51% women in the basic HACC group used one or two service types at some point over the study duration but not necessarily at the same time. More than 25% used three or four service types, and a negligible proportion (1%) used more than 10 services.

Nearly all women in the 'basic domestic' ($n = 1280$) and 'complex domestic' ($n = 914$) clusters used domestic assistance services. The former group used a lower volume of services, and a smaller proportion of them used other HACC services, than the latter group. For example, the median volume of domestic assistance used by the basic domestic group was 57 h, compared with 201 h used by the complex domestic group. Approximately one-third of the complex domestic group used 10 or more services. In contrast, only 9% of the basic domestic group used this amount (Table 2).

The other three groups were named 'home meal' (398 women), 'complex nursing care' (168 women), and 'complex transport' (814 women). Women belonging to the home meal group predominantly used meal services at home (100%), domestic assistance (72%), nursing care at home (62%), and a moderate volume and number of other services. All women in the complex nursing care group used nursing care (median = 189 h), while 63% used personal care (median = 54 h). The complex transport group primarily used transport services (92%; median = 129 instances), and centre-based day care (82%, median = 343 h). Women in the complex groups of 'transport', 'nursing care', and 'domestic' also frequently used other previously mentioned HACC services. More than one-third of women in the complex transport, complex domestic, and complex nursing care groups used 10 or more HACC service types, and ≤5% used one to two service types. The proportion of women using different HACC services differed between clusters ($P < 0.01$).

Demographic predisposing and enabling factors

There were key differences among the distinct clusters and for the broad categories including HACC non-users, basic HACC users, and moderate- to high-level HACC users ($P < 0.05$) (Table 3). The difference was especially pronounced among the broad categories. Higher proportions of women in the moderate- to high-level HACC user group were living in remote/inner/regional areas (62% vs. 50%, $P < 0.01$), widowed (53% vs. 46%, $P < 0.02$, $P < 0.01$), living alone (50% vs. 41%, $P < 0.01$), and having difficulty in managing income (31% vs. 22%, $P < 0.01$), than the HACC non-user group. A lower proportion of women who were receiving Veterans' Affairs coverage used moderate- to high-level HACC than non-users (15% vs. 27%, $P < 0.01$). The main difference between HACC non-users and basic HACC users was area of residence ($P < 0.01$).

In the competing risk analysis with adjusting demographic and health-related factors, we found that women who lived in remote/inner/regional areas had 18% higher risk of using HACC than those who lived in major cities (Table 5). Being widowed (RR = 1.08, 95%CI = 1.03–1.14) and having difficulty some/all of the time in managing income (RR = 1.17, 95%CI = 1.10–1.23) were associated with an increased risk of using HACC compared with their respective counterparts. Furthermore, those who received Veterans' Affairs coverage were 36% less likely to use HACC than those who did not receive such coverage ($P < 0.01$).

Health-related need factors

The median physical and social functioning scores on the SF-36 health-related quality of life scale differed by the three broad HACC groups ($P < 0.01$). For example, the respective scores for basic HACC users were '63 and 88', '50 and 75' for moderate- to high-level HACC users, and '70 and 100' for HACC non-users were 70 and 100 (Table 4). Consequently, an increased proportion of women who belonged to basic HACC and moderate- to high-level HACC (compared with HACC non-users) had physical, social, and mental health scores below the cut-off points (≤ 40, ≤ 52, and ≤ 52, respectively). The proportions of women who had chronic conditions were higher among both basic HACC and moderate- to high-level HACC users, than HACC non-user ($P < 0.01$).

Health-related need factors were significantly associated with the use of HACC, after controlling for demographic factors and counting death as a competing event (Table 5). Women diagnosed with chronic conditions (e.g., heart problems, diabetes, asthma, arthritis) had an increased risk of using HACC than their respective counterparts. Women who reported lower scores for physical, social, and mental functioning on the SF-36 health-realted quality of life scale had 54%, 53%, and 33% increased risk of using HACC services,

Table 2 Number of HACC services used by women in the distinct clusters across some points over the period 2001–2011

Number of services used	Clusters						All HACC clients 7747
	Basic HACC ($n=4173$)	Basic domestic ($n=1280$)	Home meal ($n=398$)	Complex nursing care ($n=168$)	Complex domestic ($n=914$)	Complex transport ($n=814$)	
1–2 services (%)	51	15	8	3	5	5	32
3–4 services (%)	26	23	15	19	10	10	21
5–6 services (%)	12	23	17	14	13	14	15
7–8 services (%)	6	18	15	16	18	16	11
9–10 services (%)	3	12	21	10	21	18	9
>10 services (%)	1	9	24	38	33	38	12

Clusters were named based on the proportion of women using services and their volume of use in the distinct cluster. For example, a lower proportion of women in the basic HACC cluster used different services and their volume of service use was also lower than all other clusters

Table 3 Distribution of baseline predisposing and enabling factors by the pattern of HACC use across at some points over the period 2001–2011 (n = 11,133)

Predisposing and enabling factors[a]	HACC non-user (n = 3386)	Basic HACC (n = 4173)	Moderate- to high-level HACC					
			Basic domestic (n = 1280)	Home meal (n = 398)	Complex domestic (n = 914)	Complex nursing (n = 168)	Complex transport (n = 814)	Overall (n = 3574)
Area of residence								
Major cities	49	42	39	38	39	36	38	38
Remote/inner/regional	51	58	62	63	63	64	62	62
Country of birth								
Australia	76	78	75	83	74	77	71	76
Other country	24	22	25	17	26	23	30	24
Highest qualification								
No formal	33	33	33	37	32	36	38	35
School certificate	39	41	39	35	35	36	37	36
High school/trade/diploma/ university	28	26	28	28	33	27	25	28
Marital status								
Married/de facto	54	52	48	49	47	48	44	47
Widowed/divorced	46	48	52	51	53	52	56	53
Living arrangements								
Live alone	41	43	49	51	51	45	54	50
With partner/spouse	47	48	43	43	43	41	38	41
With others[b]	12	9	8	6	6	14	8	8
Managing income								
Easy	26	23	18	25	15	17	20	19
Not too bad	53	51	49	50	50	49	51	50
Difficult at some/all the time	22	26	32	25	36	34	29	31
Veterans' Affairs coverage								
No	73	75	88	77	89	86	81	85
Yes	27	25	12	23	12	14	19	15

All figures are in percentage

[a]Most factors were measured in Survey 3, except for country of birth and highest qualification, which were asked in Survey 1. Data from adjacent surveys (Survey 2 and Survey 4) were used to fill in missing values

[b]Live with own children/other family members/non-family members

Discussion

The cluster analysis identified six distinct groups of HACC clients based on their volume/number of services used from 2001 to 2011. Statistical techniques may not always provide a definite number of meaningful clusters when

than those who had higher scores in their respective domains ($P < 0.01$). Furthermore, women who reported poor/fair self-rated health had 56% increased risk of using HACC than those who reported good/very good/excellent self-rated health ($P < 0.01$).

units with distinct characteristics group together (Sugar et al. 2004). However, we were able to clearly delineate (by volume, number, and type) distinct patterns of service use among HACC users. Over the 11 years of the study, the majority of women used few HACC services and typically with a low volume. In contrast, approximately one-fourth of women used complex patterns of care with high volume and number of services. More than one-third of women in the complex groups used 10 or more service types, indicating their multifaceted care needs. However, participants may not have concurrently used the entire range of services over the study period.

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Table 4 Distribution of health-related need factors by the pattern of HACC use across some points from 2001 to 2011 ($n = 11,133$)

Health characteristics	Not used HACC ($n = 3386$)	Basic HACC ($n = 4173$)	Moderate- to high-level HACC					
			Basic domestic ($n = 1280$)	Home meal ($n = 398$)	Complex domestic ($n = 914$)	Complex nursing care ($n = 168$)	Complex transport ($n = 814$)	Overall ($n = 3574$)
SF-36 physical functioning								
Median score	70	63	50	50	50	50	55	50
1st and 3rd quartiles	45–85	36–80	25–75	25–70	30–70	20–75	35–78	28–75
% of women ≤ 40	29	29	40	42	38	44	35	39
SF-36 social functioning								
Median score	100	88	75	75	75	62	88	75
1st and 3rd quartiles	75–100	63–100	50–100	50–100	50–100	38–100	50–100	50–100
% of women ≤ 52	16	21	30	32	25	36	26	28
SF-36 mental health								
Median score	84	84	80	80	80	80	80	80
1st and 3rd quartiles	72–92	24–94	68–90	68–89	68–88	64–94	64–88	68–88
% of women ≤ 52	7	9	10	10	10	12	13	11
Chronic conditions								
Heart problem (%)	16	21	23	24	24	24	24	24
Arthritis (%)	44	50	57	57	59	56	55	57
Diabetes (%)	9	10	11	15	12	16	13	12
Asthma (%)	11	15	19	18	15	19	13	17
Falls with injury (%)	12	13	15	17	15	15	16	15
Poor or fair self-rated health (%)	22	29	34	37	33	42	1	34

All health indicators were measured at Survey 3 in 2002. Missing values were filled-in if available in the adjacent survey (Survey 2 and Survey 3)

Six clusters were further divided into two broad categories: basic HACC and moderate- to high-level HACC. The latter category included five clusters, where women in the basic domestic group mostly used domestic assistance and a moderate volume of other HACC services, and women in the remaining four clusters were mostly high-level HACC users with complex service use pattern

Researchers in another Australian study found that approximately three-fourths of clients used a small number, but a wide range of services (Kendig et al. 2012). In their study, only 8% of people used complex patterns of services. Their findings were consistent with other studies in Australia and the United States, suggesting that few older people received an intensive amount of community-based health and social care services (Australian Institute of Health and Welfare 2007; Choi et al. 2006; Kendig et al. 2012). The variation with the current analysis was attributed to participants' age, gender, and study period. For example, the former Australian study focused on both men and women from the 45 and Up Study, and only considered a short period (2006–2008). In contrast, our study focused on women aged 75 to 90 years and identified a greater proportion of women who had complex patterns of HACC use. This is consistent with the literature, suggesting that

people in their eighties are more likely to experience multiple morbidities/disabilities and to be increasingly dependent on formal care services (Austad 2009; Stones and Gullifer 2016).

We observed that living in inner/regional/remote areas or alone or having difficulty in managing income were associated with an increased risk of moderate or complex patterns of HACC use. Our findings are in agreement with another study observing that HACC use was associated with living in a remote/regional area, not having a partner, having a lower household income and not having paid work (Jorm et al. 2010). Greater use of HACC services in remote/regional areas reflects a limited access to residential aged care in those areas. Women who had financial difficulties were less likely to use high-cost residential aged care, but instead were more dependent on low-cost HACC services. In some cases, women may not have used services provided

Table 5 Hazard ratios (HR) and 95% confidence intervals (CI) for baseline predisposing, enabling, and need factors

Covariates	Unadjusted models		Adjusted models	
	HR	95% CI	HR	95% CI
Area of residence				
Major cities	1.00	Referent	1.00	Referent
Remote/inner/regional	1.18	1.13–1.24	1.18	1.13–1.24
Country of birth				
Australia	1.00	Referent	–	–
Other countries	1.02	0.96–1.07	–	–
Marital status				
Married/de facto	1.00	Referent	1.00	Referent
Widowed/divorced/separated/never married	1.05	1.00–1.09	1.08	1.03–1.14
Managing income				
Easy/not too bad	1.00	Referent	1.00	Referent
Difficult some/all time	1.24	1.18–1.31	1.17	1.10–1.23
Live with				
Partner/other[b]	1.00	Referent	–	–
Alone	0.96	0.91–1.01	–	–
Veterans' Affairs coverage				
No	1.00	Referent	1.00	Referent
Yes	0.65	0.61–0.69	0.64	0.60–0.68
Heart problems				
No	1.00	Referent	1.00	Referent
Yes	1.29	1.21–1.37	1.25	1.18–1.33
Arthritis				
No	1.00	Referent	1.00	Referent
Yes	1.16	1.10-1.21	1.14	1.09-1.20
Diabetes				
No	1.00	Referent	1.00	Referent
Yes	1.32	1.21–1.42	1.28	1.18–1.39
Asthma				
No	1.00	Referent	1.00	Referent
Yes	1.24	1.15–1.33	1.19	1.11–1.28
Falls with injury				
No	1.00	Referent	1.00	Referent
Yes	1.11	1.03–1.19	1.05	0.97–1.13
Self-rated health				
Good to excellent	1.00	Referent	1.00	Referent
Poor or fair	1.59	1.51–1.69	1.56[a]	1.48–1.65
SF-36 physical functioning				
Score > 40	1.00	Referent	1.00	Referent
Score ≤ 40	1.54	1.46–1.62	1.54[a]	1.46–1.63
SF-36 social functioning				
Score > 52	1.00	Referent	1.00	Referent
Score ≤ 52	1.56	1.47–1.66	1.53[a]	1.44–1.62
SF-36 mental health				
Score > 52	1.00	Referent	1.00	Referent
Score ≤ 52	1.36	1.25–1.49	1.33[a]	1.21–1.45

[a]Adjusted for demographic variables

[b]Live with own children/other family members/non-family members

by HACC if they had overlapping coverage under the Veterans' Home Care scheme (Australian Institute of Health and Welfare 2008b).

Our findings illustrate that health-related need factors among older women are associated with different patterns of HACC use. For example, comorbid conditions were associated with poor physical functioning and disability, which may have contributed to greater aged care needs. Lower physical functioning scores also were predictive of the need for physical care support. These results are consistent with other studies that report greater HACC use among older people with lower physical functioning, poorer self-rated health, and having chronic conditions (Jorm et al. 2010; Rochat et al. 2010).

For example, low physical functioning scores (< 40) have been associated with fear of falls and an increased risk of using age care services (Cumming et al. 2000). Below this score, women often have difficulty performing vigorous activities such as walking one-kilometre, climbing stairs, having lifting/carrying. Furthermore, approximately one-third of women have difficulty walking 100 metres and 10% will require assistance with dressing and bathing (Hubbard et al. 2017). These findings have important implications for improving service delivery, such as targeting a group of women with specific needs. Future research is needed to better understand the transitions of older women between different levels of service use over time, and whether they receive services in an appropriate and timely manner.

An important strength of our study was the use of a large longitudinal survey of older women in Australia, which was linked with administrative aged care data sets. However, our findings must be considered in light of a few limitations. For example, we focused only on women who generally receive formal support in the community aged care setting for a longer time than men, with the latter entering permanent RAC at an earlier time point (Australian Institute of Health and Welfare 2018). Additionally, we were unable to establish whether HACC services were sufficient to fully meet the needs of recipients and if such services were provided in a timely fashion. Closer observation of assessed and met needs would be required to make this judgement. Our study also did not consider changes in service use over time in accordance with their evolving care needs.

Conclusions

In the current study, we observed significant diversity in the patterns of HACC use among older Australian women, according to their demographic and health characteristics.

Our findings highlight that many older women can remain living at home independently, requiring only a low-level use of a few basic community care services. However, approximately one-fourth of service users have complex care needs requiring a greater use of multiple HACC services. Finally, our study provides a baseline against which recent reforms and structural changes in community care services can be assessed.

Compliance with ethical standards

Conflict of interest The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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CHAPTER 5: Latent Patterns of Aged Care Use Over Time

Peer Reviewed Paper

Rahman, M., Efird, J. T., & Byles, J. E.)2019(. Patterns of aged care use among older Australian women: A prospective cohort study using linked data. *Archives of Gerontology and Geriatrics*, 81, 39-47.

Key Findings

- Four different patterns of aged care use across later life were identified, with wide variation in terms of timing of entry to aged care, type and combination of service use, and mortality patterns.

- Approximately 41% of women belonged to a group that did not use any aged care services (except few basic community care services) until age 85-90.

- Around 25% of women had used community care (basic or complex level) for a long period and only11% had a greater risk of using RAC, with all entering RAC by age 82-87 and the majority remaining in RAC for at least three years.

- Another 25% of women had earlier mortality, with all dying by their mid 80s. Many had records of using HACC and/or RAC in the final years before death.

5.1 Introduction

In Chapter 4, we identified risk factors for HACC use and assessed the patterns of HACC use based on the volume of service use throughout the study period. However, over the course of later life older Australians use different types of aged care services from different parts of the aged care system, according to changes in their needs and other factors that might predispose them to needing care or enabling access to services. While most people start aged care by first using HACC, a substantial proportion transition to RAC when their care needs are no longer be fulfilled by HACC or other community services including CACP. Use of different types/levels of aged care is significantly increased in the last few years before death. Current evidence regarding the patterns of service use reveals mostly cross-sectional observed patterns. This study aimed to identify, define and examine the latent patterns of different types of aged care service use across later life. In addition to levels of HACC use (basic HACC and moderate to high-level HACC; observed in the previous chapter) and RAC use, the study also included two other levels including 'non-user of aged care' and 'death' as separate categories to depict the entry and exit patterns of trajectories of aged care use throughout later life.

5.2 Peer Reviewed Published Paper

Details about the analytical methods and findings of this sub-study have been published as a peer reviewed paper in the *Acrhives of Gerontology and Geriatrics* journal, and the final published version is presented in this chapter. The actual paper can be assessed at: https://www.sciencedirect.com/science/article/abs/pii/S0167494318302188

Patterns of aged care use among older Australian women: A prospective cohort study using linked data

Mijanur Rahman[a,b,c,*], Jimmy T. Efird[a,b], Julie E. Byles[a,b]

[a] Priority Research Centre for Generational Health and Ageing, University of Newcastle, Australia
[b] Centre for Clinical Epidemiology and Biostatistics, University of Newcastle, Australia
[c] Department of Statistics, Comilla University, Bangladesh

ABSTRACT

Background: Women live longer than men and have an increased need for long-term care. The objective of this study was to identify patterns of aged care use among older Australian women and to examine how these patterns were associated with their demographic and health-related characteristics.

Methods: The sample consisted of 8768 women from the 1921–1926 birth cohort of the Australian Longitudinal Study on Women's Health (ALSWH), who had survived to age 75-80 years. ALSWH survey and linked administrative aged care and death datasets from 2001 to 2011 were utilized. Patterns of aged care use were identified using a repeated measure latent class analysis.

Results: We identified four patterns of aged care use over time, differentiated by timing of service onset, types of service use and time of death. Approximately 41% of the sample were non-users or using basic home and community care (HACC), while 24% were at high risk of using moderate to high-level HACC/community aged care package (CACP). Only 11% had a greater risk of using residential aged care (RAC) over time. Being widowed, residing in remote/regional areas, having difficulty in managing income, having a chronic condition, reporting poor/fair self-rated health, and lower SF-36 quality of life scores were associated with an increased odds of being a member of the following classes: 1) moderate to high-level HACC/CACP, 2) increasing RAC, and 3) early mortality, compared with the non-user class.

Conclusions: Distinct patterns of aged care use were identified. These results will facilitate future capacity planning for aged care systems in Australia.

1. Introduction

The demand for formal long-term care among older people (known as aged care in Australia) has been increasing in recent years. This is attributable to increasing longevity and age-related chronic conditions (Francesca, Ana, Jérôme, & Frits, 2011; WHO, 2015; Wouterse, Huisman, Meijboom, Deeg, & Polder, 2015). While most people in their sixties or seventies continue to live independently, they are likely to become frail and experience multiple morbidities and disabilities in their eighties (Austad, 2009; Stones & Gullifer, 2016). This group is particularly dependent on care in the community/residential setting. However, there is an increasing gap between the number of very old people (aged 85 and over) needing care and the availability of informal caregivers (WHO, 2015).

The proportion of very old people in Australia is ~2% of the population. This number is projected to increase to ~5% by 2050 (Australian Bureau of Statistics, 2016). Aged care use is particularly prevalent in the last few years before death. For example, among those over 65 years of age who died between 2010–2011, approximately 80% had used one or more aged care services within the eight years prior to their death. Over three-quarters entered the aged care system by first using community care services (Joenpera, Van Der Zwan, Karmel, & Cooper-Stanbury, 2016).

Most Australians aspire to stay connected with their families and communities as they grow older. Having autonomy and control over their aged care, and how and where they live remain important for this group (Productivity Commission, 2011). Overall, older Australians are a diverse group in terms of socio-demographic, cultural, and linguistic background. There exists a wide variation in their expectations and preferences of care choices (Hughes, 2011) (Australian Institute of

* Corresponding author at: Priority Research Centre for Generational Health and Ageing, School of Medicine and Public Health, The University of Newcastle, Hunter Medical Research Institute, West Wing, Level 4, Lot 1 Kookaburra Circuit, New Lambton Heights, NSW, 2305, Australia.
E-mail addresses: MdMijanur.Rahman@uon.edu.au (M. Rahman), jimmy.efird@newcastle.edu.au (J.T. Efird), julie.byles@newcastle.edu.au (J.E. Byles).

Health and Welfare (AIHW) (2012)). Understanding patterns of aged care use across later life and identifying influencing factors associated with different patterns of service use are critical for better planning and delivery of aged care services.

The vulnerability of older people with respect to demographic predisposing and enabling factors (e.g., higher age, being female and widowed, living alone, lower socio-economic status) are associated with an increased odds of using community aged care (Alkema, Reyes, & Wilber, 2006; Jorm, Walter, Lujic, Byles, & Kendig, 2010; Lafortune, Beland, Bergman, & Ankri, 2009). However, higher education has been associated with both increased (Steinbeisser, Grill, Holle, Peters, & Seidl, 2018; Wee et al., 2014) and decreased odds of utilization of long-term aged care (Fu, Guo, Bai, & Chui, 2017; Van der Heyden, Demarest, Tafforeau, & Van Oyen, 2003). Health-related needs including chronic conditions (e.g., cardiovascular diseases, diabetes), physical functioning and activities of daily living are associated with utilization of community-based aged care (Jorm et al., 2010; Rochat et al., 2010). Furthermore, various conditions (e.g., dementia, cerebrovascular disease, cardiovascular disorder, diabetes) have been associated with an increased risk of entering residential aged care (Nihtilä et al., 2008; Rosemary, Diane, Phil, Yvonne, & Stephen, 2012; Runge, Gilham, & Peut, 2009).

The current study implemented the Andersen's Behavioral Model (BM) to identify factors associated with different patterns of aged care use (Andersen & Newman, 1973). This model often has been applied to identify determinants of long-term care use in later life (Chen & Berkowitz, 2012; Slobbe, Wong, Verheij, van Oers, & Polder, 2017; Steinbeisser et al., 2018). The model categorizes the individual/societal characteristics into three groups: predisposing factors (age, widowed, and education), enabling factors (income, living arrangements, and area of residence), and need factors (physical, psychological and functional health status including illness and disability). In several recent studies, most of these factors have been found to be predictors of long-term care use in later life (Fu et al., 2017; Steinbeisser et al., 2018).

Older women are more likely to use aged care as they live longer and have a shorter disability-free life than men (Laditka & Laditka, 2001; Murtaugh, Kemper, & Spillman, 1990). In general, women are more likely to report a greater degree of disability (in particular, difficulties with instrumental activities of daily living) originating from health conditions in later life (Murtagh & Hubert, 2004). Furthermore, older women are more likely than men to live alone and without a spouse, resulting in an increased need for aged care (McCann, Donnelly, & O'Reilly, 2012). Living alone is associated with an increased risk of depending on formal long-term care; this is attributed to a lack of informal care support (Slobbe et al., 2017; Steinbeisser et al., 2018).

More than two-thirds of clients receiving aged care in Australia are women. However, limited evidence exists regarding the characteristics that influence their transition from supportive care in the community to more complex residential aged care over their lifespan. The objective of the current study was to identify patterns of formal aged care use among older women in Australia and to examine how socio-demographic (predisposing and enabling) and health-related need factors were associated with these patterns.

2. Methods

2.1. Data

Data for this study were from the 1921–1926 birth cohort of the Australian Longitudinal Study of Women's Health (ALSWH) and linked aged care and death data collected from 2001 to 2011. The ALSWH is a national population-based health study, involving almost 57,000 Australian women across four representative cohorts (Dobson et al., 2015; Loxton et al., 2015). In brief, participants were randomly sampled from the Medicare Australia database (the national universal health insurance database) with oversampling of women from remote

and rural areas (twice as many compared with those living in urban areas) (Brown et al., 1999). In 1996, 12,432 women born between 1921–1926 (then aged 70–75 years) completed a postal questionnaire. Women were surveyed every three years until 2011, and on a six-monthly rolling basis thereafter. As records of most aged care services (including Home and Community Care (HACC), the largest care type in terms of the number of clients) have been compiled from 2001, the current study included 8768 women. This excluded 847 who died before 2001, 340 who opted out of linkage of their aged care information, and 2477 who had Veterans' Affairs coverage and may have used Veteran's Home Care. The average age of women included in the sample and those excluded was similar (~78). However, compared with those who were excluded, the sample over represented women from inner/outer/remote areas (43% vs. 38%), and those born overseas (26% vs 10%), and underrepresented those who were widowed (43% vs. 63%).

The aged care administrative datasets came from two sources: a) HACC Minimum Data Sets (MDS) (available from 2001), and b) program administrative data for residential aged care (RAC) and community aged care package programs (CACP). The Australian Government maintained this database for the purpose of paying subsidies to service providers of RAC and CACP. Death records were obtained from the Australian National Death Index. The HACC MDS provided information on the quarterly use of HACC (28 available service types) for each client. Survey data for all ALSWH participants were linked with administrative aged care data and death records with approval from the Australian Government Department of Health (DOH). Data linking was performed by the Australian Institute of Health and Welfare (AIHW) using a probabilistic linkage algorithm (Karmel et al., 2010; National Statistical Services, 2017; Zinn & Havlicek, 2014). The resulting dataset consisted of unique anonymous records.

2.2. Measures

2.2.1. Age care use

The linked aged care datasets provided detailed information on aged care use including service types, start date, end date, and date of death from 2001 onward (Department of Health & Ageing, 2006). Using this information, our study determined the status of each woman in each year in terms of service use across 11 time points from 2001 to 2011, by five categories: 1) non-user, 2) basic HACC, 3) moderate to high-level HACC/CACP, 4) RAC, and 5) death. In the current study, CACP users were merged together with the Moderate to high-level HACC group. A woman who used multiple services in a year was coded according to the service which she used most frequently. In case of death, the last service category for that year was used, and in subsequent years, she was coded as deceased. The status of women in each year according to their aged care use was the indicator or observed variable in this study.

2.2.2. ALSWH survey items

A range of socio-demographic (predisposing and enabling) and health-related need factors were included in accordance with the Anderson's Behavioral Model for explaining patterns of health service use (Andersen & Newman, 1973). With the exception of the highest educational qualification (measured only in Survey 1 (1996)), variables were measured at Survey 3 (in 2002), which was the nearest ALSWH survey point to the baseline year (2001). Data from adjacent surveys (Survey 2 in 1999 and Survey 4 in 2005) were used to fill-in missing values (< 5%), rather than using model-based imputation techniques. Detailed information about the impact of attrition on the representativeness of the cohort has been published elsewhere (Brilleman, Pachana, & Dobson, 2010).

Area of residence was categorized as 'Major cities' and 'Inner/outer/remote areas' based on the Accessibility/Remoteness Index of Australia Plus. This index measures distance to services, including access to tertiary teaching hospitals (Glover & Tennant, 2003). There were a small

Table 1

Distribution of baseline demographic predisposing and enabling factors by latent patterns of aged care service use from 2001 to 2011 (n = 8768).

Demographic factors (predisposing and enabling)	Mostly non-user (n = 3626) %	Mostly high-level HACC/CACP (n = 2117) %	Increasing RAC (n = 927) %	Early mortality (n = 2098) %	P-value[a]
Area of residence					
Major cities	48	40	43	41	< 0.001
Inner/ outer/remote areas	52	60	57	59	
Country of birth Australia	69	68	72	70	
Other country	25	26	21	23	< 0.001
Missing	5	6	8	8	
Highest qualification					
No formal/school certificate	67	67	72	69	
Higher secondary/University/other[c]	28	28	22	24	< 0.001
Missing	5	5	5	7	
Widowed					
No[b]	62	51	51	56	< 0.001
Yes	38	49	49	44	
Difficulty in managing income					
Easy /not too bad	75	65	67	69	
Difficult some / all the time	24	35	32	29	< 0.001
Missing	1	< 1	1	< 2	
Living arrangement					
Live alone	38	52	51	42	
Live with partner/others	62	47	48	56	< 0.001
Missing	1	1	1	2	
Supporting sources					
Do people help you to do odd jobs?					
Yes	39	54	49	47	
No	18	17	13	13	< 0.001
I do not need help	27	15	16	13	
Do people give you information/advice?					
Yes	35	39	41	37	
No	26	27	20	20	< 0.001
I do not need advice	25	22	17	15	
Do people help you if you call upon them to do so unexpectedly? Yes	63	69	62	58	< 0.001
No	4	5	4	5	
I do not need help	17	12	11	10	< 0.001
Do people help you generally? Yes	64	74	68	63	
No	4	4	2	4	< 0.001
I do not need help	16	10	8	7	
Providing care/work for others					
To grandchildren/other people's children					
Yes (daily/weekly/occasionally)	37	31	23	22	< 0.001
No	48	57	56	51	
To any other person? Yes	24	23	17	15	< 0.001
No	64	68	67	66	
Volunteer work for the community?					
Yes (every day/week/month)	44	44	36	38	< 0.001
No	39	41	40	32	

Note 1: Percentage of missing category for the variables under 'Supporting sources' and 'Providing care/work for others' are not mentioned but can be computed by subtracting the column sum of each variable from 100.

[a] Chi-square test (not adjusted for multiplicity).

[b] Included married, de facto, separated, divorced and never married.

[c] Included trade or apprentice, and certificate or diploma.

proportion of women in the outer and remote categories, and so these categories were combined with the inner region category. The categorization of other socio-demographic (predisposing and enabling) factors are shown in Table 1.

Health-related need factors included being diagnosed with physical conditions, falls with injury in the past 12 months, self-rated health, and the physical, social and mental functioning scores of the health-related quality of life profile (Table 2). The scores were determined from the Medical Outcomes Study Questionnaire Short Form-36 (SF-36) and raw scores were linearly transformed to produce subscale scores ranging from 0 to 100 (with higher scores indicating better health).

2.3. Statistical analyses

HACC users were categorized into basic HACC and moderate to high-level HACC using a k-median cluster analysis based on the volume and number of services used from 2001 to 2011. Clusters were

identified in a two-part process by first minimizing the Euclidian distance within a cluster and then maximizing the differences between clusters. Participants were assigned to mutually exclusive clusters based on their closeness (or similarity) and volume of service use. The Calinski/Harabasz Pseudo F statistic (PFS) value was used to determine the number of clusters (Boone, 2011).

Repeated measure latent class analysis (RMLCA) was conducted to identify latent patterns of aged care use over the study period. RMLCA is a technique for analyzing longitudinal data by means of latent class analysis (LCA) and is useful for identifying time-dependent patterns of different sub-groups/populations, without imposing any restrictions. This approach works best when a small number of indicator variables are measured three or more times (Collins & Lanza, 2010). LCA has been used for a number of time-varying outcomes including health behaviors and care use (Dolja-Gore, Harris, Kendig, & Byles, 2017; S. T. Lanza & Collins, 2006; McCarthy, Ebssa, Witkiewitz, & Shiffman, 2015). As previously indicated, the outcome variable included five mutually

Table 2

Distribution of baseline health-related need factors by latent patterns of aged care use from 2001 to 2011 (n = 8768).

Health-related need factors	Mostly non-user (3626)	Mostly high-level HACC/CACP (2117)	Increasing RAC (927)	Early mortality (2098)	P-value[a]
Physical functioning	75.0	55.0	50.0	50	< 0.001
Median score	(55.0-87.5)	(35.0-75.0)	(25.0-75.0)	(20.0-75.0)	
(1st and 3rd quartile)					
Social functioning	100	87.5	75.0	75.0	< 0.001
Median score	(75.0-100)	(62.5-100)	(50.0-100)	(50.0-100)	
(1st and 3rd quartile)					
Mental health index					
Median score	84.0	80.0	80.0	80.0	< 0.001
(1st and 3rd quartile)	(72.0-92.0)	(68.0-88.0)	(64.0-88.0)	(65.0-88.0)	
Chronic conditions (%)					
None	16.7	10.1	11.6	11.8	< 0.001
Heart problems	14.8	22.6	22.5	26.3	< 0.001
Arthritis	46.0	57.6	50.9	49.3	< 0.001
Diabetes	7.1	10.6	12.7	14.3	< 0.001
Asthma	11.0	15.5	13.0	19.0	< 0.001
Leaking urine in the last 12 months (%)					
Sometimes/often	16.4	21.7	22.5	19.5	< 0.001
Had falls that caused injury (%)					
Yes	11.4	14.9	16.1	16.3	< 0.001
Self-rated health (%)					
Poor or fair	17.2	30.4	38.2	45.4	< 0.001
Hospitalized in the last 12 months (%)					
Yes	23.3	29.6	34.1	39.9	< 0.001
Regular help with daily tasks (%)					
Yes	4.6	13.6	23.4	28.1	< 0.001
Difficulty with vision (%)					
Yes	12.9	20.2	23.9	23.7	< 0.001
Difficulty with hearing (%)					
Yes	11.5	14.7	15.4	13.5	< 0.001
Difficulty with bathing / dressing (%)					
Yes	5.8	13.3	19.7	23.5	< 0.001

[a] Kruskal-Wallis test for continuous variables and Chi-square test for categorical variables (not adjusted for multiplicity).

exclusive catergories for aged care use.

Parameters were estimated from the models using the maximum likelihood method (Collins & Lanza, 2010). A model with an optimal number of classes (from 2 to 7) was determined by examining various fitting criteria (Akaike Information Criterion (AIC), Bayesian Information Criterion (BIC), likelihood-ratio G^2 diagnostic, and entropy) (Celeux & Soromenho, 1996; Nylund, Asparouhov, & Muthén, 2007). The conditional probabilities of responding to an item given membership within a latent class were graphically presented for interpretability of each of the resultant latent classes. These latent classes were then used as a response variable for further analyses. Participants were classified into mutually exclusive latent classes based on their maximum posterior probability of belonging to a particular latent class.

The characteristics of women assigned to the different classes were then explored using Chi-square or Kruskal-Wallis procedures to assess their association with latent classes. Multinomial logistic regression was used to estimate odds ratios (OR) and 95% confidence intervals (CI) for membership of different latent classes, according to their baseline characteristics. Participants who had complete information with regard to covariates were included in the model. Variables (except self-rated health and SF-36 physical, mental and social functioning scores) were simultaneously entered into the model to adjust for the independent effects of demographic (predisposing and enabling) and health-related need factors. Given the known associations with other health indicators, self-rated health, and physical, social and mental functioning scores were entered into separate models, adjusting for demographic variables. Analyses were performed using SAS 9.4 (Cary, N.C.) utilizing the LCA procedure. (S. Lanza, Dziak, Huang, Wagner, & Collins, 2013).

3. Results

Six distinct clusters were identified, with more than half of HACC clients belonging to the Basic HACC cluster. These women used a low volume and number of services such as domestic assistance and transportation. The remaining five clusters (Basic domestic, Home meal, Complex domestic, Complex transport, and Complex nursing) were categorized as Moderate to high-level HACC users, considering their volume and complex pattern of service use.

The demand for aged care increased with age, particularly in the last few years before death. Of the 8768 women in 2001 (aged 75–80), 18% used aged care, mostly basic or moderate to high-level HACC/CACP services (5% and 12% respectively) (Fig. 1). In contrast, among women who survived to 2011 (aged 85–90), ~65% used aged care. This included 15% using basic HACC, 29% moderate to high-level HACC/CACP, and 21% RAC. More than one-third of participants died during the study period, of whom 75% used one or more types of aged care, disproportionately near the time of death.

Six models were compared using 2–7 classes. Based on the fit indices and meaningfulness of the classes, a 4-class model was selected and interpreted (Supplementary Table 1). This model represented mutually exclusive patterns (classes), and distinguished women according to their level of aged care use over time. The average posterior probability
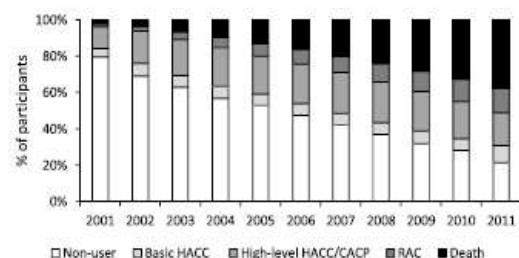

Fig. 1. Distribution of the sample by status of aged care use (indicator variable) during 2001–2011 (n = 8768 and death counted as cumulative).
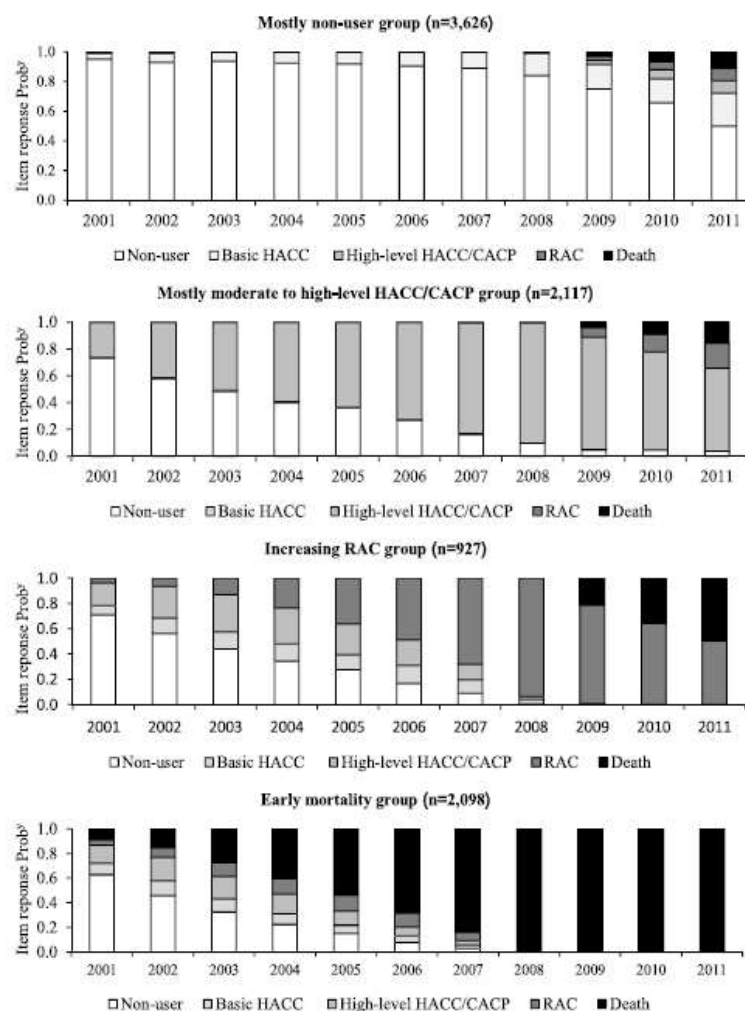
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Fig. 2. Latent patterns of aged care use from 2001 to 2011 (n = 8768).

for each of the 4 classes was ≥ 0.9, demonstrating that women were appropriately classified into latent classes (Collins & Lanza, 2010). Pathways were depicted for the latent classes illustrating how women used different types of aged care across later life (Fig. 2).

The first latent class included 41% of the sample who were categorized as 'mostly non-users'. These women had the highest probability of not using any aged care or a limited chance of using only basic HACC throughout the 11-year period. They also had the highest probability of surviving. However, even in this group, the use of aged care and the number of deaths increased over the last few years of the study when the women were aged 85 and over. The second class, constituting 24% of the sample, was classified as 'mostly moderate to high-level HACC/CACP' users. Most of the women in this class used moderate to high-level HACC/CACP. However, the probability of entering RAC increased in the last three years, with a corresponding rise in mortality.

Latent class 3 was the smallest group and included 927 women who were described as 'increasing RAC' users. These women had a greater chance of entering RAC as they aged, and many used basic HACC and moderate to high-level HACC/CACP over the first half of the study. In 2009, when most of the women were in RAC, their chance of dying rapidly increased and nearly half were deceased by the end of the study. The last latent class included 2098 women (24%) who were classified as the 'early mortality' class. These women had the highest probability of

dying. Approximately 15% died in the first two years, with a sharp increase in mortality over subsequent years. By 2008, all women in this class were deceased. Many had used different types of aged care before death.

The categories of all socio-demographic factors at baseline differed by latent class (Table 1). For example, a greater percentage of women in the non-user class resided in major cities, had difficulty in managing their income, lived with a partner/other family members, and provided care to grand children/other people's children relative to other classes (p < 0.001). Similarly, a higher percentage of women in the mostly moderate to high-level HACC/CACP class lived in inner/outer/remote areas, had difficulty in managing their income, lived alone, and received support services compared with other classes (p < 0.001).

All health-related need factors (depicted as quartile levels or descriptive categories) also differed by latent class (Table 2). For example, a greater percentage of women in the early mortality class had heart problems, asthma, and poor/fair self-reported health, while the highest median score for social functioning and mental health index were observed for women belonging to the non-user class.

Effect sizes for belonging to a particular latent class were differentially associated with demographic and health-related factors (Table 3). For example, increased odds of being in the mostly moderate to high-level HACC/CACP class was associated with living in inner/outer/

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Table 3

Odds ratios (OR) and 95% confidence intervals (CI) for membership of different latent classes on baseline predisposing, enabling and health-related need factors (n = 7617).

Covariates (reference group)	Mostly non-users OR (Ref.)	Mostly to high-level HACC/CACP users OR (95%CI)	Increasing RAC users OR (95%CI)	Early mortality group OR (95%CI)
Categorical variables				
Area of residence[†] (Major cities)				
Inner/outer/remote areas	1.0	1.3 (1.2-1.5)	1.2 (1.0-1.4)	1.3 (1.2-1.5)
Widowed[†] (No)				
Yes	1.0	1.6 (1.4-1.8)	1.6 (1.4-1.9)	1.3 (1.1-1.5)
Managing income[†] (Easy/not too bad)				
Difficult some/all of the time	1.0	1.5 (1.3-1.7)	1.3 (1.1-1.6)	1.1 (1.0-1.3)
Heart problems[†] (No)				
Yes	1.0	1.5 (1.3-1.8)	1.5 (1.3-1.9)	1.9 (1.6-2.2)
Arthritis[†] (No)				
Yes	1.0	1.5 (1.4-1.7)	1.2 (1.0-1.4)	1.1 (0.9-1.2)
Diabetes[†] (No)				
Yes	1.0	1.5 (1.2-1.8)	1.8 (1.4-2.2)	2.0 (1.7-2.4)
Asthma[†] (No)				
Yes	1.0	1.3 (1.1-1.6)	1.1 (0.9-1.4)	1.8 (1.5-2.1)
Had falls with injury[†] (No)				
Yes	1.0	1.3 (1.1-1.5)	1.4 (1.2-1.8)	1.4 (1.2-1.7)
Self-rated health[‡] (Good to excellent)				
Poor or fair	1.0	2.0 (1.8-2.3)[†]	2.9 (2.5-3.5)[†]	4.0 (3.5-4.6)[†]
Continuous variables				
Physical function score[‡]	1.0	0.981 (0.979-0.983)	0.976 (0.973-0.979)	0.974 (0.972-0.976)
Mental health score[‡]	1.0	0.986 (0.983-0.990)	0.974 (0.969-0.978)	0.979 (0.976-0.983)
Social functioning score[‡]	1.0	0.985 (0.983-0.988)	0.980 (0.977-0.983)	0.979 (0.976-0.981)

[†] Adjusted for area of residence, widowed, managing income, heart problems, arthritis, diabetes, asthma, and had falls with injury.
[‡] Adjusted for area of residence, widowed, and managing income.
Ref. = Reference class.

remote areas (OR = 1.3, 95%CI = 1.2–1.5), being widowed (OR = 1.6, 95%CI = 1.4–1.9), difficulty in managing income (OR = 1.5, 95%CI = 1.3–1.7), and having chronic conditions such as arthritis (OR = 1.5, 95%CI = 1.4–1.7). A 1-unit increase in SF-36 quality of life score in areas such as physical functioning was significantly associated with a 2% decreased odds (OR = 0.981, 95%CI = 0.979-0.983) of being included in the mostly moderate to high-level HACC/CACP class than the mostly non-user class. Furthermore, women with poor/fair self-rated health (OR = 2.0, 95%CI = 1.8–2.3) were more likely to be included in the mostly moderate to high-level HACC/CACP class than the mostly non-user class.

Women who were widowed (OR = 1.6, 95%CI = 1.4–1.9), had difficulty in managing income (OR = 1.3, 95%CI = 1.1–1.6), diagnosed with a chronic condition such as heart problems (OR = 1.5, 95%CI = 1.3–1.8), arthritis (OR = 1.2, 95%CI = 1.0–1.4), diabetes (OR = 1.8, 95%CI = 1.4–2.2), and had falls with injury (OR = 1.4, 95%CI = 1.2–1.8) were more likely to be a member of the increasing RAC than the mostly non-users class. A 1-unit increase in physical functioning, mental health, and social functioning scores were associated with a decreased odds (OR = 0.976, 95%CI = 0.973-0.979), (OR = 0.974, 95%CI = (0.969-0.978), (OR = 0.980, 95%CI = 0.977-0.981) of being a member of the increasing RAC vs. mostly non-users class.

Furthermore, a 1-unit increase in SF-36 quality of life score was associated with a decreased odds of being in the early mortality vs. the mostly non-user group. In terms of self-rated health, women who reported poor/fair self-rated health had an increased odds of being a member of the mostly moderate to high-level HACC/CACP (OR = 2.0, 95%CI = 1.8–2.3), increasing RAC (OR = 2.9, 95%CI = 2.5–3.5), and early mortality classes (OR = 4.0, 95%CI = 3.5–4.6) than the mostly non-user class.

4. Discussion

Our study identified patterns of aged care use among a nationally representative cohort of older Australian women over the period

2001–2011 (when the cohort was aged 75–80 to 85–90 years). One of the key findings is that a large proportion (41%) of the sample were not likely to use any services or used only entry-level (basic HACC) services. Approximately one quarter used moderate to high-level HACC/CACP, and a relatively smaller proportion (11%) used RAC (with many of the latter having previously used HACC/CACP). The estimated probability of using RAC across later life was higher than the cohort prevalence at any given time point. Previous research showed that at age 65, two out of three women need care at some point in their remaining life, mostly consisting of community care services. The majority of women do not enter RAC (Chomik & MacLennan, 2014; Productivity Commission, 2011).

The findings from the RMLCA suggest that there was a large variation among the women in terms of their patterns of service use across later life. Women differed with respect to timing of entry into different services, as well as the type and combination of services used. Their survival patterns also differed. The mostly non-user class accounted for over two-fifths of the sample and were the longest living group. These women were most likely to be non-users across the study period. However, with a rapid increase in both the probability of using services and mortality in the last few years, many women may have entered the aged care system at an older age (85 and over). This is when most people are increasingly dependent on some levels of aged care services (Reeve et al., 2018).

While the moderate to high-level HAC class also included long-living women, they also had the highest probability of consistently using community care services, in particular moderate to high-level HACC/CACP. Their chances of entering RAC increased in the last few years of the study, as they approached end of life. During this period, community care services were no longer able to adequately meet their increasing care needs. This is consistent with other research suggesting that long-term care begins with receiving care in the community followed by a combination of community care and respite RAC, before transitioning permanently to RAC (Australian Institute of Health & Welfare, 2017; Mehdizadeh, 2002). During the first half of the study, women in the increasing RAC class used multiple services. However,

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with increasing age they were more likely to exclusively use RAC, in agreement with the literature (Australian Institute of Health & Welfare, 2018b). Women in the early mortality class used different types of services in the last few years of life, but they had the lowest survival probability, with all being deceased by 2008. The nearer people were to death, the more likely they were to use aged care, in accordance with the findings of the AIHW study (Joenpera et al., 2016).

Our study observed that baseline sociodemographic predisposing and enabling factors were associated with membership of different latent patterns. Those who lived in inner/outer/remote areas, were widowed, had difficulty managing income, and lived alone were more likely to be a member either of the moderate to high-level HACC/CACP or increasing RAC or early mortality classes than the mostly non-user class. Researchers in another Australian study (based on the HACC database) demonstrated that the aforementioned characteristics were associated with an increased odds of using HACC services (Jorm et al., 2010). In a related study, having never married, living alone, and being socially vulnerable were associated with an increased risk of entering RAC (Kendig, Browning, Pedlow, Wells, & Thomas, 2010). The increased odds of older women living in inner/outer/remote areas reflect a lack of informal support (both from family members and community) as well as the availability of HACC/CACP services in these areas. Those who were widowed and lived alone were more likely to be frail and less likely to receive informal support, leaving them increasingly dependent on formal aged care services.

In terms of health-related need factors, we found that lower scores on the SF-36 quality of life quesnnaire, diagnosed with chronic conditions, falls with injury in the last 12 months, and reported poor/fair self-rated health were associated with an increased odds of membership in the following classes: early mortality, increasing RAC, and moderate to high-level HACC/CACP, compared with non-users. Individuals with the above mentioned health profile were found to be associated with an increased odds of HACC service use (Jorm et al., 2010). Poor physical functioning is a major driver of need for support with physical care. It also may be associated with comorbid conditions which contribute to poor survival. A lower SF-36 quality of life score (in particular physical functioning) was significantly associated with fear of falls and increased aged care admission (Cumming, Salkeld, Thomas, & Szonyi, 2000). In a US-based study, falls with injury were a significant risk factor of nursing home admission (Tinetti & Williams, 1997). Additionally, self-reported poor health status/disability was a significant predictor of nursing home admission and mortality (Guralnik et al., 1994; Weinberger et al., 1986). As reported in another study, patterns of aged care use varied widely according to different health conditions that affected their care needs (Rosemary et al., 2012). Those with musculoskeletal problems were more likely to use community care services and those with dementia or cerebrovascular disease were more likely to enter RAC. In our study, we found that those with arthritis were associated with having an increased odds of being a member of moderate to high-level HACC/CACP (OR = 1.5, 95%CI: 1.4–1.7) and increasing RAC (OR: 1.2, 95%CI: 1.0–1.4), but were not associated with being in the early mortality class. However, those diagnosed with asthma were observed to have an increased odds of belonging to the mostly moderate to high-level HACC/CACP and early mortality classes, compared with non-users. The latter finding is consistent with another study of this cohort that found women who had asthma had a 17% higher risk of death than those without asthma (Eftekhari, Forder, Majeed, & Byles, 2016).

Our study was strengthened by the use of linked data from a nationally representative sample and administrative aged care datasets. This provided a broad platform to analyze different patterns of aged care use over time. However, a few limitations should be noted. Oversampling from remote/regional areas may have introduced selection bias with respect to the care needs of older women in major cities vs. inner/outer/remote areas. Thus, other more representative samples may yield different results. Among women who used multiple services, their status in a particular year was determined based on the most frequently used service. Services that were used for a fewer number of days (such as respite RAC, or women who were admitted to RAC within a few days before death) may have been missed. Some women were excluded from the multivariable analyses because of missing covariate information, potentially biasing results. In particular, women with missing values had a greater risk of using aged care and subsequent early mortality.

The findings of our study are only representative of women, as men were not included in the ALSWH. Men tend to enter RAC earlier in life than women because the latter generally received support from other formal aged care programs such as HACC (Australian Institute of Health & Welfare, 2014). However, the average length of stay for women in RAC is 1.5 times higher than men, reflecting their longer lifespan (Australian Institute of Health & Welfare, 2018a). The study also did not include information on dementia or cognitive function. Dementia is an important determinant of RAC use, with a corresponding decrease in use of HACC. In a separate analysis, we found that 80% of women with dementia spent time in RAC in the two years prior to death (ALSWH, 2018). Our findings can motivate further study regarding the estimation of transition probabilities from one group to another and to identify influencing factors for each level of transition over time.

5. Conclusions

The first wave of baby boomers are now entering old age. Consequently, the number of individuals depending on aged care is projected to double in Australia over the next two decades (Australian Bureau of Statistics, 2016). Currently, there is a paucity of evidence as to how older people utilize different types of services, ranging from supportive care in the community to high-level care in residential settings (Productivity Commission, 2011). This study is a first step in identifying different patterns of aged care use and factors associated with each pattern. Women in the four patterns differed with respect to the timing of their entry into aged care, type and combination of service use, and their survival patterns. A relatively small proportion of women required RAC, following previous HACC/CACP use. By better understanding the differential care needs of older women, our findings will help guide policy-makers in their efforts to improve service delivery and to optimize future capacity planning in the aged care system.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.archger.2018.11.010.

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CHAPTER 6: Patterns of Home and Community Care Use and Residential Transition

Peer Reviewed Paper

Rahman, M. & Byles, J. E.)2019(. Older women's patterns of home and community care use and residential transition, in Press, *Maturiatus* Journal.

Key Findings

- 72% (n = 8062) of women in the cohort (n = 11,133 who survived to 2001) used HACC services between 2001 to 2014.

- 44% of HACC consumers (n = 8062) entered RAC by age up to 88-93 years, 33% continued to using HACC, and 23% died while in HACC over the study period.

- Delayed admission to RAC was associated with increased or complex patterns of HACC use, being overseas born, and living in a regional/remote area.

- Earlier admission to RAC was associated with living in a flat or retirement village, having lower scores in physical functioning scores, and having falls with injury.

6.1 Introduction

In the previous two sub-studies, we examined the patterns of HACC service use (current CHSP) as well as latent patterns of different types of aged care use throughout later life. The latent patterns observed in the previous study (Chapter 5) show that use of the different levels/types of aged care services by older women roughly progresses towards a patterns of higher levels of support over time (for example, begin with use of basic HACC followed by moderate to high-level HACC, RAC, and death). The Australian Institute of Health and Welfare (2017a) reports that nearly four out of five people who entered RAC also used HACC services previously. While reducing inappropriate admission to RAC is one the key aim of the HACC program, longitudinal research evidence on the service outcome of the HACC program is not available yet. The objective of this chapter was to examine whether the patterns of HACC use and person-based characteristics were associated with the time from first HACC use to subsequent admission to RAC over the period 2001 to 2014 when the women were aged from 75 to 93 years.

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6.2 Peer Reviewed Accepted Paper

Details about the study design, analytical methods, and findings of this study have accepted as a peer reviewed paper titled 'Older women's patterns of home and community care use and residential transition: An Australian cohort study' to the *Maturitas* journal. The manuscript is currently in Press, and the final accepted version is presented in this chapter.

Older women's patterns of home and community care use and residential transition: An Australian cohort study

Md Mijanur Rahman[a,b,c,*] **and Julie E**. **Byles,**[ab]

[a]Priority Research Centre for Generational Health and Ageing, University of Newcastle, Australia

[b]Centre for Clinical Epidemiology and Biostatistics, University of Newcastle, Australia

[c]Department of Statistics, Comilla University, Bangladesh

Address correspondence to: Md Mijanur Rahman

Priority Research Centre for Generational Health and Ageing, University of Newcastle,

Hunter Medical Research Institute)HMRI(,

1 Kookaburra Circuit, NSW–2305, Australia.

Email: MdMijanur.Rahman@uon.edu.au

Highlights:

- Majority of women used low to moderate community care services)74%(
- Increased community aged care use delayed admission to residential care
- Remote/regional women had lower risk of entering residential care than major cities
- Falls or low physical functioning or living in flat/retirement village increased the risk of admission to residential aged care.

ABSTRACT

Objective: To examine whether patterns of home and community care)HACC(use and person-based characteristics were associated with time to entering permanent residential aged care)RAC(.

Study design: A prospective cohort study. The sample consisted of 8062 participants of the Australian Longitudinal Study on Women's Health who used HACC between 2001-2014.

Mean outcome measures: Time from the first HACC use to entering permanent RAC. The median follow-up time was 63 months. Factors associated with time to entering RAC were identified using competing risk regression models.

Results: Of the 8062 participants, 60% belonged to the 'basic HACC' group which used few services minimally; 16% belonged to the 'moderate HACC' group, which predominantly used domestic assistance with moderate use of other services; and 24% belonged to the in 'complex HACC', which used many services frequently. Being a member of the complex HACC group was associated with a lower cumulative incidence of RAC than basic or moderate HACC)chances 15% versus 30% by the median observation period, $p<0.01$(. Living in a remote/outer region)sub-distributional hazard ratio)sdHR(= 0.83, 95%CI: 0.74 – 0.93(was associated with delayed admission to RAC. Meanwhile, earlier admission was associated with living in an apartment)sdHR = 1.29, 95%CI: 1.20 – 1.40(or a retirement village)sdHR = 1.54, 95%CI = 1.38 – 1.72(, having physical functioning score <40)sdHR = 1.16, 95%CI = 1.05 – 1.25(, and falls)sdHR = 1.15, 95%CI = 1.05 – 1.25(.

Conclusions: Our findings highlight the importance of providing more community care services, age-friendly housing, falls prevention and physical activity programs to reduce inappropriate admission to RAC.

Keywords: Community aged care; residential aged care; older women; linked data; competing risk analysis

Introduction

With the baby boom cohort)born between 1946-64(entering older age and the continued gain in life expectancy at age 65, the speed of ageing in Australia has recently accelerated (Kendig, McDonald, & Piggott, 2016). Particularly, the proportion of people aged 85 and over)the fastest growing age group(is projected to increase rapidly in the foreseeable future: from 2% in 2017 to ~ 5% by 2050)Australian Treasury, 2015(. Because of age-related disabling chronic-conditions and lack of informal support)including loss of spouse(, people in their 80s are increasingly dependent on formal aged care services)Austad, 2009(. Consequently, a growing number of older people will mean a greater demand for aged care. The number of Australians needing aged care is projected to increase from 1.3 million in 2018 to 3.5 million by 2050)Royal Commission into Aged Care Quality and Safety, 2019a). Despite considerable attention, Australia's ability to afford this increasing demand for aged care has been an issue of pressing national concern.

Australia's aged care system is predominantly government funded and regulated. Since the 1980s, there has been a considerable focus of government policy to increase the provision of aged care services in home/community settings)Jeon & Kendig, 2017(. The aim is to reduce inappropriate admission to high-cost residential aged care)RAC(facilities)which claim over two-thirds of total aged care expenditure(and to meet the preference of most Australians who wish to receive aged care at home. The system has been undergoing a significant reform following recommendations from the Productivity Commission (Australian Government Department of Health, 2012). Home and Community Care)HACC; now known as the Commonwealth Home Support Program)CHSP(is the largest aged care program in Australia which provides a range of entry-level care services to support older Australians living independently in their own home (Rahman et al., 2019). Of those who received aged care in

2017-18, around two-thirds)65%(used the CHSP, nearly a quarter)23%(entered RAC, and only 12% used home care packages)HCP(or transition care)Australian Institute of Health and Welfare, 2018d). Although most people continue to live in the community for a long period across later life, around two-fifths enter RAC when their care needs are no longer fulfilled by informal or formal community care services (Eckert, Morgan, & Swamy, 2004). Of those who entered permanent RAC in 2013-14, nearly four out of five used HACC services first)Australian Institute of Health and Welfare, 2017a).

Earlier studies have identified a number of risk factors of entering RAC, including older age, widowhood, living alone, low independence in activities in daily living)ADL(, living in a flat or retirement village, falls, and cognitive impairment)Cumming et al., 2000; Forder et al., 2017; Smith, Kokmen, & O'Brien, 2000(. Besides the individuals' factors, a number of US-based studies have reported that greater volume of home- and community-based care use are associated with a reduced risk of subsequent nursing home)NH(admission (Chen & Berkowitz, 2012; Greiner et al., 2014; Sands et al., 2012). A recent Australian study has demonstrated that each hour per week of HCP service use is associated with a 6% decreased risk of entering RAC)Jorgensen et al., 2018(. Although this study provides significant insights into service outcomes of HCP, the participants were from only one HCP provider in New South Wales and Canberra, and were studied for a relatively small observation period. Furthermore, previous separate studies on HACC and RAC have reported that living in remote/rural areas is associated with increased odds of HACC use (Rahman et al., 2019) but decreased risk of entering RAC)Forder et al., 2017(. Research is yet to explore whether high usage of HACC reduce the risk of entering RAC.

While the Australian governments policy focus is to extend aged care services in the community setting to reduce inappropriate admission to RAC, there is limited research to measure and monitor the impact of such services on older adults' outcomes. The aim of the

current study was to examine whether pattern of HACC use and person-based characteristics are associated with the cumulative incidence of RAC admission across later life. Based on earlier research, we hypothesize that high/complex use of HACC is associated with delayed transition to RAC (Chen & Berkowitz, 2012; Jorgensen et al., 2018; Rahman, Efird, & Byles, 2019a).

Methods

2.1 Data source

We utilized data from the 1921–26 birth cohort of the Australian Longitudinal Study on Women's Health)ALSWH(, linked aged care minimum datasets and the national death index between July 2001 and June 2014. ALSWH recruited the cohort in 1996 by randomly sampling from the Medicare Australia database)National Universal Health Insurance Database(, with women living in rural and remote areas sampled twice the population proportion to ensure sufficient power to detect important differences in health and use of services (Dobson et al., 2015). A total of 12,432 women completed the postal questionnaire at baseline. These women were surveyed every three years until 2011)e.g., Survey 2: 1999, Survey 3:2002(, and subsequently on a six–monthly rolling–basis. Detailed description about the ALSWH surveys have previously been published (Dobson et al., 2015).

The ALSWH survey data were linked with administrative aged care)e.g., RAC and HACC minimum data sets(, and the national death index with approval from the Australian Government Department of Health. Using a probabilistic algorithm based on full name and demographic details, the Australian Institute of Health and Welfare)AIHW(conducted the linking process. Furthermore, the current study was approved by the Human Research and Ethics Committee of the University of Newcastle.

The current study consisted of 8062 participants of the ALSWH older cohort who used HACC services for more than one month between July 2001 and June 2014 when they were aged from 75–80 to 88–93 years)Supplementary Figure 1(.

2.3 Study outcome and design

The primary outcome was time from the date of first HACC use to cessation of services owing to entering permanent RAC. Death was considered as a competing event because a noticeable proportion of participants died while in HACC)Figure 1(.
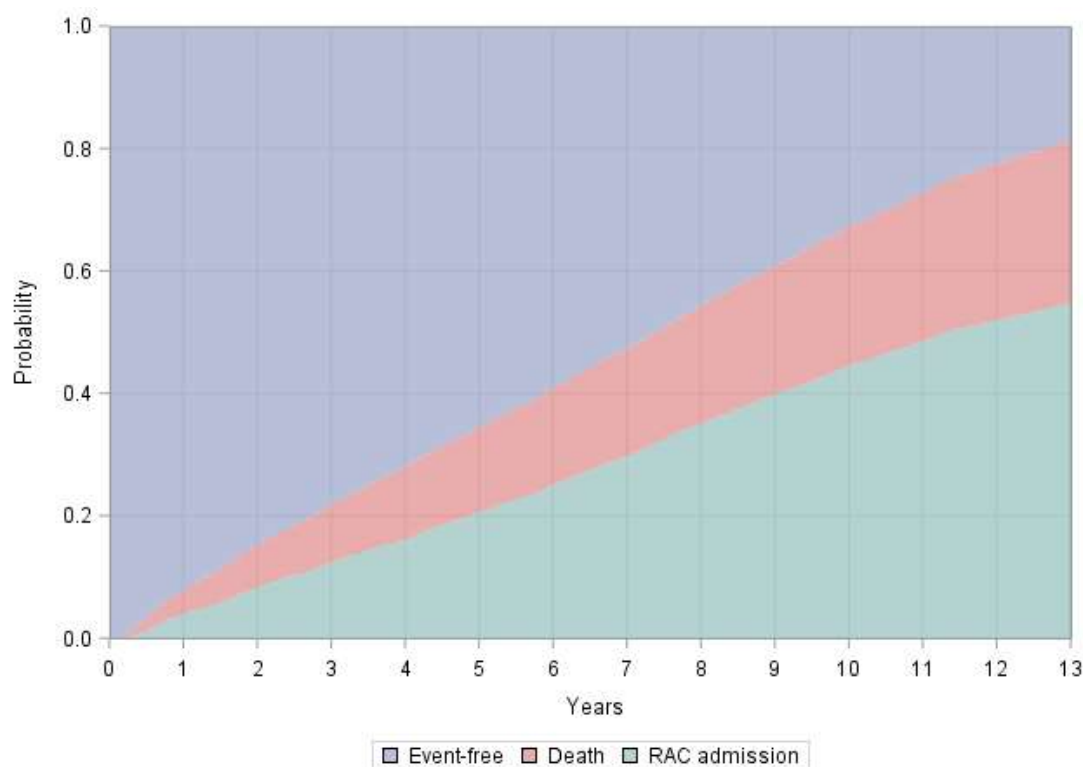

Figure 1: Stacked plot of cumulative incidence functions for the time from the first home and community care use to residential aged care admission.)This figure will be printed in colour(

This competing event, death, precluded the participants from the risk of experiencing the event of interest. Time was measured in months from July 2001 to June 2014, with maximum observation period of 156 months)13 years(. For participants who started HACC before July

2001, their follow-up started from the first month. For those who began HACC later, their entry to the study was taken as the date of first HACC use. Participants who did not enter RAC or did not die, were censored at the end of the study. The median follow–up time was 63 months)5.08 years(with an inter–quartile range of 28 to 105 months.

2.4 Predictor variables

Participants' patternof HACC service use was the key exploratory variable of interest. The HACC minimum datasets provided detailed information regarding quarterly usage of 28 service-types including domestic assistance, home maintenance, personal care, transport, centre–based day care, meal services, home modification, social care, counselling, care planning, and equipment and aids (Rahman et al., 2019). Patterns of HACC use were determined using k–median cluster analysis based on volume of each service used by participants over the study period (Kendig et al., 2012; Rahman et al., 2019). The resultant clusters were labelled with different names and further categorized into two broad patterns with ' 'basic or moderate HACC'and 'complex HACC')Table 1(. The basic or moderate HACC consisted of participants who used a low to moderate volume and number of services, while those belonging to the complex HACC pattern used a high volume and number of services.

Selection of other predictor variables in the current study were guided by Andersen's health service utilization model and previous research.(Andersen & Newman, 1973; Rahman et al., 2019) The model categorizes individual/societal characteristics into three domains namely predisposing factors, enabling factors, and need factors. The available predisposing and enabling factors were area of residence, widowhood status, highest qualification, managing with available income, living arrangements, housing type, and Veteran Affairs' coverage.

The need factors were mainly composed of health–related characteristics namely self–reported health, number of chronic conditions, specific conditions)diabetes, heart problems, arthritis, and asthma(, had a fall with injury, and physical functioning score)0–100(of SF–36 quality of life. All the variables were measured in Survey 3)2002(with the exception of highest qualification which was only asked in Survey 1)1996(. We also explored dementia which was ascertained from administrative data on health and aged care from 2001 to 2014.)Waller, Mishra, & Dobson, 2017(However, this variable was not used as a predictor of RAC admission in the current analysis as most dementia cases were identified at the time of or following RAC admission, by either the Aged Care Assessment Team)ACAT(or Aged Care Funding Instrument)ACFI(. Detailed measurements/categorization of the variables are presented in Table 1.

2.5 Statistics analysis

We estimated the cumulative incidence of RAC admission from the date of first HACC use by the Fine and Gray model according to patterns of service use over the study period)Fine & Gray, 1999(. Gray's test was used to test whether differences in cumulative incidence differed by patterns of HACC use. A stacked plot was drawn to display cumulative incidence function for both the event of interest and the competing event. We performed unadjusted competing risk regression models to estimate sub-distributional hazard ratios of participants' characteristics for time from the first HACC use to RAC admission. Factors that were associated with $p<0.20$ in the unadjusted models were considered for inclusion in the multivariable models. The final model was selected by combinations of backward elimination method and examination of the change in effect for all potential confounders (Walter & Tiemeier, 2009). Separate multivariable models were performed to estimated sub-distribution hazard ratios)sdHR(and cause specific hazard ratios)csHR(for comparison.(Fine & Gray,

1999) However, as our study objectives were more concerned with predictors and informing resources allocation, sub-distributional hazard models wereconsidered better than the cause specific models which focussed more on etiological association.

Left truncation was allowed to accommodate the differential entry time of participants into the study (Betensky & Mandel, 2015). Factors and time interactions for all variables were included in the models to test the proportional hazard assumption. If the assumption was violated for a particular variable, the interaction with time variable was included in the model as means of correction of the assumption. The results for such variables were presented for months >36, >72, and >108.

Missing covariate values were first filled in if available in adjacent waves)ALSWH Survey 2 and Survey 4(. A further <5% missing values of some covariates)e. g., country of birth, falls with injury(were imputed by the multiple imputation technique using logistic regression model for the binary variables)Van Buuren, 2007(. A complete case analysis was also conducted to confirm that the results of the models were not altered by the filled in or imputation technique. Analyses were performed using SAS, version 9.4)SAS Institute, Inc., Cary, NC(.

Results

Of the 8062 participants, 44%)n = 3530(were admitted into RAC, 23%)n = 1898(died)competing event(while in HACC over the 13 years)156 months(of the observation period, and 33%)n = 2634(were censored)event free(at the end of the study as they did not experience the event of interest or the competing event. The median age at first HACC use was 81 years with inter–quartile range of 79 to 84. The majority of participants lived outside of major cities)59%(, were born in Australia)77%(, had lower than higher school certificate

qualifications)72%(, reported easy or not too bad managing with available income)71%(, and lived in a house)72%((Table 1(.

Table 1: Distribution of the sample by participants' characteristics)measured in ALSWH Survey 3, 2002((and their pattern of HACC service use from July 2001 to June 2014

Characteristics	N=8062 %	Characteristics	N=8062 %
Area of residence[¥]		**Chronic conditions**	
Major cities	41	0–2	70
Inner regional	39	>2	30
Remote/outer regional	20	Dementia[§]	33
Country of Birth		Heart problems	22
Australia	76	Arthritis	53
Other country	24	Diabetes	11
Highest Qualification		Asthma	15
School certificate/lower	72	**Had fall with injury**	14
Higher school certificate/higher[‡]	28	No	86
Marital status		Yes	14
Not widowed	54	**Distinct clusters of HACC use**[Є]	
Widowed	46	Basic HACC	60
Living with		Domestic HACC	16
Partner	47	Complex domestic	9
Children/other	47	Complex allied health	9
Alone	6	Complex centre-based care	6
Managing income		**Ever used major HACC services**	
Easy or not too bad	71	Domestic assistance	53
Difficult some/ all the time	29	Home maintenance	34
Veteran Affairs Coverage		Personal care	27
Yes	22	Transport	31
No	78	Centre based day care	20
Housing situation		Nursing care)at home(	49
House	72	Care planning/coordination	40
Flat/unit/apartment	19	Meal services)at home(	37
Retirement village[†]	9	Allied health)at home(	26
Physical functioning		Counselling	17
Score ≥40	71	Home modification	14
Score<40	29	Counselling	17
Median age of first HACC use)IQR(	84)81–87(Yrs	Social care	28
Median observation period)IQR(	63)28-105(Mo	Aids and equipment's	11

Note: IQR: Inter quartile range, HACC: Home and Community Care, Yrs: Years, Mo: Months
[¥]The area of residence was based on the Accessibility/Remoteness Index of Australia Plus which measures

distance to services, including access to tertiary teaching hospitals.

†Also included mobile/caravan/hostel/others

‡Includes trade/apprentice, certificate/diploma, university degree, higher degree

§Time–varying and ascertained between 2001 to 2014 using multiple source of linked administrative health and aged care data, only ~6% cases were identified before admission into RAC

€Basic HACC: low volume of few services, Domestic HACC: 100% used domestic assistance with moderate volume of other services, Domestic complex: 100% used domestic assistance with high volume of other services, Complex allied health: most)96%(used allied health and high volume of other services, and Complex centre-based: most used centre-based care and high volume of other services.

In terms of health–related factors, 70% of women reported good/very good/excellent health, more than three–fifths)62%(had multiple morbidities, and almost half were overweight/obese. Almost one–third of HACC consumers)33%(were identified as having dementia over the study period.

The major HACC services that women used were domestic assistance)53%(followed by nursing care at home)49%(, care planning/coordination)40%(, meal services at home)37%(, home maintenance)34%(, transport)31%(, social care)28%(, personal care)27%(, and allied health services at home)26%(. The cluster analysis produced five distinct clusters, namely 'basic HACC')60%(, 'domestic HACC')16%(, 'complex domestic')9%(, complex allied health)9%(, and complex centre-based care)6%(Women in the basic HACC cluster used low volume of few services)e.g., domestic assistance, transport(and those in domestic HACC mostly used domestic assistance and a moderate volume and number of other services. The current study merged these two clusters into one group 'low to moderate HACC')76%(. In contrast, those who belonged to the three complex HACC clusters used a high volume and combinations of many services including personal care, nursing and allied health services, centre-based care, transport and meal services. These three clusters were merged into a 'complex HACC')24%(group.

The cumulative incidence plot for entering RAC from the first HACC use by patterns of HACC reveals that the probability was significantly higher among participants who belonged to the low to moderate HACC group than the complex HACC group with p<0.01)Figure 2(. In particular, the probability of cumulative incidence in the former group increased more sharply than the latter group until the median observation when the chances reached almost .30 and .15 respectively. However, the chances became very close by end of the study).55 vs .50(. Furthermore, there were significant differences in cumulative incidence of RAC admission by participants area of residence)p<0.01(. Of those living in a remote/outer region, the chances of cumulative of incidence of RAC admission was 0.50 by the end of the study while this was 0.60 for those living in at major cities)Supplementary figure 2(.
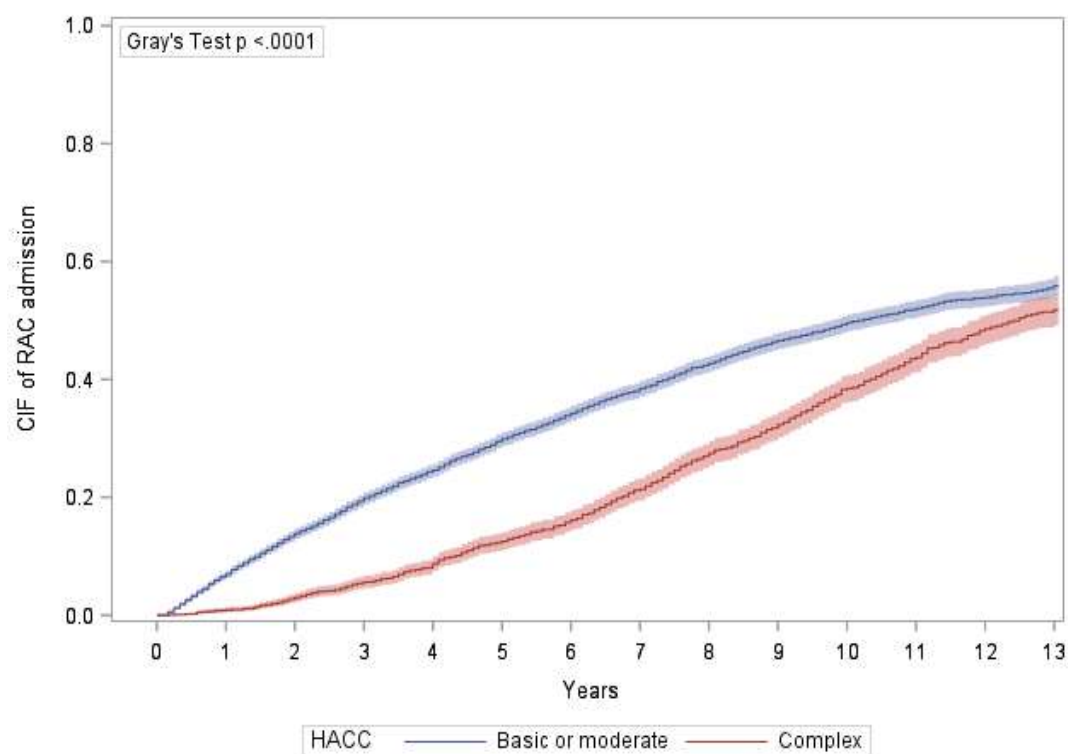

Figure 2: Cumulative incidence functions with 95% confidence intervals for the time from first HACC use to entering residential aged care by patterns of HACC use accounting death as a competing event)Note: basic HACC: included participants who used a low or moderate volume of few/some services, complex HACC: included participants who used a high volume of many services( )This figure will be printed in colour(

Table 2: Sub–distributional hazard ratios)sdHR(and cause–specific hazard ratios)csHR(with 95% confidence intervals)CIs(of participants' characteristics for time from the first home and community care)HACC(use to entering residential aged care)RAC(

Characteristics	Unadjusted sdHR)95% CIs(	Adjusted sdHR)95% CIs(	Adjusted csHR)95% CIs(
Age at first HACC use	1.10)1.08–1.12(**	1.10)1.08–1.13(**	1.06)1.05–1.08(**
Area of residence			
Major cities	Referent	Referent	Referent
Inner regional	0.89)0.83–0.96(	0.95)0.87–1.05(	0.97)0.90–1.05(
Remote/outer regional	0.79)0.71–0.88(**	0.83)0.74–0.93(**	0.88)0.78–0.99(*
Country of Birth			
Australia	Referent	Referent	Referent
Overseas born	0.89)0.80–0.98(*	0.85)0.77–0.94(**	0.87)0.78–0.97(*
Widow			
No	Referent		
Yes	0.98)0.92–1.05(		
Housing type			
House	Referent	Referent	Referent
Apartment	1.29)1.19–1.40(**	1.29)1.20–1.40(**	1.30)1.20–1.41(**
Retirement village/others*	1.57)1.40–1.75(**	1.54)1.38–1.72(**	1.52)1.36–1.69(**
Physical functioning score			
≥40	Referent	Referent	Referent
<40	1.19)1.09–1.30(**	1.16)1.05–1.25(**	1.31)1.22–1.41(**
Had a fall with injury			
No			
Yes	1.14)1.04—1.25(**	1.15)1.05—1.25(**	1.14)1.04—1.25(**
Number of comorbid conditions			
0–2	Referent		
>2	0.94)0.87—1.01(		
Patterns of HACC use†			
Basic HACC	Referent	Referent	Referent
Complex HACC)36 months(	0.74)0.68—0.80(**	0.81)0.74—0.89(**	0.68)0.62—0.74(**
Complex HACC)108 months(	0.84)0.77—92(**	0.90)0.82—0.99(*	0.85)0.77—0.94(*
Complex HACC)108 months(	1.04)0.92—1.19(	1.08)0.94—1.24(	1.09)0.95—1.26(
Veteran Affairs benefits†			
No	Referent	Referent	Referent
Yes)36 months(	0.92)0.82—1.02(	0.89)0.82—0.98(*	0.85)0.75—95(**
Yes)72 months(	0.88)0.77—1.01(	0.88)0.80—0.98(*	0.87)0.77—0.96(*
Yes)108 months(	0.82)0.66—1.01(	0.85)0.73—0.99(*	0.86)0.74—1.00(

*significant at p<0.05, **significant at p<0.01

†As the means of correction of violation of the proportional hazard assumption, the results of these variables are presented for 36 months, 72 months, and 108 months.

Results from multi-variable competing risk regression models reveal that some person-based factors were significantly associated with hazards of entering RAC from the date of first HACC use)Table 2(. A one-year increase in age at first HACC use was associated with 10% higher sub-distributional hazards of entering RAC. Living in a remote/outer region than major cities)sdHR=0.83, 95%CI=0.74-0.93(, born overseas rather than in Australia)sdHR=0.85, 95%CI=0.77-0.94(, receiving Veteran Affairs' coverage than not)sdHR=0.89, 95%CI=0.82-0.99(.were associated with decreased hazards of entering RAC. Compared to living in a house, living in an apartment)sdHR=1.29, 95%CI=1.20-1.40(or retirement village/others)sdHR=1.54, 95%CI=1.38-1.72(were associated with increased hazards of entering RAC. Women who had lower physical functioning)score<40(or a fall with injury had increased)16% and 15% respectively(hazards of entering RAC)p<0.01(. Having a complex pattern of HACC services was associated with lower hazards of entering RAC)sdHR=0.80, 95%CI=0.73-0.87(for the model with time >30 months and)sdHR=90, 95%CI=0.82-0.99(for the model with time >72 months, however, this was not found significant in the models with time >108 months.

Discussion

In this study of a large representative older cohort who used HACC services between 2001-14)age: 75-80 to 88-93(, we assessed the association of their service related and person-based characteristics with time to entering permanent RAC across later life. Cluster analysis)a data driven approach(was used to group the participants with similar pattern of service use and cumulative incidence function was calculated by patterns of service use. We found that the probability of cumulative incidence of RAC admission from the date of first HACC use was significantly lower among those who belonged to the complex HACC group than those of the basic or moderate HACC group, with 15% vs 30% by median observation period)63

months(. Our finding suggests that higher or complex use of HACC services delayed the admission to RAC among those who belonged to the complex HACC group.

Furthermore, findings from the competing risk regression models reveal that the complex HACC group was significantly associated with decreased sub-distributional hazards for participants with an observation period of more than 36 months as well as of more than 72 months but not for those with more than 108 months. This also indicates that higher or complex use of HACC services reduce the hazard of earlier admission to RAC but this may not be associated with hazard of delayed admission. This highlights the importance of RAC at certain point of later life particularly in the last few years before death when escalating care needs are no longer be fulfilled by community care services. The Australian Institute of Health and Welfare)AIHW(reported that RAC is the last program used by over half of aged care users)54%((Australian Institute of Health and Welfare, 2015a). Over the 13-years of our study, 44% entered RAC and a further 23% died without entering RAC. Despite a substantial proportion entering RAC, and using RAC on average 2.9 years (Australian Institute of Health and Welfare, 2018b), our finding suggests that increased use of HACC services can reduce the hazard of early admission to RAC, and consequently may reduce the length of stay in RAC. Several US-based regional studies reported that increased home- and community-based care use is associated with a reduced risk of transitioning to a nursing home (Chen & Berkowitz, 2012; Greiner et al., 2014; Sands et al., 2012). A recent region-based Australian study demonstrated that an hour per week of HCP service use is associated with a 6% decrease in risk of time to entering RAC over the 18-month period)Jorgensen et al., 2018(.

Another important finding is that those living in regional/remote areas rather than major cities and those born overseas rather than Australia had significantly decreased hazards of entering RAC. The decreased hazard of entering RAC in the remote/regional areas might partly be

attributed to a lower availability of RAC in that region. This is also reflected in the findings of another recent study on this cohort that women living in remote/regional areas had 58% higher odds of having a rehabilitation or convalescence hospitalisation (Chojenta, Byles, & Nair, 2018). Furthermore, AIHW reported that people born in non-English speaking countries are more likely to use HCP services which may reduce their risk of time to entering RAC (Australian Institute of Health and Welfare, 2016a).

Other person-based characteristics including being older age at first HACC use, living in an apartment or retirement village, having low physical functioning)score<40(, and having a fall with injury were associated with increased hazards of entering RAC. However, being widowed and having a higher number of chronic conditions were not statistically significant. These findings are consistent with several previous studies that report that older age, higher limitations in ADL, and falls are significantly associated with increased risk of NH/RAC admission)Cumming et al., 2000; Fong, Mitchell, & Koh, 2015(. An earlier study on this cohort that focused on housing also reported a similar association of housing type with time to first RAC admission.)Forder et al., 2017(Although, those who are widowed or have multiple conditions are found to have an increased risk of transitioning to RAC in other studies, in our study these participants might be having enough HACC services or alternative services)e.g., HCP which was not covered in our study(to manage their conditions or other care needs in community settings.

The current study is the first in Australia that utilizes the opportunity of national minimum aged care datasets and linked longitudinal survey for a large representative very old cohort over a 13-year period to better understand the interplay between community-based service use, person-based characteristics and subsequent residential transition across later life. A few limitations of our study should be acknowledged. While dementia is found to be a strong predictor of entering RAC and a corresponding reduced use of community care services

(Waller, Mishra, & Dobson, 2017), we did not include this in our models as most dementia cases were identified at the time of or following RAC admission on ACAT or ACFI data. Almost one-third)33%(of participants in our study were identified as having dementia by the end of the study. Participants' characteristics)except age at first HACC use(were measured in ALSWH Survey 3)2002(and not updated over time as many dropped out from subsequent surveys. However, we adjusted the age at first HACC use in each model. Our study included women who represent over two-thirds of program users in Australia. The findings cannot be generalizable to men as they tend to enter RAC earlier in life than women. However, with a longer lifespan, women's length of stay in RAC is longer than men and they make up the majority of RAC users (Australian Institute of Health and Welfare, 2018b).

Finally, use of a complex pattern of home and community care services was associated with delayed admission to permanent RAC. While living in a remote/regional area was associated with reduce hazards of entering permanent RAC, having lower physical functioning)score<40(, living in apartment or retirement village, and having falls with injury were associated with increased hazards of entering RAC. Our findings provide much needed information about service outcomes of the largest aged care program in Australia, which highlights the importance of providing ranges of services under this program.

Supplementary Figure 1: Derivation of the final sample)ALSWH: Australian Longitudinal

Study on Women's Health, HACC MDS: Home and Community Care Minimum Data Sets,

and RAC: Residential Aged Care(
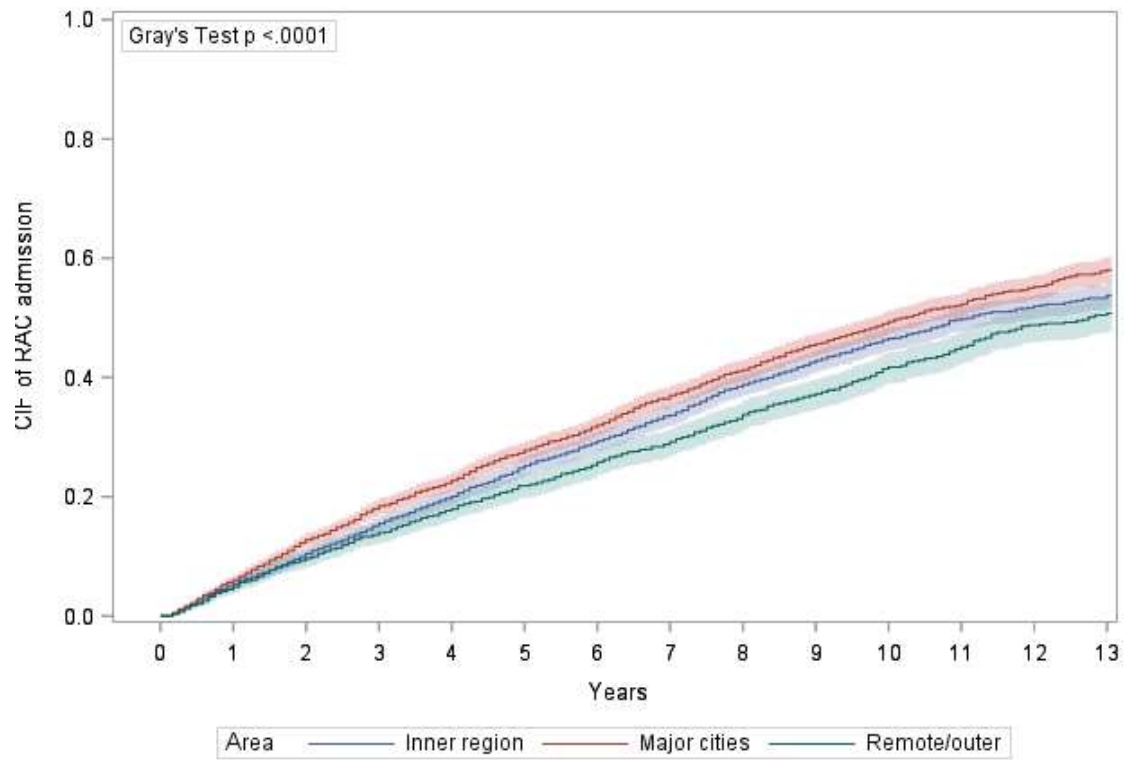
Supplementary Figure 2: Cumulative incidence function for the time from age at home and community care use to entering residential aged care by area of residence accounting death as a competing event

CHAPTER 7: Trajectories of Care Needs in Residential Aged Care

Peer Reviewed Accepted Paper

Key Findings:

- Five distinct trajectory groups were identified, with large variations in the combinations of levels of care needs over time across three ACFI domains

- Approximately 28% of residents belonged to a group which had high care needs in all three domains, and one-third (31%) included in two trajectory groups, which had low or low to medium care needs over time.

- Overall, around two-thirds of the residents had high ADL limitations, and nearly half of the residents had complex care needs which was associated with their multiple comorbid conditions

7.1 Introduction

We observed in the previous study (Chapter 6) that a substantial proportion of women entered residential aged care at some point in later life when their escalating care needs could no longer be fulfilled by the services delivered under home and community care program. Additionally, a small proportion enter RAC without using services from the HACC program (Australian Institute of Health and Welfare, 2017a). We also reported in the Chapter 5 that a group of women were increasingly likely to enter RAC and stay in RAC for at least three years. The Australian Institute of Health and Welfare (2018b) reports that women's average length of stay in RAC is 2 years 10 months. While some older women spend a substantial amount of their late life in RAC, evidence relating to how their trajectories of care needs change over time from the date of admission to exit from RAC (mostly occurred by death) is not available. Consequently, there is a lack of understanding on care planning and how to facilitate appropriate care for them. The specific objectives of the current sub-study were to:

- identify distinct groups of residents having similar trajectories of care needs over time
- examine whether residents' characteristics are associated with being a member of different trajectories groups
- examine the survival outcomes by different trajectory groups

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7.2 Peer Reviewed Accepted Paper

Details about the study design, analytical methods, and findings of this sub-study have accpeted as a peer reviewed paper titled 'Trajectories of Long-Term Residential Care Needs Among Older Australian Women: A Cohort Study Using Linked Data' to the *Journal of the American Medical Directors Association.* The manuscript is currently in Press, and the final submitted version is presented in this chapter.

Trajectories of Long-Term Residential Care Needs Among Older Australian Women: A Cohort Study Using Linked Data

Mijanur Rahman, MSc[abc] and Julie E. Byles, PhD[ab]

[a]Priority Research Centre for Generational Health and Ageing, University of Newcastle, Australia

[b]Centre for Clinical Epidemiology and Biostatistics, University of Newcastle, Australia

[c]Department of Statistics, Comilla University, Bangladesh

Address correspondence to: Md Mijanur Rahman

Priority Research Centre for Generational Health and Ageing, University of Newcastle

HMRI, NSW-2305, Australia. Email: MdMijanur.Rahman@uon.edu.au

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References: 35, and Tables/Figure: 3

Brief summary

Five distinct trajectory groups were identified, with large variations in the combinations of levels of care needs over time. This will facilitate appropriate care planning and service delivery in long-term residential facilities.

ABSTRACT

Objective: Older women are more likely than men to enter residential aged care)RAC(and generally stay longer. We aimed to identify and examine their trajectories of care needs over time in RAC across three fundamental care needs domains, including activities of daily living)ADL(, behaviour, and complex health care.

Design: Population-based longitudinal cohort study.

Setting: Residential aged care facilities in Australia.

Participants: A total of 3519 participants from the 1921-26 birth cohort of the Australian Longitudinal Study on Women's Health)ALSWH(, who used permanent RAC between 2008 and 2014.

Methods: We used data from the Aged Care Funding Instrument, National Death Index, and linked ALSWH survey. Participants' care needs in the three domains were followed six-monthly up to 60 months from the date of admission to RAC. Trajectories of care needs over time were identified using group-based multi-trajectory Modelling.

Results: Five distinct trajectory groups were identified, with large variation in the combinations of levels of care needs over time. Approximately 28% of residents belonged to 'high dependent-behavioural and complex need' group which had high care needs in all three domains over time, while around one-third of residents)31%(were included in two trajectory groups)'less dependent-low need' and 'less dependent-increasing need'(, which had low or low to medium care needs over time. Over two-fifths of residents)41%(comprised two trajectory groups)'high dependent-complex need' and 'high dependent-behavioural need'(, which had medium to high care needs in two domains. Higher age at admission to RAC and multiple morbidities were associated with increased odds of being a member of high dependent-complex need group than less dependent-increasing need group.

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Conclusions and Implications: Identification of the differential trajectories of care needs among older women in RAC will help to better understand the circumstances of their changing care needs over time. This will facilitate appropriate care planning and service delivery for RAC residents who are mostly older women.

Keywords: Long-term care needs; residential aged care; older women; multi-trajectory Modelling; Australia

In recent years, demand for long-term residential aged care)RAC(has risen in many developed countries as a result of an aging population. This is particularly true for people aged 85 and over)the fastest growing population(who are likely to have increased age-related chronic conditions (Agarwal et al., 2016; Boyd et al., 2011; Nakanishi et al., 2014). When their care needs are no longer met at home or in the community, over two-fifths of people aged 65 and over enter RAC in Australia, New Zealand, Finland and the USA (Australian Institute of Health and Welfare, 2014c; Broad et al., 2015; Friedberg et al., 2014; Martikainen et al., 2013). Residents in RAC are increasingly older, frailer, and have disabilities and complex health care needs on admission and throughout their stay)Theou et al., 2017(. In particular, a majority have dementia, stroke or other neurodegenerative diseases, severe disability in ADL, and required assistance with their mobility (Bowman, Whistler, & Ellerby, 2004; Waller, Mishra, & Dobson, 2017).

It is, however, documented that a substantial proportion of older people enter residential aged with low dependency (Challis et al., 2000). For example, approximately one-fifth of nursing home residents in the USA are high-functioning)0-2 ADL limitations(, but require rehabilitation services or chronic care for mobility or sensory impairment, incontinence, or medical conditions (McNabney et al., 2007). The proportion of low dependency residents in

RAC has been declining over the last few decades. Higher proportions of residents have been classified in the high dependency category in Australian and New Zealand (Andrews-Hall, Howe, & Robinson, 2007). However, most studies, which focus on care needs in RAC are cross-sectional in nature including descriptive or trend analysis. A plethora of studies has focused on estimating the risk or likelihood of admission into nursing homes/residential care (Andel, Hyer, & Slack, 2007; Bharucha et al., 2004; Broad et al., 2011; Forder et al., 2017). So far no study has addressed the changing care needs of residents over time throughout their stay in RAC. Consequently, there is a lack of understanding of how to facilitate appropriate care for them.

Although most older Australians prefer to receive care at home or in the community, over a quarter million used RAC in 2017-18. This accounted for an annual government expenditure of AU$12.4 billion which is two-thirds of total expenditure in aged care (Australian Institute of Health and Welfare, 2018d, 2018e). Government subsidy payments for RAC residents are allocated using assessed care needs in the Aged Care Funding Instrument)ACFI(, which has three domains, namely ADL, behaviour)BEH(, and complex health care)CHC(. In 2018, the majority of residents were classified as needing high care on BEH)64%(, ADL)59%(, and CHC)55%(, with 31% having high care needs in all three domains (Australian Institute of Health and Welfare, 2018c). There is a concern about the sharp increase in the proportion of residents needing high care in the CHC domain, which was only 9% in 2009. Having a specific combination of levels of care needs, for example, high-level care needs in all three domains can affect the nature of care provision as well as the amount of subsidy to be paid. As such, it is of utmost importance for providers and the Government to identify the distinct groups of participants with their particular combination of care assistance across the three domains over time. This allows them to evaluate the expected

tenure of the residents with a specific combination, and chances of moving into another combination of care assistance.

We used a national cohort of RAC residents who participated in the Australian Longitudinal Study on Women's Health to examine trajectories of care assistance across the three ACFI domains for up to 60 months)five years(from the date of admission to RAC. We were mainly interested in assessing distinct groups of residents who had similar trajectories across the three care assistance domains over time, and to explore their characteristics and survival probabilities according to their group membership. Based on earlier research and clinical experience (Australian Institute of Health and Welfare, 2018a; Rahman, Efird, & Byles, 2019a), we hypothesized that trajectories of care assistance over time differed according to residents' characteristics)e.g., older age, multiple morbidities(and by their survival patterns.

Methods

Data source and study sample

The current study included 3519 participants of the 1921-26 birth cohort of the Australian Longitudinal Study on Women's Health)ALSWH(who received RAC services between March 2008 and December 2014. The original cohort was recruited in 1996 by randomly sampling the Medicare Australia database)National Universal Health Insurance Database(, with 12,432 women completing the self-reported postal questionnaires at the baseline.(Brown et al., 1999) These women were followed up every three years until 2011, and thereafter on a six-month rolling-basis. Details about ALSWH surveys have previously been published (Dobson et al., 2015; Lee et al., 2005).

ALWH survey data were linked with the ACFI and the National Death Index)NDI(with approval from the Australian Government Department of Health. The linking process

was conducted by the Australian Institute of Health and Welfare)AIHW(using a probabilistic algorithm based on full name and demographic details (Karmel et al., 2010; National Statistical Services, 2017) Use of ALSWH survey data in the current study has been approved by the Human Research and Ethics Committee)HREC(of the University of Newcastle.

The ACFI, which was introduced in March 2008, aims to allocate resources)government subsidies(to care providers based on assessed core care needs of residents living in RAC. Care needs are assessed based on a rating of 'High', 'Medium', 'Low', and 'Nil' in 12 questions, which are contextually positioned in three ACFI domains: ADL, BEH, and CHC. Details about the ACFI have previously been published)Australian Government Department of Health, 2017a).

Study design

The current study was a longitudinal cohort study. Participants' care needs across the three ACFI domains were updated every six months from the date of RAC admission until death or up to maximum 60 months)five years(. For those who were admitted to RAC before the initiation of ACFI)n = 760(, their follow up were started from March 20, 2008)when ACFI was launched(. Those who did not receive further ACFI assessments over the next six-months of follow ups, their previous assessment of care needs was carried forward. Given that the ACFI is used to determine funding allocations, we expect that a new ACFI rating would be generated if the care needs had substantially changed. Data were censored if the person was known to have died prior to the six-month data point.

Outcome/Indicator variables

Participants' care needs across three domains))i.e., ADL, BEH, and CHC(of the ACFI were considered as indicator/outcome variables. ACFI scores for ADL measured the need for assistance with nutrition, mobility, personal hygiene, and toileting, and arranging of urinary and faecal continence. The scores were provided as a scale from 0-100, with scores ≥88: high-level, scores ≥62: medium-level, scores ≥18: low-level limitations. The ACFI BEH score was based on levels of cognitive impairment, wondering, verbal behaviour, physical behaviour, and depression. These scores were also provided on scale 0-100, with scores ≥50 indicate high-level, scores ≥30: medium-level and scores ≥13: low-level behaviour problems. The ADL scores <18 and BEH scores <13 are considered mostly independent and no subsidy is allocated for these levels. The ACFI CHC scores were based on assistance with medications and one or more ongoing complex health care procedures)except nursing interventions(. A 3-level CHC score was provided, with score = 3: high-level, score = 2: medium level, and score = 1: low-level complex care needs. The current study categorized the CHC scores into binary levels where 0 = low or medium and 1 = high needs. Details about the measures of the three domains are available in the ACFI user guide.(Australian Government Department of Health, 2017a)

Predictor variables

Participant's demographic and health-related characteristics including age at admission to RAC, area of residence, widowhood, history of smoking, body mass index)BMI(, and number of chronic conditions were measured at ALSWH Survey 5)2008(except the highest qualification which was only measured at Survey 1)1996(. Missing values were filled in if available in adjacent surveys)Survey 4)2005(, and Survey 6)2011((. Detailed measurements/categorization of the predictor variables are presented in Table 1.

Statistical analysis

We applied group-based multi-trajectory)GBMT(Modelling technique to group participants with distinct trajectories of care needs over time across three ACFI domains (Nagin et al., 2018; Twisk & Hoekstra, 2012). The GBMT Modelling is designed to identify distinct groups of participants who experience similar developmental trajectories across multiple indicators/outcomes of interest over time. Within the GBMT model, multiple regression models are estimated simultaneously through maximization of a combined likelihood which collects information from all sub-models. In our analysis, care needs in ADL and BEH domains were modeled using the censored normal distribution by setting the lowest score)0(as the censored minimum and the highest score)100(as the censored maximum, while the CHC scores)0 or 1(were modeled using binomial distribution.

As part an optimum GBMT model selection, initially we performed group-based trajectory)GBT(models for each of the three outcome variables separately up to seven groups with a combination of linear and quadratic polynomials)Niyonkuru et al., 2013(. For each outcome variable, a model with an optimum number of trajectory groups was selected based on AIC, BIC and average posterior probability of group membership for the participants assigned to each trajectory group)Akaike, 1974; Nagin & Odgers, 2010; Schwarz, 1978(. Finally, GBMT models with up to seven groups were performed using all three outcome variables together. A model with an optimum number of groups was chosen based on fit indices of the GBMT models)AIC and BIC(and consideration of the optimum model for each of the outcome variable separately. Furthermore, the trajectory groups were plotted over time in terms of the three indicator variables to check the shape of the trajectory groups over time. Selection of the best fitting model involves a combination of formal statistical criteria, explanatory power and clinical relevance of the obtained groups (Nagin & Odgers, 2010).

The Kaplan-Meier survival plot by trajectory groups was drawn, and log rank test was used to test survival differences between the trajectory groups)Goel, Khanna, & Kishore, 2010(. To check the impact of attrition due to death on the size and shape of the trajectory groups, we performed separate GBMT models among the participants who survived at least 30 months)n = 1235(and who died before that time)n = 2284(. Similar procedures)as discussed previously for the main GBMT model(were applied to determine models with the optimum number of groups in the sub-group analysis.

Multivariable multinomial logistic regression model was used to estimate odds ratios)OR(and 95% confidence intervals)CI(of participants' characteristics for the membership of different trajectory groups compared to a reference group. Variables were entered in the model by the combination of a stepwise selection procedure and change in estimate criterion(Walter & Tiemeier, 2009). Analyses were performed using SAS, version 9.4)SAS Institute, Inc., Cary, NC(and Stata version 15 (Jones & Nagin, 2013).

Results

Of the 3519 participants, 35%)n = 1235(resided in RAC for more than 30 months and only 13%)n = 439(for more than 60 months. The median age at admission to RAC was 86.8 years with inter-quartile range 85.2 to 88.5 years. The majority were widowed)59%(, lived in major cities)45%(/inner cities)38%(, had less than secondary school certificate qualifications)74%(, had normal BMI)50%(, never smoked)65%(, and had 2-3 comorbid conditions)39%(/more than three conditions)33%( )Table 1(.

Based on the model selection strategy)including model fit indices(, a five-group multi-trajectory model has been selected)Supplementary Table A1(. Figure 1 presents the preferred model with five trajectory groups. There was a large variation across the trajectory groups in terms of combinations of levels of care needs in each of the three domains over

time from the date of RAC admission up to 60 months or until death. The trajectory groups are briefly described below:
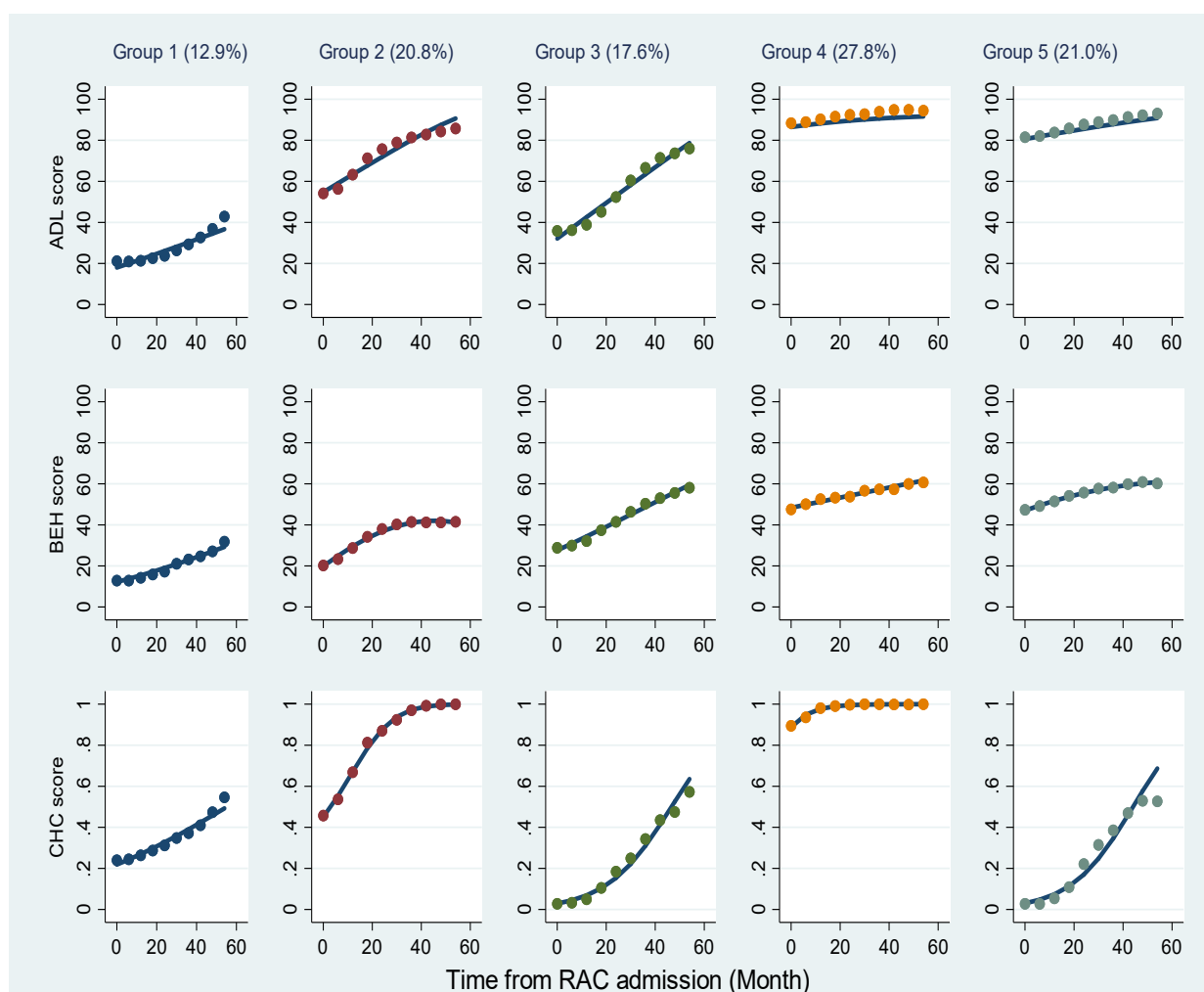
Figure 1: A five-group multi-trajectory model for activity of daily living)ADL(, behavioural)BEH(and complex health care)CHC(scores up to 60 months from the date of admission to residential aged care)RAC( )n=3519(

Group 1: **Less dependent-low need**

This group included 12.9%)n = 447(of the residents who had low care needs across all three domains at the time of RAC admission, with a moderate increase over time throughout the study period.

Group 2: **High dependent-complex need**

This group consisted of 20.8%)n = 716(of the sample who had high ADL limitations and complex care needs over time. However, they had low behavioural problems, with moderate increase over time

Group 3: **Less dependent-increasing need**

Approximately 17.6%,)n = 636(of the residents are included in this group. They had low care needs across the three domains at the time of RAC admission, but their care needs gradually increased to moderate- to high-level over time. This trajectory group was considered as the reference category considering many older people enter RAC with low needs but increase over time.

Group 4: **High dependent-behavioural and complex need**

This trajectory group composed 27.8%)n = 972(of the sample, is the most distinct with regard to level of care needs across all three domains. The women in this group were admitted into RAC with high ADL limitations, BEH problems, and CHC needs and these needs continued to increase over time.

Group 5: **High dependent-behavioural need**

Approximately 21%)n = 748(of the sample belong to this group. The residents of this trajectory group had high ADL limitations and behavioural problems over time. However, they had less complex care needs than all other groups.

Table 1: Odds ratios)OR(and 95% confidence intervals)CIs(of the member of different trajectory groups

Covariates	n=3519 %	OR)95%CI(by different trajectory groups				
		Group 3	Group 1	Group 2	Group 4	Group 5
Median age at admission)Inter quartile range(	86.8)85.2-88.5(	1.00	0.97)0.91-1.03(	1.15)1.10-1.22(	1.12)1.06-1.18(	1.05)0.99-1.11(
Area of residence						
Major cities	45.2	Ref				
Inner cities	38.3	1.00	1.17)0.87-1.56(	1.13)0.87-1.47(	0.82)0.64-1.05(	1.30)1.01-1.69(
Remote/outer region	16.5	1.00	1.60)1.07-2.40(	0.88)0.62-1.24(	0.90)0.66-1.23(	1.07)0.76-1.50(
Marital status						
Not widowed	41.4	Ref				
Widowed[†]	58.6	1.00	0.92)0.68-1.25(	0.94)0.71-1.21(	0.67)0.52-0.86(	0.68)0.52-0.89(
Highest qualification						
>Secondary school[‡]	26.1	Ref				
≤Secondary school	73.9	1.00	0.84)0.63-1.13(	0.90)0.67-1.18(	1.00)0.77-1.27(	0.86)0.66-1.13(
Body mass index)BMI([‡]						
Normal)BMI=22-27(	55.5	Ref				
Underweight)BMI<22(	26.0	1.00	0.92)0.65-1.30(	0.90)0.65-1.23(	0.94)0.70-1.26(	1.15)0.84-1.56(
Obese)BMI>27(	18.5	1.00	1.25)0.87-1.78(	1.17)0.85-1.62(	1.21)0.89-1.65(	0.93)0.63-1.25((
History of smoking						
Never smoked	64.7	Ref				
Smoker[¥]	35.3	1.00	1.26)0.93-1.70(	1.20)0.91-1.57(	1.34)1.03-1.73(	1.10)0.83-1.45(
Comorbid conditions[§]						
0-1	29.0	Ref				
2-3	38.5	1.00	1.35)0.97-1.87(	1.43)1.04-1.96(	1.15)0.85-1.53(	1.02)0.75-1.39(
>3	32.5	1.00	1.53)1.03-2.25(	1.53)1.07-2.17(	1.24)0.90-1.73(	0.82)0.52-1.18(

[†]partner died, [‡]included higher second, diploma/apprentice/trade, university or higher qualification & [¥]Current or previous smoker

[§]Collapsed into three categories based on 16 chronic conditions including high blood pressure, osteoporosis, osteoarthritis, asthma, Parkinson's disease, angina, heart attack, other heart problems, diabetes, bronchitis/emphysema, stroke, glaucoma, cataract, cancer except skin cancer, depression/nervous disorder, and Alzheimer's disease/dementia

[‡]BMI was categorized according to Nutritional Intervention Manual for Professional Caring for Older Americans)1992(

Note: Group 1: Less dependent-low need, Group 2: High dependent-complex need, Group 3: Less dependent-increasing need, Group 4: High dependent-behavioural and complex need, and Group 5: High dependent-behavioural need

Table 2 presents results of the multivariable multinomial logistic model. It reveals that participants' characteristics, except for highest qualifications and body mass index, were significantly associated with membership of different trajectory groups compared with the reference group 'less dependent-increasing need'. Higher age at RAC admission was associated with greater odds of being a member of the trajectory 'high dependent-complex')OR = 1.15, 95% CI = 1.10-1.22(and 'high dependent-behavioural and complex need' group)OR = 1.12, 95% CI = 1.06-1.18(than less dependent-increasing need group. Widowed women were less likely to be members of the 'high dependent-behaviour and complex need')OR = 0.67, 95% CI = 0.52-0.86(and high dependent-behavioural need groups)OR = 0.68, 95% CI = 0.52-0.89(than less dependent-increasing need group. Those who had a history of smoking were 34% more likely to be a member of the high dependent-behavioural and complex need than less dependent-increasing need group. Compared to none or one chronic condition, having, 2 or3 conditions and >3 conditions were associated with increased odds)OR=1.43, 95%CI=1.04-1.94 and OR=1.40, 95%CI=1.07-217, respectively(of being in the high dependent-complex need group than less dependent-increasing need group.

Figure 2 illustrates the Kaplan-Meier survival plot by trajector groups. There was a significant difference between the trajectory groups with regard to 60 months)five years(survival probabilities from the date of RAC admission with p<0.001. Residents of the high dependent-behavioural and complex need group consistently had the lowest survival probabilities, with approximately 15% chance of surviving five years from the date of RAC admission. In contrast, those belonging to 'less dependent-low need' trajectory group

had the highest survival probabilities, with over 50% chance of surviving five years from the date of RAC admission. The five years survival probabilities for residents of less dependent-increasing need, high dependent-complex and high dependent-behavioural were approximately 38%, 27%, and 22% respectively.
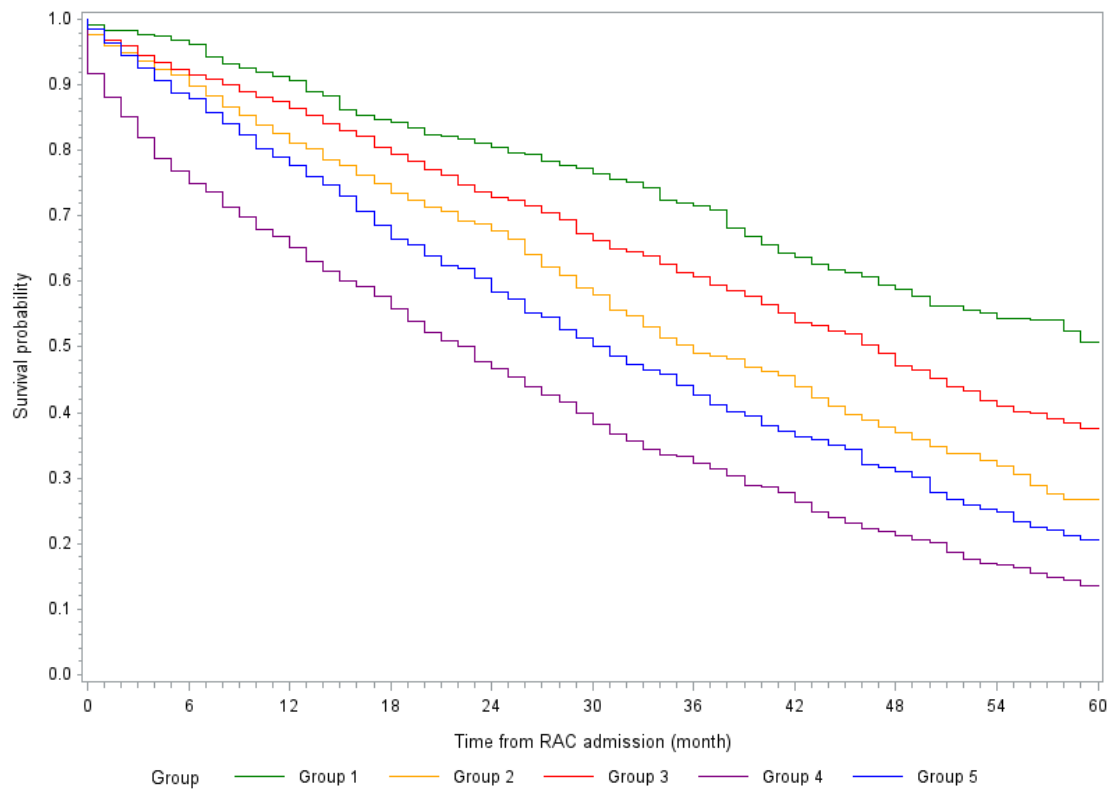

Figure 2: Survival probabilities)Kaplan-Meier(by trajectory groups up to five years from the date of RAC admission)log rank p < 0.001(

)Note: Group 1: Less dependent-low need, Group 2: High dependent-complex need, Group 3: Less dependent-increasing need, Group 4: High dependent-behavioural and complex need, and Group 5: High dependent-behavioural need(

Discussion

Using linked administrative AFCI datasets from a nationally representative cohort of older women)born in 1921-26(from 2008 to 2014, we identified five distinct trajectory groups in terms of levels of care needs across three domains)ADL, BEH, and CHC(over time. There were large variations among women in different trajectory groups with regard to the combinations of levels of care needs over time as well as their survival probabilities. Those belonging to the less dependent-low need trajectory group)13%(had low care needs in all three domains, and they had the highest survival probability. In contrast, those belonging to the high dependent-behavioural and complex need group)28%(consistently had high care needs across three domains, and they had the lowest survival probability. In a cross-sectional study, the AIHW reported that 31% of residents had high care needs in all three ACFI domains in 2018 (Australian Institute of Health and Welfare, 2018c). This moderate variation with our findings was attributed to a different study design and time period, for example, currently older people are supported longer in the community with the increased provision of HCP services, and subsequently they enter RAC at relatively older ages with more complex needs than before.

Nearly one-third of residents in RAC)less dependent-low need and less dependent-increasing need groups(had low or low to medium care needs over time in all three domains. Considering their higher survival probabilities compared to other groups, they were most likely to be long stay residents. Particularly, residents of the low-dependent group entered RAC earlier than expected which could be explained by the previous low- and high-level care provision in RAC. However, this distinction in RAC has been removed since July 1, 2014 (Australian Institute of Health and Welfare, 2015c). While community-

based aged care in Australia provides a range of entry-level services, particularly through the Commonwealth Home Support Programme)formerly known as Home and Community Care(, the provision of high-level community care services, for example, Home Care Packages)HCP(are not increasing as of the rapid speed of increasing demand. This has been reflected in the steadily increasing wait time to access this service in recent years (Visvanathan et al., 2019; Yu & Byles, 2019). A recent study in Australia found that HCP service use is significantly associated with decreased odds of entering RAC.(Jorgensen et al., 2018) In a U.S. based study, nearly one-fifth of residents in nursing homes were found to be high functioning and could potentially be supported in community-based care (McNabney et al., 2007). The recent growth in HCP services in Australia may reduce the care trajectory in RAC as an increasing number of older people prefer to stay at home for longer and enter RAC with a higher care trajectory than before.

Furthermore, increased complex care needs among participants of the high dependent-complex need group were partly be attributed to higher likelihood of having multiple morbidities, and higher age at admission to RAC. This is also consistent with recent concern regarding higher than predicted funding claims in the CHC domain.(Department of Health 2016) On the other hand, residents of high dependent-behavioural group had very low needs in CHC provided they had medium to high care needs both ADL and BEH domains over time, indicating that these limitations are not leading to complex care needs among these residents

The major strength of our study is the follow-up of participants' levels of care needs every six months up to five years/death from the date of RAC admission using administrative and linked survey data for a large representative older cohort. However, a

few limitations of the study should be acknowledged. First, our study findings may not be generalizable to men, as ALSWH did not include men. However, it should be noted that most aged care residents are women. Further research is required to understand trajectories for males, who may have different care needs. For example, a lower proportion of men than women reported high care needs across three ACFI domains (Australian Institute of Health and Welfare, 2018c). Second, ACFI assesses overall care needs in fundamental care domains; and it is not a comprehensive assessment tool which would include a broader range of care needs than required for the purpose of funding instruments. Furthermore, trajectories of care needs for the short stay and for the long stay residents may be different. Our separate analysis shows that the size of the low care needs groups)less dependent-low need and less dependent-increasing need(increased for the long stay residents)>30 months(, while for the short stay residents there was a moderate change in all groups particularly a noticeable increase in size with high CHC groups)Supplementary Figure A1 and Figure A2(.

Conclusions and Implications

Large variations in the combinations of care needs across the trajectory groups over time suggest that differential care planning is essential for each trajectory group. Our findings have the potential to help design long-term or short-term care planning and to estimate the required amount of funding for residents of each trajectory group through their stay in residential aged care. Furthermore, the findings can be utilized to evaluate policies for increased provision of HCP services in the community and how this affects the size of a particular trajectory group)e.g., low care need group(in residential aged care. However,

comprehensive assessment of residents' care needs)other than ACFI(is necessary to fully

understand their changing circumstances of care needs over time. Finally, our findings will

facilitate appropriate care planning and service delivery for older women living in RAC.

Conflicts of Interest: The authors have no financial or personal conflicts of interest with

this work.

Supplementary Table A1: Model selection indices for the different group-based

trajectory models and group-based multi-trajectory models

No of classes	GBT model on ADL		GBT model on BEH		GBT model on CHC		GBMT model on ADL, BEH, CHC	
	AIC	BIC	AIC	BIC	AIC	BIC	AIC	BIC
2	-79643	-79668	-76113	-76138	-12283	-12307	- 170960	- 170891
3	-76832	-76875	-73769	-73806	-9253	-9290	- 168029	- 167931
4	**-73551**	**-73606**	-72794	-72841	-9236	-9289	- 165365	- 165234
5	-74891	-74952	**-71952**	**-72010**	**-6272**	**-6306**	-163798	-163634
6	-74409	-74483	-71454	-71524	-6017	-6060	- 162594	- 162390
7	-74500	-74413	-70970	-71054	-5943	-5995	- 170960	- 170891

GBT: Group-based trajectory, GBMT: Group-based multi-trajectory, BIC: Bayesian Information criterion, AIC: Akaike Information Criterion, ADL: Activities of daily living, BEH: Behavioural, CHC: Complex health care

Note: The lowest AIC and BIC values were found for a four-group trajectory model on ADL, while for models on BEH and CHC, these values continue to decline as the number of groups increased in the model)Appendix Table A1(. However, there was a big drop of these values from a four-class model to a five-group model. Afterwards there was a moderate decline for the models with more than five groups. Consequently, a five-group model was considered as the preferred model for both BEH and CHC. Based on this model search, we concluded that at least a four-group GBMT model was required to model the three outcomes. In the main model, the BIC and AIC values declined with increasing numbers of groups up to six. After which the values increased again. While the lowest BIC values were found in the six group model, this model did not include any additional substantive distinct groups other than the five group model. As such, in the interest of parsimony, the five group multi-trajectory model was considered as the preferred model. Furthermore, the average posterior probability for belonging to each of the assigned groups was >0.93, indicating that participants were appropriately grouped into the trajectory groups.
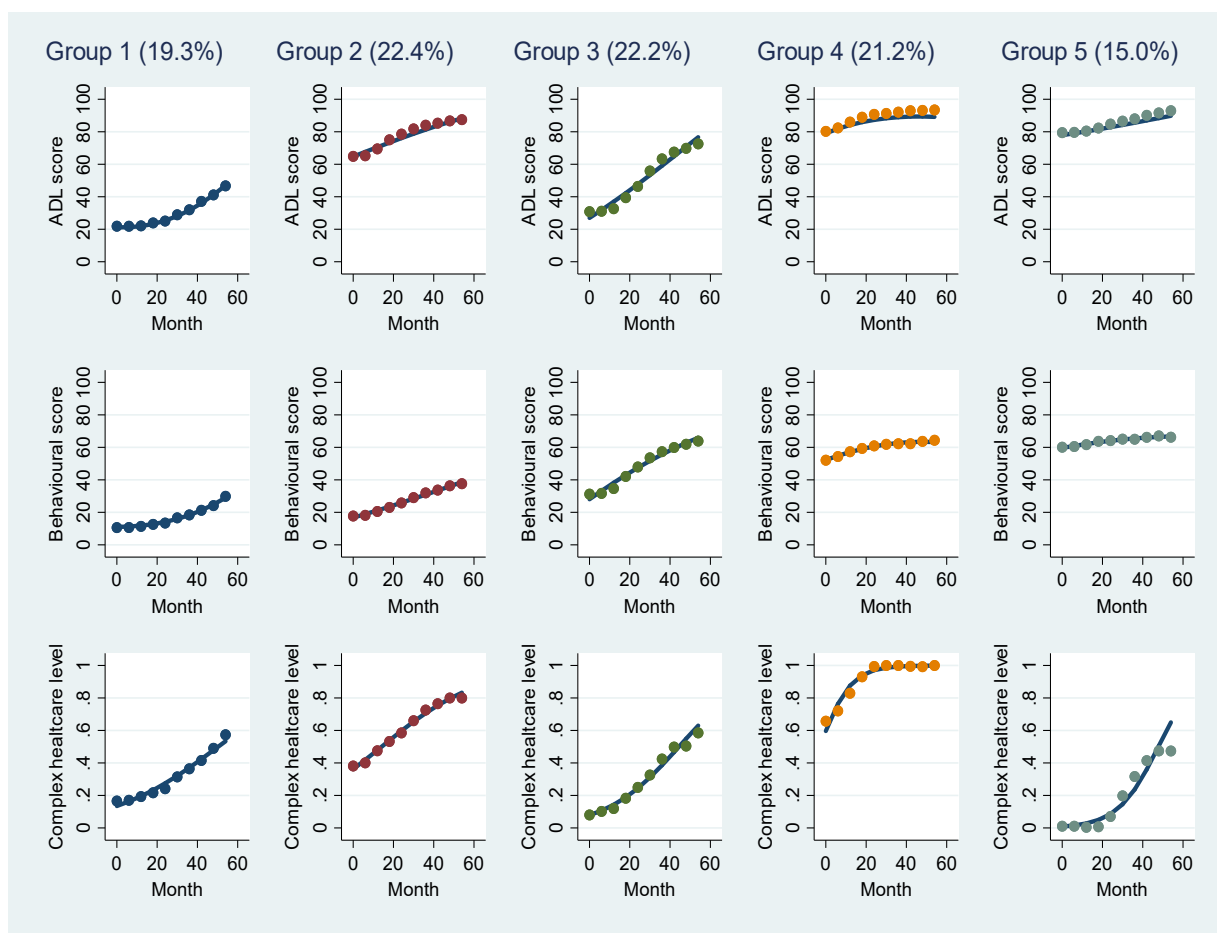
Supplementary Figure A1: Five class multi-trajectory model for residents who stayed in RAC more than 30 months up to 60 months)n=1235( )ADL=Activity of daily living(
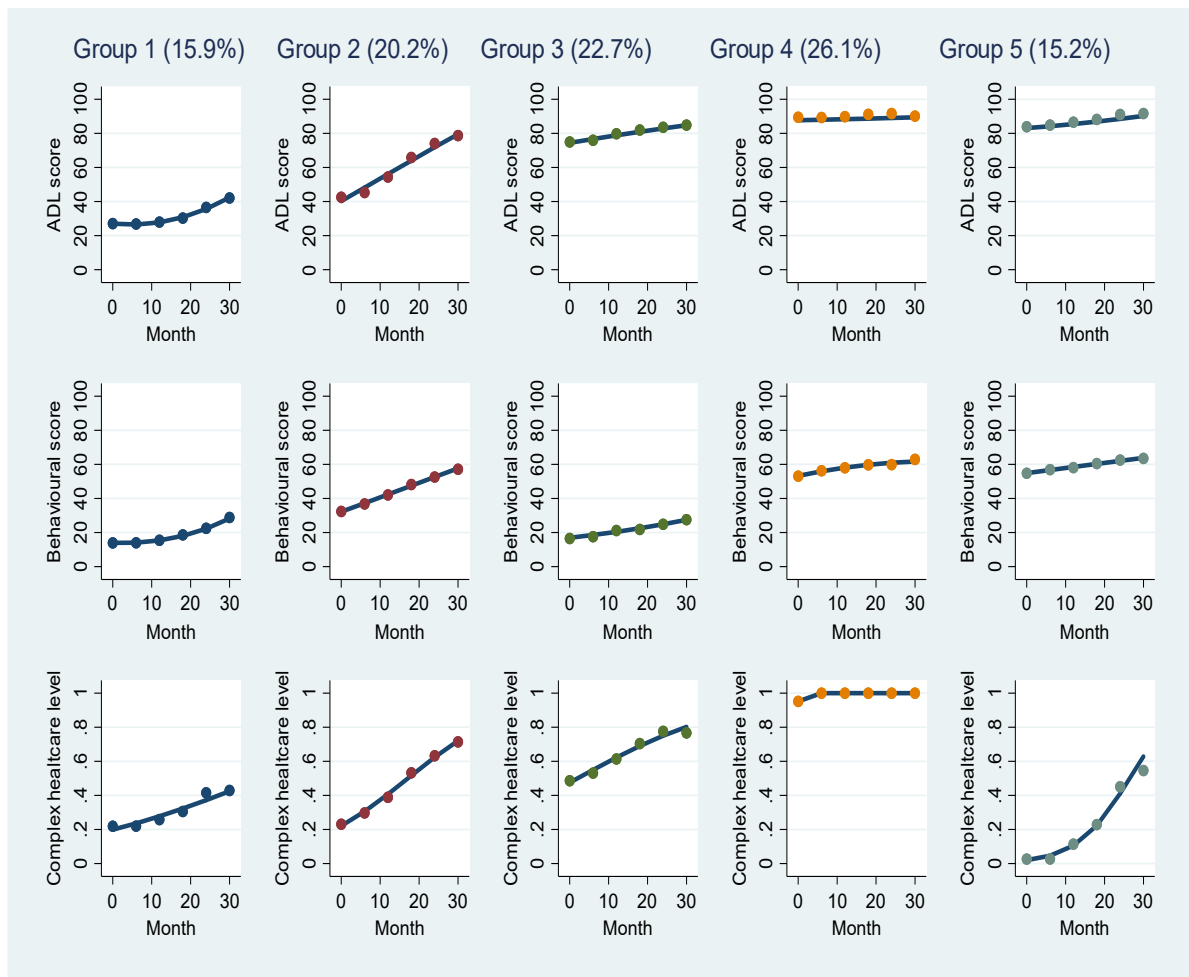
Supplementary A2: Five class multi-trajectory model for residents who stayed in RAC less than 30 months)n=2284( )ADL = Activity of daily living(

CHAPTER 8: Transition into and Through the Aged Care Care System

Peer Reviewed Accepted Paper

Key Findings:

- We estimated transition rates from one care state to another. For example, women transitioned from non-user to HACC at a rate of 11 time higher than the rate of transitioning to RAC.

- We estimated the transition probabilities for moving to another level of care or remaining in a particular level of care over time after adjusting for participants' baseline characteristics. For example, at age 76-81, a woman had a 28% chance of surviving another 10 years without using any aged care services and a 36% chance of dying. The chances of remain in HACC was 24% and in RAC was 11% after 10 years.

- The predicted length of HACC and RAC use were 5.0 years and RAC: 2.5 years, respectively.

- We estimated survival probabilities for each care state over time. For example, at age of 76-81, the 10-year survival chance for a non-user was 67%, for a HACC user was 36%, and for a RAC resident was 10%

8.1 Introduction

This chapter includes a comprehensive analysis of older women's later life trajectories, with particular focus on their journey into and through the two mainstream aged care programs - home and community care (HACC) and residential aged care (RAC) until death. While the four latent patterns observed in the Chapter 5 provided an understanding of the latent pathways of aged care use across later life given a member of a particular latent group, but failed to show the amount of certainty in transitioning from one level of care to another. Currently, longitudinal research evidence regarding the transition of older people from one level of care to another according their changing needs and circumstance are lacking. This information is pivotal not only to assist older people to plan their later life care pathways but also to help guide policymakers to design the future capacity of the aged care system including workforce and funding management. The specific objectives of the current study presented in this chapter were to:

- estimate the probabilities of transitioning from one level of care to another over time across later life
- identify the risk factors that influence older people transitioning from one level of service use to another.
- estimate the length of stay and the survival probabilities at each level.

8.2 Peer Reviewed Accepted Paper

The findings of this study have accepeted as a peer reviewed paper titled 'Transitioning of Older Australian Women into and Through the Long-term Care System: A Cohort Study Using Linked data' in the *BMC Geriatrics* journal. The manuscript is currently in Press, and the final accepted version is presented in this chapter.

Transitioning of Older Australian Women into and Through the Long-term Care System: A Cohort Study Using Linked data

Mijanur Rahman, MSc,[1,2,3,] [*] **Jimmy T. Efird, PhD, MSc,**[1,2] **and Julie E. Byles, PhD**[1,2]

[1]Priority Research Centre for Generational Health and Ageing, University of Newcastle, Australia, Email: jimmy.efird@newcastle.edu.au and julie.byles@newcastle.edu.au

[2]Centre for Clinical Epidemiology and Biostatistics, University of Newcastle, Australia

[3]Department of Statistics, Comilla University, Bangladesh

*Address correspondence to Md Mijanur Rahman

Priority Research Centre for Generational Health and Ageing, University of Newcastle

Hunter Medical Research Institute, West Wing, Level 4, Lot 1 Kookaburra Circuit,

New Lambton Heights, NSW 2305, Australia. Email: MdMijanur.Rahman@uon.edu.au,

Phone: +61-0240420612

Abstract

Background: Over two-thirds of older Australians use different types/levels of aged care at some point in later life. Our aims were to estimate transitional probabilities and to identify risk factors influencing the movement between different levels of long-term care.

Methods: The sample consisted of 9,007 women from the 1921-1926 birth cohort of the Australian Longitudinal Study on Women's Health. Transitional probabilities between different levels of long-term care were estimated using a continuous-time Markov model.

Results: An 11-fold transition rates ratio was observed for the movement from non-user to home and community care)HACC(versus non-user to residential aged care)RAC(. The predicted probabilities of remaining in the non-user state, HACC, and RAC after 10 years from the baseline were .28, .24, and .11, respectively. While the corresponding probabilities of dying from these states were .36, .65, and .90. The risk of transitioning from the non-user state to either HACC or RAC was greater for participants who were older at baseline, widowed, living outside of major cities, having difficulties in managing income, or having chronic condition, poor/fair self-rated health, or lower SF-36 scores)p < .05(.

Conclusion: Women spend a substantial period of their later life using long-term care. Typically, this will be in the community setting with a low level of care. The transition to either HACC or RAC was associated with several demographic and health-related factors. Our findings are important for the planning and improvement of long-term care among future generations of older people.

Trial registration: Not applicable

Background

The number of older people needing formal long-term care)referred to as 'aged care' in Australia(has significantly increased over the last 50 years. In many countries including Australia, this trend is expected to continue over the foreseeable future (Steinbeisser et al., 2018; WHO, 2015; Wouterse et al., 2015). There is a global debate on how to best provide care services for this population (Organization for Economic Co-operation and Development, 2011). An increasing challenge for health care systems is to develop effective and sustainable long-term care plans which meet the needs of a rapidly ageing population (Mieke Deschodt & SLP, 2017).

The proportion of older people)aged 65 and over(in Australia's total population was 15% in 2017 which is projected to increase to 21-23% by 2066 (Australian Bureau of Statistics, 2018). Given the rapid increase in the number people aged 85 over who depend more on formal care services, the increase in the demand of aged care services is expected to correspondingly increase in the foreseeable future (Royal Commission into Aged Care Quality and Safety, 2019a). Australia has a comprehensive aged care system to provide the best possible care to every older Australian. This ranges from supportive care in the community to high-level care in the residential setting, with emphasis on retaining people in the community (Productivity Commission, 2011). In 2017-18, over 1.2 million older Australians used different types of formal aged care services)Commonwealth Home Support Program)65%(, residential aged care)23%(, home care packages)10%(, and

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transition care)2%((, with two-thirds were women (Australian Institute of Health and Welfare, 2018d). However, there is a paucity of evidence on how and when older people utilize different types of aged care services across later life. With the baby boomer generation)born from 1946-1964(entering older age, the number of individuals requiring aged care is projected to double in Australia in the next two decades (Australian Bureau of Statistics, 2016). Consequently, it is important to understand how older people use different forms of aged care services, and the factors influencing the extent and duration of these services.

Older people may use different types/levels of aged care, according to changes in their needs. This is precipitated by predisposing and enabling factors)e.g., living alone, decreased socioeconomic status, inadequate social support(as well as their declining physical and mental status. However, there are substantive differences between men and women with respect to their aged care needs and lifespan patterns. Among older women, comorbid health conditions are key determinants of disabilities and quality of life (Murtagh & Hubert, 2004). Compared with men, women live longer with disabilities, and consequently are more dependent on formal aged care (Laditka & Laditka, 2001; McCann, Donnelly, & O'Reilly, 2012; Murtaugh, Kemper, & Spillman, 1990).

Approximately, two-thirds of recipients in the Australian aged care system are women (Australian Institute of Health and Welfare, 2017b). Their patterns of aged care use are quite different with respect to when they enter aged care, type and combination of services, volume of service use, and lifespan (Rahman, Efird, & Byles, 2019a). For example, one group of women)representing approximately one-quarter of the sample(mostly used community aged care service for a prolong period, while another group

moved to residential aged care owing to their escalating care needs or died early without entering RAC. Accounting for these variations provides meaningful information when forecasting the demand of aged care services.

Previous studies on the transitions of older people into community care and residential facilities were typically based on a small number of participants (Cheek et al., 2006) or focused on particular population groups (Mehdizadeh, 2002), and/or characteristics)e.g., health conditions( )Karmel et al., 2012(. Currently, knowledge is limited regarding the movement of women into and through the aged care system according to their predisposing, enabling and health characteristics. Such information is pivotal for service delivery, forecasting future demand, and capacity planning of the aged care system in Australia.

Based on the linked administrative aged care, national death records, and survey data for a large representative cohort of women from the Australian Longitudinal Study on Women's Health, we addressed three research questions. First, we aimed to estimate transition rates and predicted probabilities for the movement of older women between different levels of aged care use from 2002 to 2011 when they were aged 76 to 91 years. Given the Australian policy emphasis on providing care in the community setting, we hypothesized that older women had a greater risk of transitioning to home and community care)HACC(than to either residential aged care)RAC(or death (Australian Institute of Health and Welfare, 2017a). Second, we asked whether transitioning to different levels of aged care differed by participants' characteristics. We anticipated that a woman's level of long-term care use to be influenced by demographic vulnerability)e.g., being widowed, living alone, lower socioeconomic status(and health disadvantage)e.g., multiple

morbidities and disability((Martikainen et al., 2009; Mehdizadeh, 2002). Finally, we aimed to estimate the length of stay and survival probabilities for each level of aged care use. Based on our previous research (Rahman, Efird, & Byles, 2019a; Rahman et al., 2019), we hypothesized that older women)aged 76-81 year at baseline(would spend more time as a non-user of formal aged care services versus receiving care at home or in a residential setting.

Conceptual framework

Our conceptual model has two dimensions. The first describes the expected pathways into and through aged care use, with four distinct states. A woman's level of aged care use was categorized into four hierarchical states: 1(State 1: Non-user, 2(State 2: HACC 3(State 3: RAC, and 4(State 4: Death. The first three denote transitional states, while the fourth is an absorbing state. We used a covariate-adjusted Markov model to estimate transition probabilities through these four states (Islam, Chowdhury, & Huda, 2013; Jackson, 2011; Xie, Chaussalet, & Millard, 2005).

The second dimension concerns factors)demographic predisposing and enabling, and health-related needs(which may influence long-term care use, in accordance with the Andersen health behavioral model (Andersen & Newman, 1973). This model has been used in several studies to identify determinants of long-term care in later life (Chen & Berkowitz, 2012; Slobbe et al., 2017; Steinbeisser et al., 2018).

The framework)depicted in Figure 1(illustrates the movements of older women into and through the aged care system over the study period, by taking into account participants' characteristics. At baseline,)January 2002(participants were in State 1. The

transitions between the states with associated risk factors are shown by arrow signs. No reverse transitions)e.g., movement from RAC to HACC(were considered in our model. In Australia, RAC is generally used only when the person cannot be supported in the community. While the transition from HACC to non-user is theoretically possible, it is not likely as care needs increase over time (Kendig et al., 2010; Wu et al., 2014). The transition intensities)q_{ij}(indicate the instantaneous risk of moving from State i to State j. In a Markov process, transitions into the next state adhere to the memoryless property of this model, wherein information from previous states are independent of future transitions.
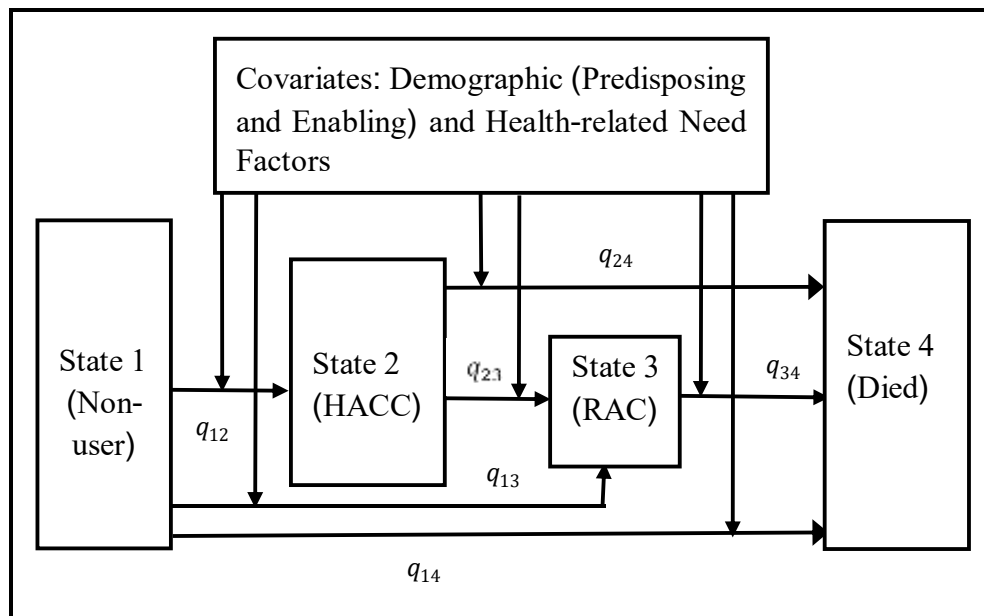

Figure 1: Framework for the four-state Markov model with possible transitions and associated covariates)HACC: Home and Community Care and RAC: Residential Aged Care(
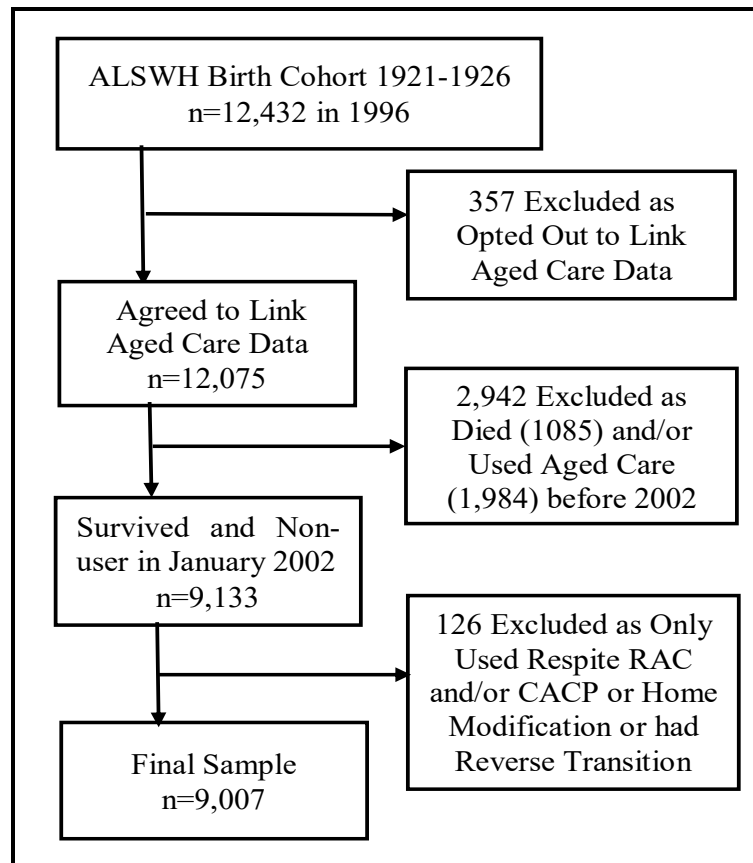
Methods

Study design and sample

We used data from the 1921-1926 birth cohort of the Australian Longitudinal Study on Women's Health)ALSWH(and linked aged care and death records from 2002 to 2011. ALSWH is a national population-based study on the health of Australian women. Participants were randomly sampled from the Medicare Australia database)National Universal Health Insurance Database((Brown et al., 1999). At the time of recruitment in 1996, 12,432 women completed self-reported postal questionnaires. They were followed up every three years until 2011)e.g., Survey 1: 1996; Survey 2: 1999; Survey 3: 2002(, and thereafter on a six-month rolling-basis. Details of ALSWH have been previously published (Dobson et al., 2015).

ALSWH data were linked with administrative aged care data)< 5% opted out(and national death records with approval from the Australian Government Department of Health. The data were combined by the Australian Institute of Health and Welfare)AIHW(using a probabilistic linkage algorithm based on full name and demographic details (Karmel et al., 2010; National Statistical Services, 2017).

A total of 9,007 women were included in the final analysis dataset)Figure 2(. This consisted of participants who had no previous record of using formal aged care services at baseline)January 2002(and those who agreed to having their aged care information linked with other databases. Women)n = 112(who used respite residential aged care, home modification, or community care packages)CACP(, and no other services, were excluded. The former two programs were not ongoing service types and the usage of the later

program was low in this cohort. Furthermore, 12 women who transitioned from RAC to HACC were excluded as this is not a common trajectory.

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┌─────────────────────────────────────────────────────────┐
│   ┌─────────────────────────┐                            │
│   │ ALSWH Birth Cohort      │                            │
│   │ 1921-1926               │                            │
│   │ n=12,432 in 1996        │                            │
│   └───────────┬─────────────┘                            │
│               │           ┌──────────────────────┐        │
│               ├──────────▶│ 357 Excluded as       │        │
│               │           │ Opted Out to Link     │        │
│               │           │ Aged Care Data        │        │
│               ▼           └──────────────────────┘        │
│   ┌─────────────────────┐                                │
│   │ Agreed to Link      │                                │
│   │ Aged Care Data      │                                │
│   │ n=12,075            │                                │
│   └───────────┬─────────┘ ┌──────────────────────┐        │
│               ├──────────▶│ 2,942 Excluded as     │        │
│               │           │ Died (1085) and/or    │        │
│               │           │ Used Aged Care        │        │
│               │           │ (1,984) before 2002   │        │
│               ▼           └──────────────────────┘        │
│   ┌─────────────────────┐                                │
│   │ Survived and Non-   │                                │
│   │ user in January 2002│                                │
│   │ n=9,133             │                                │
│   └───────────┬─────────┘ ┌──────────────────────┐        │
│               ├──────────▶│ 126 Excluded as Only  │        │
│               │           │ Used Respite RAC      │        │
│               │           │ and/or CACP or Home   │        │
│               │           │ Modification or had   │        │
│               ▼           │ Reverse Transition    │        │
│   ┌─────────────────────┐ └──────────────────────┘        │
│   │ Final Sample        │                                │
│   │ n=9,007             │                                │
│   └─────────────────────┘                                │
└─────────────────────────────────────────────────────────┘
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Measures:

Aged care use

The aged care linked dataset provided detailed information on the types of services used by older Australians)e.g., service types, start date, end date, and date of death((Department of Health and Ageing, 2006). The Australian Government routinely maintains this database to pay subsidies to service providers. The current study considered two mainstream aged care services: 1(HACC)other than a one-time service for home

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modifications(, and 2(Permanent RAC. The former program provided 'entry-level' support services)including some nursing care(at home, while the later provided the highest level of support in residential facilities when individual's care needs were no longer being met at home.

Baseline characteristics

Participants' baseline characteristics were measured in 2002)ALSWH Survey 3(when they were aged 76-81 years. Demographic factors included age at baseline, area of residence)major cities, inner/regional/remote areas(, being widowed)yes, not(, and having difficulties in managing income)easy/not too bad, difficulties in some/all the time(. Health-related need factors included being diagnosed with or treated for chronic conditions such as arthritis, heart problems, diabetes, and asthma; experiencing falls with injury in the past 12 months; self-rated health; and the Short Form)SF-36(scores of health-related quality of life including physical, social and mental functioning ranging from 0-100)with higher scores indicating better health(. Cut-off points for each domain were based on values pre-specified in the literature or technical reports)e.g., lower physical function ≤ 40, lower mental function ≤ 52, and lower social function ≤ 52, with scores above these thresholds reflecting better functional capacities((Australian Longitudinal Study on Women's Health, 2018b; Berwick et al., 1991; Stevenson, 1996).

Statistical analysis

Descriptive statistics were used to summarize participants' baseline characteristics. Categorical variables were presented as frequencies and percentages, while continuous variables were depicted as medians and interquartile ranges)IQR(.

Levels of aged care use were modelled as a finite-state Markov chain transitioning through a continuous time scale from 2002 to 2011. We generated a multi-state frequency table to illustrate transitions between the different states from 2002 to 2011. The transition probability P)t(of being in State j at time)t+u(, given the state at time t)i.e., i(was computed as $P(t) = Exp(tQ)$)where Q denotes the state transition matrix(.

The effects of covariates on a particular transition intensity were modelled as $q_{ij}(z(t)) = q_{ij}^{(0)} \exp\left(\beta_{ij}^T z(t)\right)$, where $z(t)$ represents the column vector predisposing, enabling and health-related need factors (Marshall & Jones, 1995). Covariates were simultaneously entered in the main model, except for self-rated health and SF-36 quality of life profile)physical, mental and social functioning(. Given the known association with other health indicators, these variables were modelled separately, only adjusting for demographic characteristics.

The transitional probabilities from different states over the study period were visualized using multiple line plots. Transition rates ratios)TTR(, the probability of the next state, total length of stay in each state, and survival probabilities associated with each transition were estimated from the main Markov model. The prevalence of observed and expected frequencies were plotted to check model goodness-of-fit)Figure 1,

Supplementary(. Analyses were implemented using the R-msm package available in the Comprehensive R Archive Network)CRAN(library (Jackson, 2011).

Results

The median age at baseline)2002(of the participants)n = 9,007(was 78 years)interquartile range)IQR(= 2.5(, with a minimum of 75 years and maximum 82 years. Approximately 57% lived outside of major cities, 46% were widowed, and 75% had moderate-to-excellent self-reported health)Table 3(.

Table 1. Multi-state frequency table over the period 2002 - 2011)at baseline, all women were in non-using state)State 1(

Status of women	State 1)Non-user(	State 2)HACC(	State 3)RAC(	State 4)Death(	Total
State 1 (Non-user)	1855[c]	5685	604	863[d]	9007[a]
State 2 (HACC)	0	2892[c]	1739	1054[d]	5685[b]
State 3 (RAC)	0	0	1140[c]	1203[d]	2343[b]
State 4 (Death)	0	0	0	3110[c]	3110[b]

[a]Total number of women in State1 at baseline
[b]Total number of women who visited the respective state by the end of the study
[c]Number remaining in the respective state by the end of the study
[d]Number of women who died when transitioning from the respective state
HACC: Home and Community Care
RAC: Residential Aged Care

At baseline, all participants were in State 1)non-users( )Table 1(. More than one-third of women died)State 4(by the end of the study)2011(, with approximately three-quarters of this group having used either HACC)State 2(and/or RAC)State 3(prior to death. Of those who started HACC)63%(, more than half remained HACC users by the end of the study. A quarter of the women used RAC, with three-quarters having used HACC before starting RAC.

From State 1, women were more likely to start using HACC vs. RAC or dying, with transition rates ratios of 11.08)95% CI = 10.04 - 12.24(and 7.72)95% CI = 7.10 - 8.40(, respectively)Table 2(. Once women started HACC, they were 70% more likely to enter RAC than to die without using RAC. Those who entered RAC were more likely to die than HACC or non-users, with transition rates ratio of 3.88)95% CI = 3.53 - 4.26(and 17.56)95% CI = 15.86 - 19.45(, respectively.

Women who were non-users had the highest probability of using HACC).82, 95% CI = .81 - .83(followed by dying without using either HACC).11, 95% CI = .10 - .12(or RAC).07, 95% CI = .06 - .08(. The probabilities of transitioning from HACC to RAC or dying without using RAC were .63)95% CI = .61 - .65(and .37)95% CI = .36 - .39(, respectively. The average length of stay over the study period was 7.9 years for non-users)in State 1(, 4.9 years for HACC)State 2(, and 2.5 years for RAC)State 3(.

Table 2. Transition rates ratios)TRR(with 95% confidence intervals)CI(, probability of next state with 95% CI and average length of stay with 95% CI

Description[a]		TRR)95% CI((
Transition rates		
State1 to State 2 vs. State 1 to State 3		11.08)10.04-12.24(
State1 to State 2 vs. State 1 to State 4		7.72)7.10-8.40(
State1 to State 3 vs. State 1 to State 4		1.44)1.27-1.62(
State 2 to State 3 vs. State 2 to State 4		1.69)1.55-1.85(
State 2 to State 4 vs. State 1 to State 4		4.54)4.07-5.02(
State 3 to State 4 vs. State 1 to State 4		17.56)15.86-19.45(
State 3 to State 4 vs. State 2 to State 4		3.88)3.53-4.26(
Probability that each state is next		**Probability)95% CI(**
From State1	to State 2:	.82).81-.83(
	to State 3:	.07).06-.08(
	to State 4:	.11).10-.12(
Form State 2	to State 3:	.63).61-.65(
	to State 4:	.37).36-.39(
From State 3	to State 4:	1.00
Average length stay		**Average)95% CI(**
State 1		7.95)7.74-8.17(,
State 2		5.04)4.82-5.27(
State 3		2.51)2.34-2.69(

[a]State 1 = Non-user, State 2 = Home and Community Care,
State 3 = Residential Aged Care, and State 4 = Death

The probability of remaining in the respective state sharply declined over time. In contrast, transitional probabilities to other states increased over time)Figure 3(. A typical non-user woman had a 36% probability of dying in the following 10 years, and a 28% probability of surviving over the same period, without using any formal aged care)adjusting for predisposing and enabling and health-related need factors(. Considering death as a competing risk, the probabilities of remaining in HACC or RAC by the end of the study were .24 and .11, respectively. For women in HACC or RAC, the probability of being alive and remaining as users of these services until the end of the study was

relatively low).19 and .10, respectively(. Correspondingly, the chances of dying were very high).65 and .90(. The predicted 10-year survival probabilities of transitioning from State 1)non-user(, State 2)HACC(, and State 3)RAC(were .65, .35 and .10, respectively)Figure 2, supplementary(.
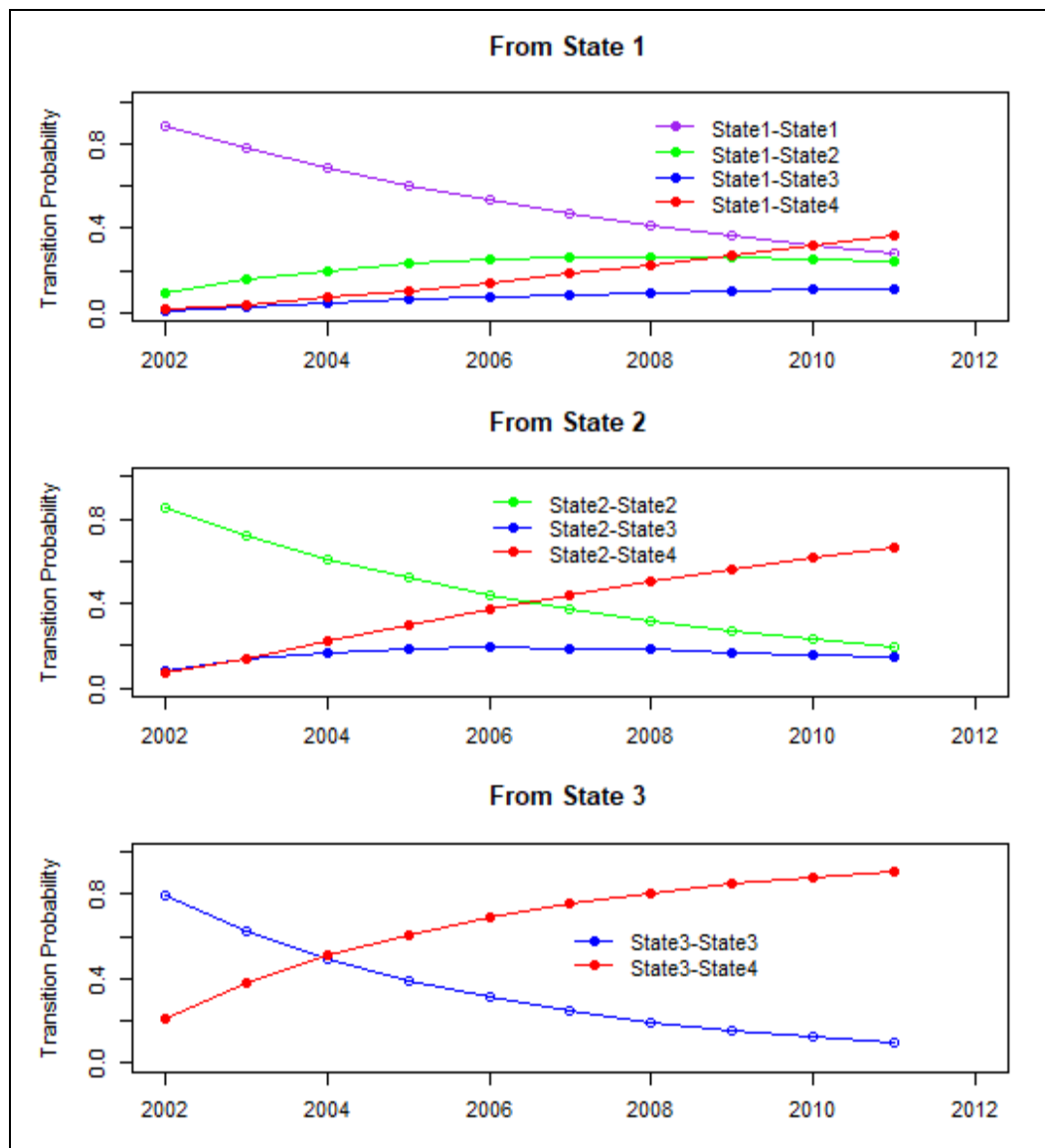

Figure 2: Transition probabilities from different states over the period 2002-2011)State 1 = Non-users, State 2 = Home and Community Care, State 3 = Residential Aged Care, and State 4 = Death(

Baseline age was significantly associated with an increased hazard of transitioning from the non-user state to either HACC)HR = 1.05, 95% CI = 1.03 - 1.07(or RAC)HR = 1.26, 95% CI = 1.19 - 1.34(or death)HR = 1.12, 95% CI = 1.07 - 1.18(, and from HACC to RAC)HR = 1.13, 95% CI = 1.09 - 1.17( )Table 3(. Those who lived in remote/inner/regional areas had an increased hazard of transitioning from the non-user state to HACC)HR = 1.17, 95% CI = 1.11 - 1.24(but a decreased hazard of transitioning from the non-user state to RAC)HR = 0.85, 95% CI = 0.71 - 1.00(than women who lived in major cities. Being widowed was associated with an increased risk of transitioning from the non-user state to either HACC)1.08, 95% CI = 1.02 - 1.14(or death)HR = 1.31, 95% CI = 1.13 - 1.53(. In contrast, we observed a decreased risk of transitioning from HACC to death)HR = 0.85, 95% CI = 0.74 - 0.97(, and from RAC to death)HR = 0.89, 95% CI = 0.78 - 1.00(, for widowed women compared with those who were not widowed. Those who had difficulties in managing their income had an increased risk of transitioning from the non-user state to HACC)HR = 1.13, 95% CI = 1.07 - 1.21(than those who had no difficulties.

Women with chronic conditions had an increased hazard of transitioning from the non-user state to HACC, than those without these conditions. An increased hazard of transitioning from the non-user state to death was associated with asthma)HR = 1.28, 95% CI = 1.04 - 1.57(, diabetes)1.31, 95% CI = 1.03 - 1.66(, and heart problems)HR = 1.28, 95% CI = 1.08 - 1.55(. Furthermore, women with heart problems or asthma had higher risks of transitioning from HACC to death)62% and 37%, respectively(, than those without these conditions. Falls with injury were associated with an increased hazard of transitioning from the non-user state to RAC)HR = 1.34, 95% CI = 1.05 - 1.71(

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Table 3. Hazard Ratios)HR(and 95% Confidence Intervals)CI(for the Baseline Characteristics on Transitioning to Different Levels

Covariate)reference group(	N=9007 %	Non-user to HACC	Non-user to RAC	Non-user to Death	HACC to RAC	HACC to Death	RAC to Death
		HR and 95% CI on different levels of transition					
Age at baseline)IQR(	78.4[b])2.5(	1.05)1.03-1.07(	1.26)1.19-1.34(	1.12)1.07-1.18(	1.14)1.09-1.18(	1.03)0.98-1.07(	1.01)0.97-1.05(
Area)major cities(	43.3						
Remote/Inner/outer regional	56.7	1.17)1.11-1.24(	0.85)0.71-1.01(	0.92)0.80-1.07(	0.89)0.81-0.98(	1.12)0.98-1.28(	1.02)0.90-1.15(
Widow)No(	54.1						
Yes	45.9	1.08)1.02-1.14(	0.96)0.80-1.15(	1.31)1.13-1.53(	0.98)0.88-1.08(	0.85)0.74-0.97(	0.89)0.78-1.00(
Managing income)easy/not bad(	74.4						
Difficulties some/all of the time	25.6	1.13)1.07-1.21(	0.86)0.69-1.07(	0.92)0.77-1.09(	1.01)0.90-1.12(	0.91)0.78-1.05(	0.90)0.78-1.04(
Arthritis)No(	51.2						
Yes	48.8	1.16)1.10-1.23(	1.00)0.83-1.19(	0.83)0.72-0.98(	0.96)0.86-1.06(	0.97)0.85-1.11(	0.98)0.83-1.11(
Heart problem)No(	80.9						
Yes	19.1	1.20)1.12-1.29(	0.98)0.78-1.23(	1.29)1.08-1.55(	1.04)0.92-1.17(	1.62)1.40-1.86(	1.20)1.04-1.79(
Diabetes)No(	90.4						
Yes	9.6	1.17)1.07-1.28(	1.39)1.05-1.83(	1.31)1.03-1.66(	1.12)0.96-1.31(	17.1)0.97-1.43(	1.13)0.94-1.36(
Asthma)No(	86.7						
Yes	13.3	1.16)1.07-1.25(	1.04)0.80-1.35(	1.28)1.04-1.57(	0.95)0.82-1.10(	1.37)1.16-1.61(	1.06)0.88-1.27(
Falls with injury)No(	87.7						
Yes	12.3	1.04)0.96-1.13(	1.34)1.05-1.71	1.15)0.92-1.43(	1.12)0.97-1.29(	1.03)0.86-1.24(	0.92)0.77-1.09(
Physical functioning)score > 40(	74.4						
Score <= 40	25.3	1.43)1.34-1.52([a]	1.95)1.62-2.34([a]	1.66)1.41-1.95([a]	1.27)1.14-1.41([a]	1.59)1.40-1.82([a]	1.11)0.98-1.26([a]
Mental functioning)score > 52(	92.3						
Score <= 52	7.6	1.23)1.11-1.36([a]	1.77)1.34-2.33([a]	1.62)1.27-2.07([a]	1.18)1.00-1.40([a]	1.15)0.92-1.44([a]	0.87)0.71-1.06([a]
Social functioning)score > 52(	81.6						
Score <= 52	18.4	1.41)1.32-1.51([a]	1.96)1.61-2.40([a]	1.68)1.41-2.00([a]	1.23)1.06-1.43([a]	1.24)1.07-1.43([a]	1.02)0.89-1.17(
Self-rated Health)moderate to excellent(	75.2						
Poor/fair	24.8	1.42)1.34-1.51([a]	1.90)1.57-2.28([a]	2.17)1.86-2.53([a]	1.19)1.07-1.32([a]	1.59)1.40-1.82(	1.05)0.93-1.19(

[a]Adjusted only for demographic factors, [b]Median, IQR: Inter-quartile range, HACC: Home and Community Care, RAC: Residential Aged Care

Women with lower SF-36 scores for physical)≤ 40(, mental)≤ 52(, and social functioning)≤ 52(, had an increased hazard of transitioning from the non-user state to either HACC or RAC or death, and from HACC to RAC, than those who had higher scores in their respective domains)Table 2(. Women who reported poor/fair self-rated health had an increased hazard of transition from the non-user state to either HACC)HR = 1.42, 95% CI = 1.34 - 1.51(, RAC)HR = 1.90, 95% CI = 1.57 - 2.28(, or death)HR = 2.17, 95% CI = 1.86 - 2.53(, and from HACC to death)HR = 1.59, 95% CI = 1.40 - 1.82(, than those who reported moderate to excellent health.

Discussion

In this cohort study of women born from 1921 to 1926, we estimated probabilities of transitioning between different levels of aged care use as they aged from their late 70s to late 80s. Women were most likely to first use HACC, with approximately half continuing to use this service until age 86-91. Additionally, transitioning from HACC to RAC was more likely than transitioning from HACC to death. This is consistent with findings of the Australian Institute of Health and Welfare)AIHW(, wherein over two-thirds of consumers entered aged care by first using HACC. The majority of women in RAC reported previous HACC use (Australian Institute of Health and Welfare, 2017a).

Our findings are important to ongoing policy debate pertaining to the preference for community care, and the appropriateness of residential care)Productivity Commission, 2011(. For some women, RAC may be an unavoidable necessity based on their high care needs but many may have opportunities to avoid RAC through prevention and

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management of chronic diseases, attention to social needs, and better support in the community)Blackburn, Locher, & Kilgore, 2014; Nishita et al., 2008(.

During the 10 years of this study, approximately 28% of women did not use aged care)HACC and/or RAC(. This was equivalent to the percentage of older women) ≥ 75 years of age(in the Australian Productivity Commission report who never required formal aged care during their lifetime (Productivity Commission, 2011). On average, women aged 75 - 80 years in the current analysis survived for almost eight years without using aged care services.

The predictive length of stay in HACC)5 years(and RAC)2.5 years(, when considered cumulatively, suggests that older women spend a substantial proportion of their later life living at home with formal support or in a residential facility. In contrast, our finding for RAC was slightly lower than the AIHW's study, which reported an average stay of 2.9 years (Australian Institute of Health and Welfare, 2018b). This variation was mainly attributed to study participants; the latter study included only those who were discharged from RAC)mostly decedents(, while in our study both decedents and existing residents were included. We may have under-estimated the lifetime length of stay in RAC, as we did not know the exact length of time for surviving residents.

Participants with higher baseline age had an increased risk of transitioning from the non-user state to either HACC, RAC, death or transitioning from HACC to RAC. Those who lived in remote/inner/regional areas were associated with an increased hazard of transitioning from the non-user state to HACC (Jorm et al., 2010) but a decreased hazard of transitioning from the non-user state to RAC (Forder et al., 2017). These findings may reflect the availability of HACC in those areas, compared with limited

accessibility to RAC. In some cases, women living in rural and remote settings may be cared for in acute hospitals)as long-term convalescent or rehabilitation patients(, in lieu of an available residential aged care bed (Chojenta, Byles, & Nair, 2018). These women were not accounted for in the current, as admission to hospital was not included in the aged care datasets.

Widows had an increased hazard of transitioning from the non-user state to either HACC or death, owing to a lack of informal support and a higher likelihood of being frail (McCann, Donnelly, & O'Reilly, 2012). Difficulties in managing income were associated with an increased hazard of transitioning from the non-user state to HACC but with a decreased hazard of entering RAC (Jorm et al., 2010). It may be that women with financial difficulties were less able to access high cost RAC, and were instead more dependent on low cost HACC. Since most older Australians own their own home, community care recipients do not pay for accommodation costs. In contrast, residential care incurs additional costs for accommodation and other services (Ergas & Paolucci, 2011). While these costs are subsidised, they are subject to means and asset testing, wherein some costs may need to be covered by the individual.

Most health-related need factors were found to be associated with an increased hazard of transitioning to either HACC, RAC, or death. Poor physical functioning is a major determinant of the need for physical care support, and may be associated with comorbid conditions, which contribute to high care needs and lower lifespan. In other studies, being diagnosed with chronic conditions)e.g., arthritis, heart problems, diabetes, and asthma(were associated with an increased hazard of using HACC (Jorm et al., 2010; Karmel et al., 2012). Those who were diagnosed with diabetes (Baena-Diez et al., 2016)

heart problems)Karmel et al., 2012(and asthma (Eftekhari et al., 2016) had an increased hazard of death. Falls with injury were associated with an increased hazard of transitioning to RAC, in agreement with a US-based study (Tinetti & Williams, 1997). Lower SF-36 quality of life score)particularly physical functioning(was significantly associated with fear of falls and increased aged care admission (Cumming et al., 2000). Additionally, self-reported poor health status/disability was associated with an increased hazard of transitioning to HACC (Jorm et al., 2010) or RAC, followed by death (Guralnik et al., 1994; Weinberger et al., 1986). The association between aged care use and functional limitations suggests that the former is reaching those with higher needs of support. It also highlights opportunities to reduce demands for care by enhancing functional capacities in later life. Accordingly, providing better support at the earliest indication of need will help women to remain functionally independent throughout later life.

Strength and limitations

An important strength of our study is the use of longitudinal data from a nationally representative sample, linked to administrative aged care and national death index datasets. To our knowledge, this is the first Australian based study that estimated the transitional probabilities for the movements of older women between different levels of aged care use and identified risk factors associated with each level of transition.

However, a few limitations should be noted when interpreting our results. We did not model the effects of dementia. Dementia is a strong determinant of increasing residential aged care use, with a corresponding reduced use of community care services (Australian Longitudinal Study on Women's Health, 2018a). It has been estimated that

approximately 26% of women in ALSWH have dementia by the time they reach 76-91 years of age and many of these women will be in residential aged care at some time in their later life (Waller, Mishra, & Dobson, 2017). We have also not assesssed the role of informal suports and how these influence the transitions into and through aged care service types. Furthermore, we were unable to assess the quality of aged care services and whether such services were adequate to meet the needs of older women in Australia. By design, our study also did not include men. Women tend to receive more support from HACC and tend to enter RAC later in life than men (Australian Institute of Health and Welfare, 2014c). However, because of their longer lifespan, the average length of stay of women in RAC is 1.5 times longer than men (Australian Institute of Health and Welfare, 2018b).

Conclusions

The number of older Australians needing formal aged care is anticipated to double in the next two decades. Owing to their greater life expectancy, more women than men use aged care services. Typically, they first enter HACC and then transition to RAC, compared with dying while in HACC. The use of aged care services varied by baseline demographic)predisposing and enabling(and health-related need factors. Understanding these factors and the probabilities of transitioning between different levels of service use have important implications for better planning and capacity design of the aged care system in Australia.

Abbreviations

HACC: Home and Community Care **RAC**: Residential Aged Care

ALSWH: Australian Longitudinal Study on Women's Health

CACP: Community Aged Care Packages **AIHW**: Australian Institute of Health and Welfare

SF-36: Short Form-36 **IQR**: Inter Quartile Range

TRR: Transition Rates Ratio **CRAN**: Comprehensive R Archive Network

HR: Hazard Ratio **CI**: Confidence Interval

Declarations

Availability of data and materials

ALSWH data sets are available for researchers provided a formal application)details available at www.alswh.org.au,(. The linked aged care administrative sets are only available to the approved ALSWH investigators.

Authors' Contributions

All authors)MR, JE, and JB(conceptualized the study, MR performed statistical analysis and drafted the manuscript, JE and JB revised the manuscript. All authors have read and approved the final version of the manuscript.

Ethics approval and consent to participate

This study)registered as ALSWH project A553(was approved by the Human Research and Ethics Committee of both the University of Newcastle and University of Queensland. Ethical clearance for the linkage of ALSWH survey data to aged care data sets was received from the Australian Institute of Health and Welfare Ethics Committee. Approval no's. H-076-0795 and -2011-0371

Consent for publication

Not applicable

Competing of Interests: The authors have no financial or personal conflicts of interest with this work.
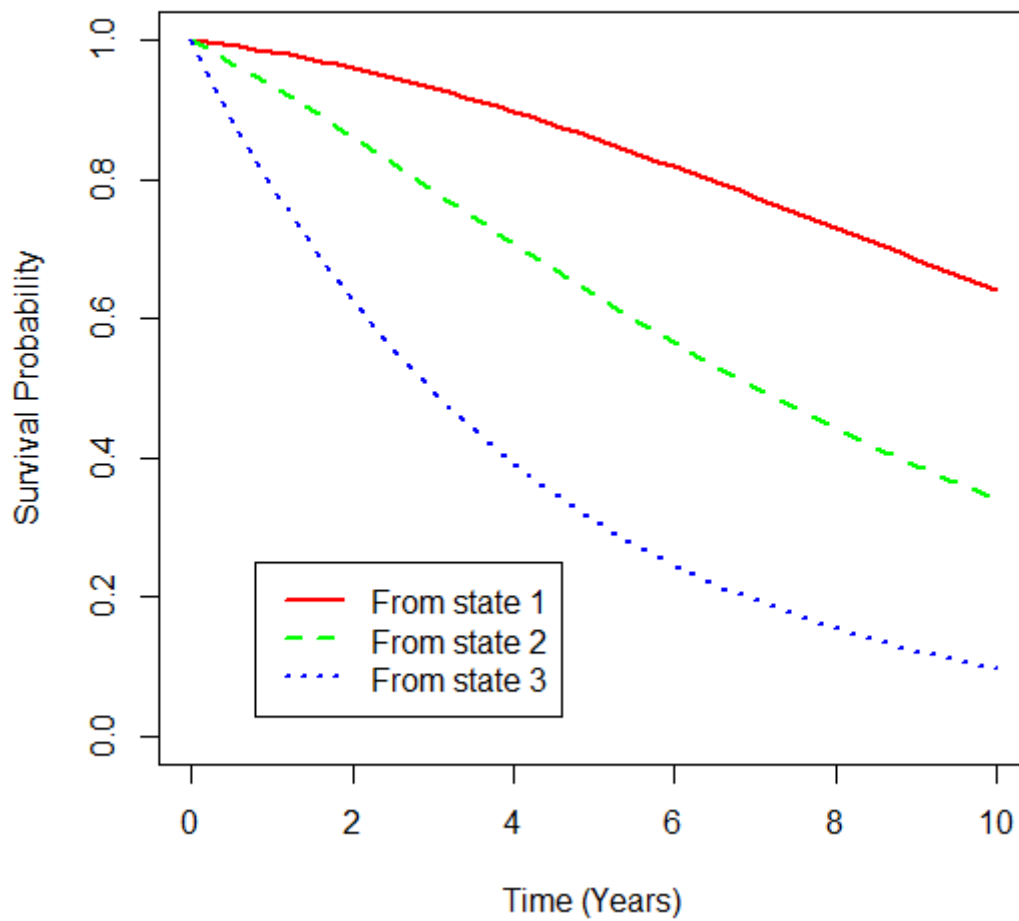
Supplementary

Supplementary figure 1: 10-years survival probability for the women as being non-user)from State 1(, home and community care)from State 2(and residential aged care)from State 3(
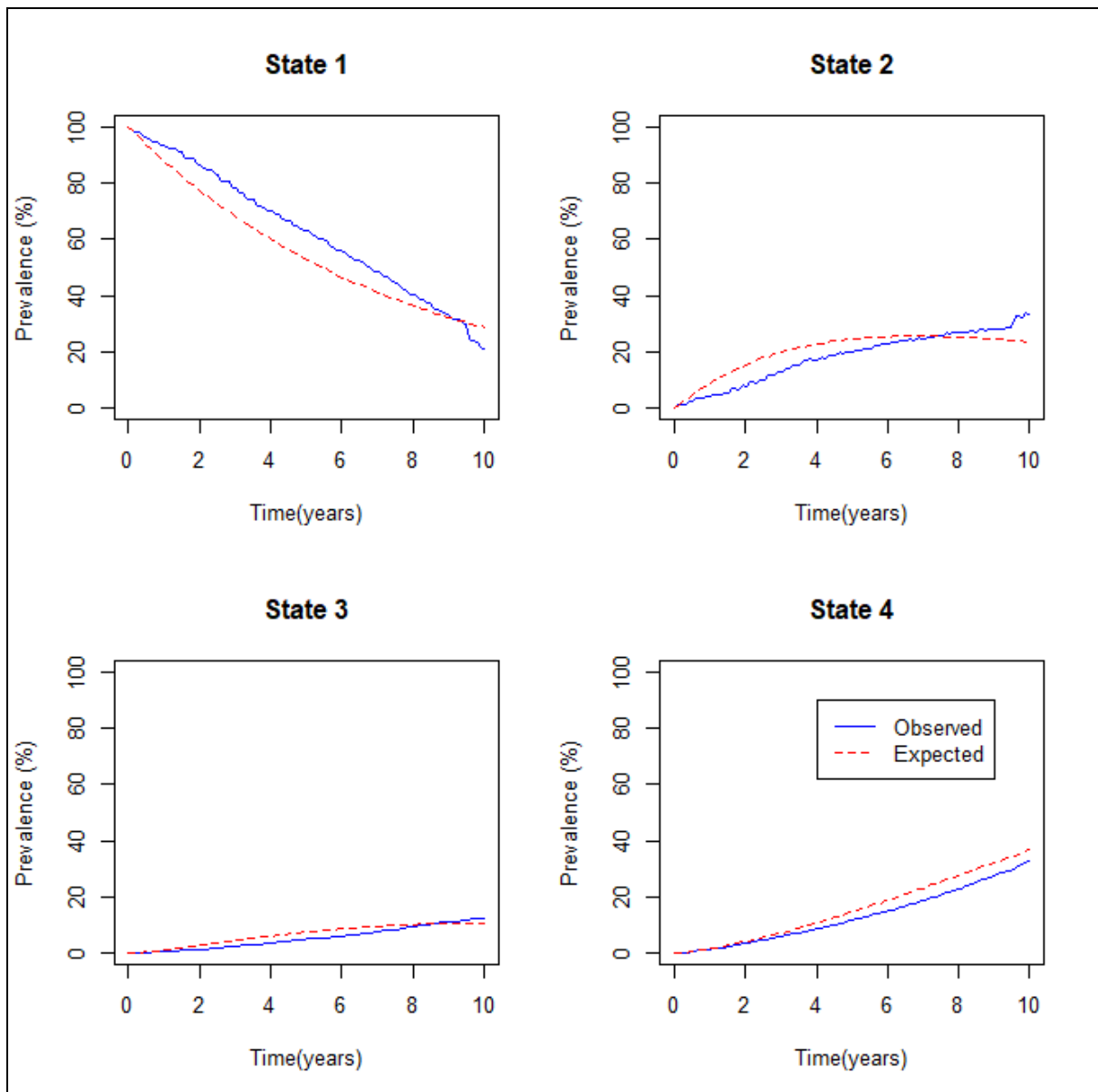
Supplementary figure 2: Observed and expected prevalence of different states

CHAPTER 9: Discussion

9.1 Overview

With the ageing of Australia's population, both the number and proportion of older people in the population are increasing. There is also an increased demand for aged care services which is projected to further increase in accordance with the ageing of the large baby-boomers cohort (Australian Government Department of Health, 2017b; O'Loughlin, Browning, & Kendig, 2016). Like many other countries with ageing populations, aged care has become a significant part of Australia's healthcare and social policies. While the government has undertaken and implemented a range of reform initiatives over the last few decades, aged care is yet to be a sustainable system that can support the wellbeing of older Australians, deliver care in ways that respect their dignity, and meet the challenges ahead.

Several reviews have identified that the current aged care system is complex, and older people experience multifaceted journeys through the fragmented systems to meet their care needs)National Health Hospitals Reform Commission, 2009; Productivity Commission, 2011(. Particularly, there is a lack of understanding about how older people use different types of aged care services over time, according to their changing needs and circumstances, and what the factors are that influence them in moving to complex or high-level service use. Using the survey data of the 1921-26 birth cohort of the Australian Longitudinal Study on Women's Health, linked aged care, and National Death Index data, the current study has examined the patterns of aged care service use over time and how the

movements of older women between different levels of aged are influenced by their changing needs and circumstances throughout later life.

9.2 General Discussion

9.2.1 Patterns of Home and Community Care

We found that approximately 70% of women in the cohort)n=11,133(used HACC services at some point from 2001-2011 when they were aged 75-90 years. The Australian Institute of Health and Welfare)2018d(reports that most people who enter aged care first use HACC services. Our analysis identified six distinct groups of women based on their volume/number of HACC services utilised. Over the 11 years of the study, the majority of women used a few basic services including domestic assistance, transport, personal care, nursing, and allied health services. In contrast, approximately one-fourth of women used complex patterns of care with a high volume and number of services. More than one-third of women in the complex groups used 10 or more service types, indicating their multifaceted care needs. However, participants may not have concurrently used the entire range of services over the study period. Researchers in another Australian study report that approximately three-fourths of consumers used a small number, but a wide range of services (Kendig et al., 2012). Only a small proportion of older people received an intensive amount of community-based health and social care services (Australian Institute of Health and Welfare, 2007; Choi, Morrow-Howell, & Proctor, 2006; Kendig et al., 2012). However, a relatively greater proportion of participants in our study had complex patterns of HACC use, which can be attributed to their older age, gender, and longer study period)Austad, 2009; Stones & Gullifer, 2016(.

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The recent transition of HACC to CHSP may have a significant effect on service provision as CHSP is designed to provide consumers easier access and greater flexibility across a range of services. We may see a growth in the cluster with complex patterns of service use as greater autonomy among consumers in choosing services may increase the combination of services, and possibly the volume of service use. With the increased provision of HCP services in recent years, some consumers who would have been in the complex patterns of service user groups may have had the opportunity to use HCP level 1. However, we also recognize that there is a long waiting time for HCP packages, which includes people waiting for higher care packages according to their assessed needs (Australian Goverment Department of Health, 2019c; Yu & Byles, 2019). The proportion of participants using community care packages)currently HCP(was very low in our study cohort as the provision of these programs was relatively limited during that time. As for the patterns of HACC use, we assume that patterns of service use will not change significantly under the current CHSP system. Our findings can contribute to improving service delivery by targeting distinct groups according to service use as well as their needs and other characteristics.

9.2.2 Patterns of Aged Care Use

Four different trajectories of aged care use were identified over the period 2001 to 2011, when the cohort was aged 75-80 and 85-90 years, respectively. Our findings suggest there was a large variation among women in terms of their patterns of service use across later

life. For example, women differed with respect to the timing of entry to different services, the type and combination of services they used, and their survival patterns.

A large proportion of women)41%(included in the 'mostly non-use group' were likely to not use any services or used only limited entry-level HACC services until age 85. However, with a rapid increase in both the probability of using services and mortality in the last few years, many women may have entered the aged care system at an older age)85 and over(. This age or the life-stage is when most people are increasingly dependent on some level of aged care service)Reeve et al., 2018(.

Approximately one-quarter of women belonged to the 'moderate to high-level HACC/CACP' group who had the highest probability of consistently using community care services through the study period. Their chances of entering RAC increased in the last few years of the study, as they approached the end of life. During this period, community care services were no longer able to adequately meet their increasing care needs. This is consistent with other research suggesting that long-term care begins with receiving care in the community, followed by a combination of community care and respite RAC, before transitioning to permanent RAC (Australian Institute of Health and Welfare, 2017a; Mehdizadeh, 2002).

A small proportion)11%(of women entered RAC, with many having previously used HACC/CACP services. For this group, the chances of using RAC during later life was higher than the cohort prevalence at any given time point. Researchers in previous studies

report that from age 65, two out of three women need aged care at some point in their remaining life, mostly consisting of community care services use. The majority of older people do not enter RAC)Chomik & MacLennan, 2014; Productivity Commission, 2011(. During the first half of the study, women in the 'increasing RAC' class were also likely to use community care services. However, with the increasing age, they were more likely to exclusively use RAC, in agreement with the findings of the Australian Institute of Health and Welfare)2018a(.

Over one-quarter women of the sample were in the 'early mortality' class, with many using different types of services in their last few years of life. However, they had the lowest surviving probability, with all being deceased by their mid 80s. The closer participants were to death, the more likely they were to use aged care services (Joenpera et al., 2016).

Our findings are based on the data collected prior to recent significant reforms. Post-reform, we would expect similar patterns according to whether and when people need community care or residential care. Under the recent reforms, new community care programs CHSP)previous HACC(and HCP)previous CACP(have been launched, which offer greater flexibility across a wider range of services to meet consumer-specific needs. Particularly, consumer directed care provision has been implemented in the HCP program. In accordance with a high demand for HCP services among older Australians, there has been a significant increase in the provision of these services in recent years. Consequently, we may see a growth in the group that can be sustained in the community: either in the

size of the group, or in the length of time they remain supported by community services, thus decreasing the time spent in residential care.

9.2.3 Trajectories of Care Needs in Residential Aged Care

Five distinct trajectory groups were identified among the women)n = 3,519(who were in RAC for up to 60 months between 2008 to 2014. There was large variation among the residents in different trajectory groups according to the combinations of care needs across three ACFI domains)including ADL, behaviour, and complex health care needs(over time, as well as their survival probabilities.

Residents who belonged to the 'less dependent-low need' trajectory group)13%(had low care needs in all three domains, and had the highest survival probability. Considering their higher survival probabilities compared to other groups, they were most likely to be long-stay residents. These residents entered RAC earlier than expected, which could be explained by the previous low-and high-level care provision in RAC. However, this distinction in RAC has been removed since July 1, 2014 (Australian Institute of Health and Welfare, 2015c). While community-based aged care in Australia provides a range of entry-level services, particularly through the CHSP, the supply of HCP services is noticeably lower than the skyrocketing demand for these services among older Australians in recent years. This has been reflected in the steadily increasing wait time to access these services in recent years)Visvanathan et al., 2019; Yu & Byles, 2019(. A recent study in Australia found that HCP service use is significantly associated with decreased risk of entering RAC (Jorgensen et al., 2018). In a U.S. based study, nearly one-fifth of residents

in nursing homes were found to be high functioning and could potentially be supported by community-based care (McNabney et al., 2007). The recent growth in HCP services may reduce the number of care trajectories in RAC, particularly, this low-dependent less care needs group may not exist as an increasing number of older people may be supported to stay at home for longer and enter RAC with a higher care trajectory than before.

In contrast, those belonging to the 'high dependent-behavioural and complex need' group)28%(consistently had high care needs across all three domains, and they had the lowest survival probability. In a cross-sectional study, the Australian Institute of Health and Welfare)2018c(reported that 31% of residents had high care needs in all three ACFI domains in 2018. This variation from our findings could be attributed to a different study design and periods; for example, the aim of the current policy is for older people to be supported longer in the community with the increased provision of HCP services.

Furthermore, increasingly complex care needs among participants of the 'high dependent-complex need' group)21%(could be attributed partly to their higher likelihood of having multiple morbidities, and older age at admission to RAC. Across the different trajectories, around two-thirds of the residents (comprised in three groups: high dependent-complex need and high dependent-behavioural and complex need') had high and increasing ADL limitations over time. Nearly half (49%) of the residents (comprised in two groups: high dependent-complex need and high dependent-behavioural and complex need) had high and increasing complex complex care needs. This is consistent with government reports of providers' higher funding claims on a specific domain)e.g., complex healthcare need(The

the Government has described this as 'providers behaviour' (Australian Government Department of Health, 2019a; Department of Health 2016), but the could be also reflect true increased morbidity and complexity of the care needs. On the other hand, residents of 'high dependent-behavioural need' group)21%(had very low needs in complex health care until 2 years of stay, thereafter sharly increasing. However, they had medium to high care needs in both ADL and BEH domains over time, indicating that these limitations are not associated with complex care needs among these residents.

9.2.4 Transitioning into and through the Aged Care System

We estimated transition rates and probabilities of older women between different levels of aged care use)non-user, HACC user, RAC user, and death(as they aged from their late 70s to late 80s. Women were almost 11 times more likely to enter aged care with HACC than RAC as the former is the most common entrant service and the latter is often the last service. Approximately half the HACC users continued to use this service until age 85-90. Additionally, transitioning from HACC to RAC was more likely than transitioning from HACC to death)i. e., died without entering RAC(. This is consistent with findings of Joenpera et al. (2016), who found that 84% of people enter the aged system through community-based aged care)mostly HACC(and only 10% first use permanent RAC. Furthermore, over two-thirds of consumers entered aged care by first using HACC and over three-fourths of residents in RAC reported that they had used HACC services previously (Australian Institute of Health and Welfare, 2017a).

Our findings are important to ongoing policy debate pertaining to the preference for community care, and the appropriateness of residential care)Productivity Commission, 2011(. For some women, RAC may be an unavoidable necessity based on their high care needs but many may have opportunities to avoid RAC through prevention and management of chronic diseases, attention to social needs, and better support in the community)Blackburn, Locher, & Kilgore, 2014; Nishita et al., 2008(.

During the 10 years of study)2002 to 2011(, approximately 28% of women did not use aged care)HACC and/or RAC(until age 85-90. This was equivalent to the percentage of older women) ≥ 75 years of age(reported in the Australian Productivity Commission report who required no formal aged care during their lifetime)Productivity Commission, 2011(. Over one-third of participants)34.5%(died during the study period, with 9.5% dying without using any aged care services. That is, of those who died within the study period, 27% did not use aged care during their lifespan. This is moderately higher than the findings of Joenpera et al. (2016) study who reported that 20% of people aged 65 and over who died between 2010-2011 did not use any aged care services. The variation may partly owe to the age of our study cohort and the study period. For example, by end of our study period the maximum age of the cohort was 85-90 years. Those who die beyond that age are more likely to be dependent on aged care services. The Australian Institute of Health and Welfare reports that 91% of people who died at age 85 or over used aged care services, compared to 57% of people who died between ages 65-74)Australian Institute of Health and Welfare, 2015a(.

9.2.5 Length of Stay in Aged Care

In the current analysis, women aged 75-80 years survived for almost eight years without using the mainstream aged care services)HACC or RAC(. The most common age at entry to age care was 85-90 years)Australian Institute of Health and Welfare, 2018a(. However, women may use Veteran Home Care services or other short-term aged care services including respite care, restorative care or transition care, and these services were not included in the current analysis. The predicted average duration of older women's care and support by HACC was almost 5 years. This mostly comprised use of a few entry-level basic services including domestic assistance, transport, nursing, and allied health services. However, some may require a combination of many services)complex patterns(including personal care, centre-based day care, meals, and other food services.

The predicted average length of stay in RAC was 2 years and 6 months which is slightly lower than reported in the Australian Institute of Health and Welfare)2018b(study, which reported that women's average length of stay was 2 years 10 months. This variation may be mainly attributed to study participants, with the latter study including only those who were discharged from RAC)mostly decedents(, while in our study both decedents and existing residents were included. We may have under-estimated the lifetime length of stay in RAC, as we did not know the exact length of time for surviving residents. Average length of stay in permanent residential aged care has been declining in recent years)3.3 years in 2003 versus 2.97 in 2018(. This is mainly attributable to an increased proportion of older people having high-level complex care support from HCP packages, which delays their entry to RAC)Jorgensen et al., 2018(. Evidence regarding the combined period of

aged care use in the community and residential aged care suggests that older women spend a substantial proportion of their later life either living at home with formal support or in a residential facility.

9.2.6 Transitioning Between Different Levels of Aged Care

9.2.6.1 Risk Factors of Home and Community Care Use

We identified a range of factors associated with risk of age at first HACC use across later life. Living in inner/regional/remote areas or living alone or having difficulty in managing income were each associated with an increased risk of using HACC services. Our findings are in agreement with another study observing that HACC use was associated with increased odds of living in a remote/regional area, not having a partner, and having a lower household income (Jorm et al., 2010). Greater use of HACC services in remote/regional areas reflects more limited access to residential aged care and/or a long waiting list to access HCP services in those areas (Australian Goverment Department of Health, 2019c). Women who had financial difficulties were less likely to enter high-cost RAC, but instead they were more dependent on low-cost HACC services. Based on the actual need-based demand, many women may have been eligible to access HCP or admission to RAC but their need was unmet. In some cases, women may not have used services provided by HACC if they had overlapping coverage under the Veterans' Home Care scheme, which was not included in the current analysis)Australian Institute of Health and Welfare, 2008(.

Health-related need factors, including comorbid conditions, were associated with increased use of HACC services. Diagnoses of comorbid conditions such as diabetes, heart disease, and asthma were associated with poor physical functioning and disability, which may have contributed to greater aged care needs. For example, lower physical functioning scores predicted the need for physical care support. Another Australian study reported greater HACC use among older people with lower physical functioning, poorer self-rated health, and chronic conditions)Jorm et al., 2010; Rochat et al., 2010(. Low physical functioning scores)<40(have been associated with fear of falls and an increased risk of using age care services (Cumming et al., 2000). Women with such scores often have difficulty performing vigorous activities such as walking long distances, climbing stairs, and lifting or carrying. Furthermore, approximately one-third of such women havedifficulty walking 100 meters and 10% require assistance with dressing and bathing (Hubbard, Wass, & Pepper, 2017).

9.2.6.2 Predictors of Transitioning from HACC to Residential Aged Care

We found that the probabilities of cumulative incidence of admission to RAC from the date of first HACC use were significantly lower among those who belonged to the 'complex HACC' group)who used high volume and number of services(than those in the 'basic or moderate HACC' group, with probabilities of 15% and 30%, respectively, at the median observation time)63 months(. Our finding suggests that higher or complex use of HACC services delayed admission to RAC among those who belonged to the complex HACC group. Furthermore, findings from the competing risk regression models showed that membership of the complex HACC group was significantly associated with decreased

sub-distributional hazards for participants with an observation period of more than 36 months or more than 72 months but not for those with more than 108 months. This also indicates that higher or complex use of HACC services reduce the hazard of earlier admission to RAC, but this may not be associated with hazard of delayed admission. This highlights the importance of RAC at a certain point of later life, particularly in the last few years before death when escalating care needs are no longer be fulfilled by community care services. The Australian Institute of Health and Welfare (2015a) reports that RAC is the last program used by over half of the aged care users)54%(.

Over the 13-years of our study, 44% entered RAC, and a further 23% died without entering RAC. Despite a substantial proportion who entered RAC and used RAC for an average 2.9 years)Australian Institute of Health and Welfare, 2018b(, our findings suggest that increased use of HACC services can reduce the hazard of early admission to RAC, and consequently may reduce the length of stay in RAC. Several US-based regional studies report that an increased use of home- and community-based care service is associated with a reduced risk of transitioning to a nursing home)Chen & Berkowitz, 2012; Greiner et al., 2014; Sands et al., 2012(. A recent region-based Australian study demonstrates that an hour per week of HCP service use is associated with a 6% decrease in risk of time to entering RAC over the 18-month period)Jorgensen et al., 2018(.

Those living in regional/remote areas rather than major cities and those born overseas rather than Australia had significantly decreased hazards of entering RAC. The decreased hazard of entering RAC in the remote/regional areas might partly be attributed to the

lower availability of RAC in that region. This is also reflected in the findings of another recent study on this cohort that women living in remote/regional areas had 58% higher odds of having a rehabilitation or convalescence hospitalisation (Chojenta, Byles, & Nair, 2018). Furthermore, the Australian Institute of Health and Welfare (2016a) reported that people born in non-English speaking countries were more likely to use HCP services, which may in turn reduce their risk entering RAC.

Other factors associated with an increased hazard of entering RAC included being older age at first HACC use, living in an apartment or retirement village, having low physical functioning)score<40(, or having falls with injury. These findings are consistent with several previous studies reporting that older age, higher limitations in ADL and falls were significantly associated with increased risk of RAC admission)Cumming et al., 2000; Fong, Mitchell, & Koh, 2015(. An earlier study of the ALWSH cohort that focused on housing also reported a similar association of housing type with time to first RAC admission)Forder et al., 2017(.

While being widowed and having a higher number of chronic conditions were significantly associated with transitioning to HACC service use, these factors were not significantly associated with transitioning from HACC to RAC. It is possible that such participants were receiving enough HACC services or alternative services)e.g., HCP which was not covered in our study(to manage their conditions or other care needs in community settings. Although those who were widowed or had multiple conditions had an increased risk of transitioning to RAC in other studies (Forder et al., 2017; Kendig et al.,

2010), these studies were not based only on participants who had already started using community-based aged care services.

9.2.6.3 Predictors for the Membership of Different Latent Patterns

Women who lived in inner/outer/remote areas, were widowed, had difficulties in managing income, or who lived alone were more likely to be a member either of the moderate to high-level HACC/CACP, increasing RAC, or early mortality class than the mostly non-user class. Participants' with the aforementioned characteristics had an increased odds of using HACC services)Jorm et al., 2010(and an increased risk of entering RAC (Kendig et al., 2010). The increased odds of service use among older women in inner/outer/remote areas reflect a lack of informal support)both from family members and community(as well as the availability of HACC/CACP services in these areas. Those who were widowed and lived alone were more likely to be frail and less likely to receive informal support, leaving them increasingly dependent on formal aged care services.

Furthermore, health-related need factors including lower SF-36 quality of life scores, diagnosed chronic conditions, falls with injury in the last 12 months, or poor/fair self-rated health were associated with increased odds of membership of the following classes: early mortality, increasing RAC, and moderate to high-level HACC/CACP, compared with the non-user class. Individuals with the above mentioned health profiles had an increased odds of HACC service use)Jorm et al., 2010(. Falls or fear of fall has been reported as a significant risk factor for nursing home admission (Cumming et al., 2000; Tinetti &

Williams, 1997). Additionally, self-reported poor health status or disability is a significant predictor of nursing home admission and mortality (Guralnik et al., 1994; Weinberger et al., 1986).

Karmel et al. (2012)report that people's patterns of aged care service use varies widely according to different health conditions that affected their care needs. Those with musculoskeletal problems were more likely to use community care services, and those with dementia or cerebrovascular disease were more likely to enter residential aged care. In our study, we found that those with arthritis were associated with having increased odds of being a member of moderate to high-level HACC/CACP)OR=1.5, 95%CI: 1.4-1.7(or increasing RAC class)OR: 1.2, 95%CI: 1.0-1.4(, but they were not associated with being in the early mortality class. However, those diagnosed with asthma were observed to have an increased odds of belonging to the mostly moderate to high-level HACC/CACP and early mortality classes, compared with the non-user class. The latter finding is consistent with another study of this cohort that found women who had asthma had a 17% higher risk of death than those without asthma (Eftekhari et al., 2016).

9.3 Strength and Limitations

This Ph.D. project includes five distinct original and novel studies. An important strength is the use of longitudinal data from a nationally representative sample, linked to administrative aged care and National Death Index databases. This provided us a broad platform to follow-up the women and assessing their patterns of aged care service use over time, trajectories of care needs over time within RAC, and transitions into and through the

aged care system across later life, according to their characteristics. The application of sophisticated statistical Modelling techniques)including Markov multi-state Modelling, competing risk analysis, multi-trajectory Modelling, repeated measures latent class analysis and cluster analysis(is another strength. Each of the studies used robust methodology with a large sample size, ensure sufficient statistical power.

However, a few limitations should be noted when interpreting our results. Specific limitations in each of the five studies were discussed in the relevant chapters. Some common limitations are noted below:

- The findings of our study are only representative of women, as men were not included in the ALSWH. Men tend to enter permanent RAC earlier in life than women because the latter generally receive support from other formal aged care programs such as HACC (Australian Institute of Health and Welfare, 2015d). However, the average length of stay for women in permanent RAC is 1.5 times higher than men, reflecting their longer life span)Australian Institute of Health and Welfare, 2018b(. Further research is required to understand the patterns and trajectories of aged care service use by males, who may have different care needs. For example, a lower proportion of men than women have reported high care needs across three ACFI domains)Australian Institute of Health and Welfare, 2018c(.

- While dementia is found to be a strong predictor of entering RAC and corresponding reduced use of community care services (Waller, Mishra, & Dobson, 2017), we did not include this in our models, as most dementia cases were identified at the time of or following RAC admission on ACAT or ACFI data.

Almost one-third)33%(of participants in our study were identified as having dementia by the time they reached 76-93 years of age.

- We have also not assessed the role of informal supports and how these influence the transitions into and through aged care service types. Furthermore, we were unable to assess the quality of aged care services and whether such services were adequate to meet the needs of older women in Australia.

- Participants' characteristics)except age at first HACC use(were measured in ALSWH Survey 3)2002(and were not updated over time, as many dropped out from subsequent surveys. However, we adjusted for age at first HACC use in each model.

- Oversampling from remote/regional areas may have introduced selection bias with respect to the care needs of older women in major cities vs. inner/outer/remote areas. Thus, other more representative samples may yield different results.

- Among women who used multiple services, their status in a particular year was determined based on the most frequently used service. Services that were used for a fewer number of days)such as respite RAC, or women who were admitted to RAC within a few days before death(may have been missed.

- Some women were excluded from the multivariable analyses because of missing covariate information, potentially biasing results. In particular, women with missing values had a greater risk of using aged care services and subsequent early mortality.

- Care needs of residents in RAC were based on ACFI data which assesses overall care needs in fundamental care domains, and it is not a comprehensive assessment

tool which would include a broader range of care needs than required for the purpose of funding instruments.

- Trajectories of care needs in RAC for the short-stay and for the long-stay residents may be different. Our separate analysis shows that the size of the low care needs groups)less dependent-low need and less dependent-increasing need(increased for the long-stay residents)>30 months(, while for the short-stay residents there was a moderate change in all groups particularly a noticeable increase in size with high CHC groups)Appendix Figure A1 and Figure A2(.

9.4 Conclusions and Future Direction

Ageing of the large baby boomer generation will see a rapid increase in the demand for aged care services over the next two decades. The new entrants of the aged care sector are likely to have higher education, greater awareness and understanding of health issues and greater expectations of healthcare services than the current older population. This generational transition poses additional challenges, which may influence future models of aged care provision. Understanding the patterns of aged care service use across later life and chances of transitioning to different levels of aged services over time according to individual changing needs and circumstances are important for planning service delivery, forecasting future demand, and building workforce capacity for the aged care sector in Australia. Currently, there is a paucity of evidence to show how older people utilize different types of services, ranging from supportive care in the community to high-level care in residential settings)Productivity Commission, 2011(. This study represents a first step in identifying different patterns of service use within and across the aged programs

over time, chances of transitioning from one level)type(of care to another over time and length of stay at each level, according to participants' characteristics.

With their longer lifespan, older women are more likely than men to use aged care services. By better understanding differential patterns of usingindividual service types and service type combinations, the timing of entrance to different aged care programs, and survival patterns, our findings can contribute to planning for improved service delivery and optimize future capacity planning of the aged care system. For example, profiling of the client groups at the community settings and targeting people who have a complex pattern of service use may need further assessment/reablement or who have been consumers for a long time their changing needs may not have been recognized. It is important to know their unmet care needs, particularly for those who live in regional/remote areas, have difficulties in managing income, are widowed, or live alone. The findings of the current study provide a baseline for further study to examine the unmet care needs among these women groups and whether the unmet care needs are mitigated by the current increased provision of HCP services.

Our findings provide much needed information regarding service outcomes and effectiveness of the HACC program, which allows older women to stay at home for longer and highlights the importance of providing a range of services under this program. A recent regional study demonstrated that increased HCP service use is associated with a decreased risk of entering RAC. However, these findings need to be translated into policy

after further study based on national data on the current CHSP and HCP programs for both male and female populations.

We found that older women's aged care use was not only driven by their demographic predisposing factors but also by their need factors, including lower physical functioning and the presence of chronic health conditions. The major health conditions included heart problems, diabetes, arthritis, and asthma, which are prevalent in this cohort and age group. These conditions are also associated with significant disability and low physical functioning. Therefore, to reduce the risk of premature residential admission, in addition to increasing the provision of CHSP and HCP services, we would recommend the current policy should prioritize the prevention of functional decline and falls, managing chronic illness, and reablement focus.

The patterns of different levels of aged care service use over time demonstrate that women's entrance to age care system widely varied, with the increased level of care use being highly concentrated at the end of life. Many women can live independently without using any aged care services or using a low volume of few community care services until age 85-90. However, a substantial proportion enter RAC at some point)maybe at young old or very old age(when their escalating care needs can no longer be supported by community care; this is more likely as they approach the last few years of life. Evidence regarding the predictors of membership of the different patterns of aged care use as well as risk factors for transitioning from one level of care to another can be useful to policymakers for planning the equitable delivery of aged care services across different

groups. Older Australians and their familiescan benefit from knowledge about prior trajectories for people with similar characteristics, and can thus better plan for their own later life.

The probabilities of transition between different levels of age care use over time, the survival probabilities at each level of aged care use, and information regarding the length of stay, have important implications for better planning and capacity design of the future aged care system. In addition, this information is important to care providers, carers, care recipients, and other stakeholders of the aged care system. For example, providers can use this information to plan for the expected demand for different levels of care and the workforce required for delivering the care services. For older people and their family, this information will help guide planning for their long-term care insurance, asset management, and care planning. Furthermore, our study provides a baseline for further study that can determine the aged care free life expectancy, in particular, RAC free life expectancy and examine the impact of the predisposing, enabling and need factors on these life expectancies.

Significant variation in the combinations of care needs across the trajectory groups over time in RAC suggests that differential care planning is essential for each trajectory group. Our findings have the potential to help design long-term or short-term care planning and to estimate the required amount of funding for residents of each trajectory group through their stay in residential aged care. Furthermore, the findings can be utilized to evaluate policies for increased provision of HCP services in the community and how this affects the

size of a particular trajectory group)e.g., low care need group(in RAC. However, a comprehensive assessment of residents' care needs)other than ACFI(is necessary to fully understand their changing circumstances of care needs over time. Furthermore, our findings provide evidence to compare and evaluate the recent government policy to replace the ACFI with a new funding assessment tool AN-ACC version 1)Eagar et al., 2019(.

Finally, the findings presented in the current study provide insights and a more comprehensive understanding of the aged care pathways of older women across later life, and how their trajectories into and through the pathways are influenced and shaped by a wide range of predisposing, enabling, and health factors. Our study highlights the power of linkage between routinely collected administrative and longitudinal survey data to underpinning the pathways, contextual factors, and predictive capabilities towards the future direction of the aged care system. As a large and complex system, aged care policies should be based on evidence produced from the comprehensive analysis of such powerful database as well as simulation of real-life scenarios, for example, dynamic Modelling including inputs from all stakeholders.

CHAPTER 10: Policy Brief

Patterns and Prediction of Aged Care Use Across Later Life: Policy Implications

Overview

The Australian aged care sector will see a rapid increase in the demand of aged services over the next two decades in accordance with the ageing of the baby boom generation. The new entrants to the aged care sector are likely to have higher education, greater awareness, and understanding of health issues and greater expectations of healthcare services than the current older population. Consequently, the variations in the expectation and preference for care are expected to further widen in coming years. The need to reform the aged care sector is the product of both the rapidly ageing and increasingly diverse populations.

Over the course of later life, many older Australians use different types of services from different parts of the aged care system, according to changes in their needs, and to other factors that might predispose to needing care or enable easier access to and uptake of services. Because of longer lifespan along with a higher likelihood of being widow and living alone, older women are more likely than men to use aged care services than older men. Around two-thirds consumers in the Australian aged care system are women (Australian Institute of Health and Welfare, 2018d). However, limited research evidence is available about how their journey from the entry-level community care to high-level care

in the residential aged care and until death, according to their characteristics that determine needs for service use over times. Understanding their patterns of aged care service use across later life, predicted length of stay and chances of transitioning from one level of care to another over time, are important not only to plan (e.g., long-term care insurance, assessment, and selection of care) for their care pathways but also will help guide policymakers to future capacity design of the aged care system including workforce and funding management.

Problems

- There is a need for longitudinal evidence on how older Australians use different types of aged care services, what is their latent patterns of service use across later life, and how is their trajectories of care needs change over time in RAC are missing.

- Evidence relating to chances of using different types of aged care services across later life and what factors influence older people transitioning to increased level of service use are limited

Objectives of the Policy Brief

Using data of the 1921-26 birth cohort of the Australian Longitudinal Study on Women's Health)ALSWH(, linked aged care data, and National Death Index from 2001 to 214, this study aimed to provide evidence on

- the patterns of home and community care use (currently known as Commonwealth Home Support Program) across later life and how the patterns of service use are associated with subsequent residential care admission

- the latent pathways of different types of aged care use over time throughout the later life

- the predicted probabilities of transitioning from one level of care to another, length of stay, and the risk factor associated with each transition.

- Trajectories of care needs over time among the residents living in RAC

Who is This Policy Brief for?

- Aged care strategic policy branch, Australian Government Department of Health

- Older Australians and their family

- Aged care providers and care professional including nurses, care manager, care assistant.

Key Findings

- Nearly three out of four women used Home and Community Care (HACC) over the period 2001-2014 when they were aged 75 to 93 years. Five distinct groups were identified based on their volume of HACC use over the study period (Rahman et al., 2019). Majority (60%) belonged to 'basic HACC' group who used a low volume of few HACC services with a range of service options)mainly domestic assistance, transport, social care, and nursing care at home(and around

one-quarter (24%) belonged to three complex care use groups used high volume of many services (including nursing, personal care, meal and other food services(.

- An increased risk of HACC use was associated with a(living in remote/inner/regional areas, b(being widowed or divorced, c(having difficulty managing on available income, d(having chronic conditions, e(reporting lower scores on the SF-36 health-related quality of life, and f(poor/fair self-rated health.

- Complex patterns of HACC use were significantly associated with delayed admission to RAC, after adjusting for person-based characteristics

- Living in regional or remote areas was associated with decreased risk of transitioning time from HACC to RAC

- Increased risk of transitioning from HACC to RAC was associated with living in an apartment or a retirement village, having low physical functioning score, and falls with injury.

- Around 44% of HACC consumers were eventually admitted to RAC by age 88-93, with average length of stay 2.5 year. Majority of them have multiple health conditions, particularly dementia in the last two years of life.

- Over time, four different patterns of changes in aged care use were identified (Rahman, Efird, & Byles, 2019a). Women in the four patterns differed with respect to the timing of their entry into aged care, type and combination of service use, and their survival patterns:

  o Over two-fifths of women belonged to a group, which did not use any aged care services except for few basic community care services)e.g., domestic assistance, transport(until age 86-91.

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- - Around one-quarter had a long use of community care)provided by HACC/CACP as available at that time(.

  - 11% had a greater risk of using residential aged care)RAC(with all entered RAC by age 82-87 and. majority remain in RAC for at least three years

- We estimated transition rates from one level of care to another over time. For example, transitioning from non-user to HACC is 11 time higher than transitioning to RAC.

- We estimated the transition probabilities for moving from one level of care to another state or remaining in a particular level of care over time after adjusting for participants' baseline characteristics. For example, at the age of 76-81, a woman had 28% of chance to survive another 10 years without using any aged care services, with chances of dying 36%. The chances of remain in the HACC 24% and in RAC 11% after 10 years from that age.

- The predicted the length of HACC use: 5.0 years, and in RAC: 2.5 years

- We estimated survival probabilities for each care state over time. For example, at age of 76-81, the 10-year survival chance for a non-user was 67%, for a HACC user was 36%, and for a RAC resident was 10%.

- Five distinct trajectory groups were identified among the residents of RAC, with large variations in the combinations of levels of care needs over time across three domains of the Aged Care Funding Instrument (Rahman & Byles, 2019b).

  - Approximately 22% of residents belonged to a group which had high care needs across all three domains, and One-third)31%(included in two trajectory groups, which had low or low to medium care needs over time.

- o Overall, around two-thirds of the residents had high ADL limitations, and nearly half of the residents had complex care needs which was associated with their multiple comorbid conditions

Policy Options

At planning level

- Policy should focus individual as a whole, not just single characteristic. For example, planning for services must be based on more than just age, but also on other demographic characteristics, health needs, and disability.

- Prediction of the future demand for age care services must be based on research evidence that produced through a comprehensive analysis of the existing administrative aged care database and account for the individual characteristics and circumstances throughout later life.

- In accordance with the increased demand for services, the future capacity design of the aged care system (including workforce, number of places, and funding management) must be based on the current patterns of service across later life, transition rates and predicted probabilities for transition from one level another over time, length of stay, and survival patterns (Rahman, Efird, & Byles, 2019a, 2019b). All these information produced in our study can be updated by replacing the characteristics of the future cohorts of older people (e.g., baby boomer generation). Predictive analytical tools including simulation Modelling can test the validation of the potential findings.

At Service Level

- Given many women use few community services for a long time, there should be a focus on helping these women remain independent in the community, ensuring their potential for healthy ageing through ongoing support from their families and community, and helping them to maintain their abilities through health promotion activities.

- RAC should not be seen as the less desirable option over community care but a part of trajectory meeting different needs at later life. Given older women were in RAC for a long time)2.5 years(, RAC should be seen as a place for living, with a focus on lifestyle and quality of life.

- Given increased use of the both HCP and CHSP services delays the admission to RAC(Jorgensen et al., 2018; Rahman & Byles, 2019a, 2019b), policy should focus on increasing the provision of CHSP and HCP services, particularly reducing the wait time for access HCP levels. Furthermore, we would recommend the current policy should prioritize the prevention of functional decline and falls, managing chronic illness, and reablement focus.

- A comprehensive assessment tool (beyond the ACFI) is needed to measure complex health care needs among residents in RAC, and there should be a greater focus on their health and medical care needs.

Contact Address

Md Mijanur Rahman MSc	**Associate Professor Liz Holliday**
PhD candidate	School of Medicine and Public Health
Priority Research Centre for Generational Health and Ageing	Faculty of Health and Medicine
The University of Newcastle	The University of Newcastle
Email: MdMijanur.Rahman@uon.edu.au	Email: liz.holliday@newcastle.edu.au
Mobile: 0421621127	Phone:)02(40420508

Professor Julie Byes

Director, Priority Research Centre for Generational Health and Ageing

Global Innovation Chair in Responsive Transitions in Health and Ageing

The University of Newcastle

Email: julie.byles@newcastle.edu.au

Phone:+61 (02) 40420668

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Appendix 1: Conference Abstract

The Types and Patterns of Hacc Service Use Among A Large Cohort of Older Australian Women

RAHMAN Mijanur[1], EFIRD T. Jimmy[1] and BYLES E. Julie[1]

[1]Priority Research Centre for Generational Health and Ageing, The University of Newcastle

The Australian aged care system aims to provide a continuum of services to meet the diverse needs of people as they age, depending on whether they are able to be maintained in their own home with sufficient supports, or whether they need to receive residential aged care. Most older people will need some form of aged care services at some time, in addition to the mainstay of care and support provided by partners, family and friends. The aim of this study was to classify the pattern of Home and Community Care)HACC(service use by older Australian women based on actual volume of service use over the period 2001 through 2011 and to understand association with predisposing, enabling and need factors. This study utilized survey and linked aged care data for the 1921-1926 cohort of size 11,596 of the Australian Longitudinal Study on Women's Health. Data were collected from the inception of HACC service in 2001 through 2011 when the women were 76-81 years to 86-91 years of age respectively. A K-Median cluster analysis was performed on 7754 HACC consumers of linked dataset based on their types and volume of service use over the whole period of service use. Nine distinct clusters of consumers were

identified of whom one cluster consisting of more than half of the consumers was considered as the least service user group. Two of the clusters were considered as 'complex cluster' in terms of range of community service and assistance received while other clusters comprised mostly of one or two dominant service users. The analysis will have implications for planning delivery of care services for different groups of women in the community and point to ways to increase the effectiveness of service delivery.

Repeated time to admission and length of stay in residential aged care: A recurrent event analysis using counting process model

Mijanur Rahman, MSc[1,2], Jimmy T. Efird, PhD, MSc[1,2], Julie E. Byles, PhD[1,2]

[1]Priority Research Centre for Generational Health and Ageing, The University of Newcastle
[2]Centre for Clinical Epidemiology and Biostatistics, The University of Newcastle

Backgorund: People in residential aged care)RAC(can have multiple episodes of service use, including respite care and interruptions in long-term stay. However, most analyses of health service use include only the occurrence of first event or treat multiple events as independent, ignoring the correlation within subject. This study examined the risk of admission and length of stay)LOS(in RAC among older Australian women while counting for the first and subsequent admissions and length of each episode.

Methods: The Andersen-Gill)AG(counting process model was used to analyse self-completed survey and linked aged care data for 10,424 participants in the Australian Longitudinal Study on Women's Health. Data for the period 2001-2011, from when the women were 75-80 years of age until 85-90, were included in the analysis. Variables examined in the adjusted model were participant's area of residence, country of birth, marital status, highest qualification, ability to managing income and past Home and Community Care)HACC(service use.

Results: reveal that approximately 38% of women had one or more RAC admission records, with incidence rate of 1.6 admissions per woman over the 10 years, and average LOS per RAC user of 26.4 months)95%CI:25.6-27.3(. Women who did not have a partner had 1.24 times higher risk of admission in RAC compared with partnered women. Participants who previously used HACC services had 2.06 times higher risk of admission

in RAC but their LOS in RAC was almost 10 months less than the LOS for women with no past HACC services.

Conclusions: The findings of this analysis have implications for the effective planning of aged care services including the role of HACC use in delaying the admission in RAC and minimizing the LOS in RAC.

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Trajectories to aged care service use among older Australian women: A repeated measures latent class analysis

Mijanur Rahman, MSc[1,2,3], Jimmy T. Efird, PhD, MSc[1,2], Julie E. Byles, PhD[1,2]

[1]**Priority Research Centre for Generational Health and Ageing, The University of Newcastle**
[2]**Centre for Clinical Epidemiology and Biostatistics, The University of Newcastle**

Most older Australian need some form of aged care services at some point in later life, in addition to the mainstay of care and support provided by partners, family and friends. However, little is known about the journey from supportive care in the community to more complex and higher volume use, to residential care, according to the characteristics of the individual that determine their need for service use at different times. This study aims to identify latent patterns of aged care service use among older Australian women and to examine how socio-demographic predisposing and enabling, and health-related need factors are associated with these patterns. Survey data from 11,245 women of the 1921-26 birth cohort of the Australian Longitudinal Study on Women's Health)ALSWH(and linked aged care and death data from 2001 to 2011 are used. Repeated measures latent class analysis)RMLC(are applied to identify latent patterns of aged service use over time, and multinomial logistic regression is performed to estimate odds of factors associated with membership of different latent patterns. Four latent patterns are identified with over time approximately 44% of women belong to mostly non-user to basic Home and Community Care)HACC(user, 23% mostly moderate to high-level HACC user, 11% HACC to increasing RAC user, and 22% early mortality group after using different levels of services. The findings have implication in planning aged care services for older women through identifying factor associated with transition from low-level community care to high-level residential age care over time.

Title: Predicting Transition of Older Women into and Through the Aged Care System over Time: A Multi-state Modelling Approach Using Aged Care Linked Data

Mijanur Rahman, MSc[1,2]*, Jimmy T. Efird, PhD, MSc[1,2], and Julie E. Byles, PhD[1,2]

[1]Priority Research Centre for Generational Health and Ageing, University of Newcastle, Australia;

[2]Centre for Clinical Epidemiology and Biostatistics, University of Newcastle, Australia.

Abstract

Over the course of later life, most older people make use of different types and levels of care, from different parts of the aged care system, according to changes in their needs, and to other factors that might predispose to needing care or enable easier access to and uptake of services. However, limited research evidence is available on the movement older people into and through the aged care system over time according to their characteristics. This study aims to estimate probability of transition of older women between different levels of aged care services, length of stay at each level, and to examine the factors associate with transition into higher levels of service use and mortality. The current study utilized both survey and administrative aged care linked datasets of 9,050 eligible women of the cohort 1921-26 of Australian Longitudinal Study on Women's Health over the period January 2002 to December 2011 when the women were aged from 75-80 to 85-90 years. Based on the records of service use in each year, women were categorized into four hierarchical states including Non-user, Home and Community Care)HACC(user, Residential Aged

Care)RAC(user, and Death. A continuous time Markov model was used to estimate the transition probabilities and effect of covariates on the progression of higher-level service use including up to death. Result shows that a typical woman of the non-user cohort, had a probability of 0.36 of being died 10 years from January 2002, and probabilities of 0.28, 0.24 and 0.11 of being alive up to December 2011 with still remain in non-user or using HACC or RAC, respectively. Women who were widowed, living in remote or region areas, and had difficulty on managing their income were significantly more likely to transition from Non-user to HACC service use. Poor/fair self-rated health, lower SF-36 health related quality of life score, and having chronic conditions including heart problem, diabetes, asthma were associated with higher hazards for most transitions. The findings provide an insight into trajectories of aged care service use across later life and can help guide planning for future capacity of aged care systems.

Trajectories of Long-Term Care Needs Among Older Australian Women in RAC

M. Rahman and J. E. Byles

Priority Research Centre for Generational Health and Ageing, University of Newcastle

ABSTRACT

BACKGROUND: Over one-third of older Australians enter residential aged care)RAC(at some point in later life when their care needs are no longer fulfilled at home or in the community. Women are more likely than men to enter and stay longer in RAC. We aimed to identify groups of women who had similar trajectories over time across three care need domains including activities of daily living)ADL(, behavioral)BEH(and complex health care)CHC(.

METHODS: The sample consisted of 3,063 participants in the 1921-1926 birth cohort of the Australian Longitudinal Study on Women's Health)ALSWH(, who were in RAC for more than six months from 2008-2014. Analysis was based on linked data from ALSWH surveys, the need-based aged care funding instrument)ACFI(, and national death index. Participants' care needs were followed bi-annually up to 5 years from the date of admission to RAC. Group-based multi-trajectory Modelling were used to identify trajectory groups over tome.

RESULTS: Five trajectory groups were identified, with a greater variation in levels of care needs across three ACFI domains over time. Women who belonged to the first trajectory group)16%(had low care needs across three domains, while those belonging to the fourth group)22%(consistently had the highest care needs. The third group included women)21%(who had low to increasing care needs over time. Women of the other two groups had high limitations in ADL but differed by BEH and CHC. Higher age at admission to RAC, overweight/obese, and having multiple conditions were associated with increased odds of belonging to high care need groups than the third group.

CONCLUSIONS: The differential trajectories of care needs identified in our study will facilitate long-term care planning and service delivery among older Australian women in RAC, noting groups with the greatest need and the increasing acuity of need over time.

(This abstract has been selected for the 2019 Arthur Everithh Award)

Association between Patterns of Community Care Use and RAC Admission
Md Mijanur Rahman[1] & Julie Byles[1]

[1.]Prority Research Centre for Generational Health and Ageing, University of Newcastle

Abstract

Objective: Most older people who enter residential aged care)RAC(have previously used community aged care. Our study examined whether consumers' characteristics and their patterns of Home and Community Care)HACC(use,)now Commonwealth Home Support Program(, were associated with transitioning to RAC.

Methods: The sample consisted of 7,933 participants from the older 2001-2014. Patterns of HACC use were determined by using K-median cluster analysis. Predictors of transition from HACC to RAC were identified by survival analysis, with death as a completing event.

Results: Cluster analysis produced 7 distinct groups of HACC users: approximately 60% of women belonged to a basic HACC cluster with low volume and number of services; 24% belonged to three moderate HACC clusters)'Home meal', 'Domestic assistance', and 'Home maintenance'(who used predominantly one service with moderate volume of other service; and 16% belonged to three complex HACC clusters who used a greater volume and number of services. Compared to basic HACC users, moderate HACC users)HR=0.81, 95% CI: 0.75-0.88(and complex HACC users)HR=0.67, 95%CI=:0.61-0.74(were significantly less likely to enter RAC, after adjusting for demographic and health characteristics. Living in remote or outer regional areas than major cities)HR=0.85, 95%CI: 0.75-0.95(was associated with a decreased hazard of entering RAC compared with major cities; while compared with living in a house, apartment)HR=1.25, 95%CI:

1.14-1.37(and retirement village)HR=1.43, 95%CI=1.27-1.62(were associated with increased hazards of entering RAC. Dementia was the key predictor of entering RAC)HR=4.90, 95%CI=4.53-5.32(. Furthermore, increased physical and social functioning scores were associated with decreased hazards of entering RAC)p<0.05(.

Conclusions: The findings highlight the significance of providing a range of HACC services to support older people longer in the community and to reduce RAC admission.

Appendx 2: Co-author Statement

CO-AUTHORS STATEMENT

This is to certify that Research Higher Degree candidate Md Mijanur Rahman has contributed to the following papers by his contributions to conceive and design the study, performed the data analysis, interpretation of results, and writing of the manuscript.

1. Rahman, M., Efird, J. T., Kendig, H., & Byles, J. E. (2019). Patterns of home and community care use among older participants in the Australian Longitudinal Study of Women's Health. *European Journal of Ageing*, 1-11.

2. Rahman, M., Efird, J. T., & Byles, J. E. (2019). Patterns of aged care use among older Australian women: A prospective cohort study using linked data. *Archives of Gerontology and Geriatrics*, 81, 39-47.

3. Rahman, M. & Byles J. E. (2019). Older women's patterns of home and community care use and residential transition: An Australian cohort study, currently under review in the *Maturitas* journal.

4. Rahman, M. & Byles J. E. (2019). Trajectories of older Australian woman in the residential settings: A multi-trajectories modelling approach, in Press, *Journal of the American Medical Directors Association*.

5. Rahman, M., Efird J. T. & Byles J. E. (2019). Predicting Transition of older women into and through the aged care system over time: A Multi-state Modelling Approach Using Aged Care Linked Data, in Press, *BMC Geriatrics*.

Co-authors' Name	Signature	Date
Professor Jimmy T. Efird		30 Sep 2019
Professor Hal Kendig		
Professor Julie Byles		

Dr Lesley MacDonald-Wicks
Assistant Dean (Research & Training)   09/10/19

Appendix 3: Copyright Declaration

Chapter 4: *European Journal of Ageing*

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Research Centre for Generational Health and Ageing
School of Public Health and Medicine
Faculty of Health and Medicine
The University of Newcastle
HMRI Building Level 4 West Wing
Kookaburra Circuit
New Lambton Heights NSW 2305
Australia

Chapter 5: *Archives of Gerontology and Geriatrics*

Appendix 4: Ethics Approval

The ALSWH survey data are approved by the ethics committees of the University of Newcastle and the University of Queensland: The Australian Longitudinal Study on Women's Health (Reference No: H 076 0795), and Australian Longitudinal Study on Women's Health (Data Linkage Project) (Reference No: H-2011-0371).

Linkage of survey and aged care data is also approved by the Department of Health Ethics Committee and the Australian Institute of Health and Welfare Ethics Committee. The Australian Institute of Health and Welfare (AIHW) is the integrating authority for the creation of the statistical linkage key that allows linkage of de-identified survey data and Aged Care Data.

Access to these data are approved by the ALSWH Data Access Committee under Expression of Interest A553 and subject to confidentiality agreement. Under the terms of this agreement the following principles apply: Complying with information, privacy and principles (Section 14 of the Privacy Act of 1988).

Data will only be used for purposes as outlined in the approved Expression of Interest. Access to data will be restricted as per the Privacy Protocol of the ASLWH (Document E) including that linked data can only be accessed from the RCGHA offices Level 4 west HMRI Building.