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THE LIVED EXPERIENCE OF YOUNGER PEOPLE WITH A DISABILITY LIVING IN RESIDENTIAL AGED CARE FACILITIES: A PHENOMENOLOGICAL STUDY

A Thesis submitted by

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ABSTRACT

The topic of younger people with a disability living in aged care facilities is somewhat hidden and undiscussed in Australia. The term "younger people" is defined in health and disability policy as people aged between 18 and 65 years of age. For the purpose of this research, "younger people" include people under the age of 65 years with a disability (Australian Institute of Health and Welfare, 2012). Younger people with a disability requiring high level needs have limited options in relation to the provision of care because there is insufficient funding, negligible facilities and limited community-based structures to assist individuals to remain living in regional or rural communities. Of note, community-based care is minimal and unavailable to over 7000 younger Australians who currently reside in aged care facilities (Commonwealth of Australia, 2015). Therefore, this study involves younger people with a disability who reside in residential aged care facilities because of inadequate support in the community to meet the level of care they require.

Constantly emerging technological advances in health care enable people with disabilities to live longer and healthier lives. However, ageing carers can struggle to meet the subsequent care requirements of a person with a disability who is also ageing. Likewise, the carer themselves may be experiencing health and age-related difficulties, resulting in an inability to adequately provide the care and support required for the younger person with a disability. Furthermore, the nature of families in today's society means it is not always viable for relatives to provide informal care to a younger person with high level care needs. The financial burden placed on people today require adult family members to be engaged in paid employment as opposed to remaining at home to care for an

individual. Inadequate resourcing by governments to supplement informal care provision results in disabled younger people having to be placed in residential aged care facilities. Therefore, it is essential to gain an understanding of the experiences of younger people with a disability placed in residential aged care facilities to provide a realistic account surrounding this hidden topic.

The research presented in this thesis is an exploration of the experiences of younger people with a disability living in residential aged care facilities. This study aims to gain insight into the psychosocial impacts of placement in a residential aged care facility and identify strategies the younger person with a disability utilises to adjust to their living environment. Interpretive phenomenology was employed as the methodology to explore the essence of the individual's experience. Focussing on individual experiences and what was important to participants enabled a more thorough understanding of the impact of living in a residential aged care facility as a younger person. Moreover, this study assisted to identify strategies the participants adopted to help them adjust to the aged care environment and findings highlighted aspects that could be improved to better meet the needs of this marginalised group.

The key findings of this study indicate that younger people with a disability living in residential aged care facilities experience significant loss. Loss of relationships with family and friends, loss of independence, and loss of connection with the broader community were common themes. Participants countering the losses exercised resilience and adopted resilience-enhancing strategies. For instance, meaning making and benefit finding were strategies that assisted the participant to adjust to living in the residential aged care

environment, while acknowledging that the quality of their lives maybe enhanced

by meeting aspects of their social, emotional and psychological needs.

CERTIFICATION OF THESIS

This thesis is entirely the work of Melissa D'Or except where otherwise acknowledged. The work is original and has not been submitted for any other award, except where acknowledged.

Student and supervisors signatures of endorsement are held at USQ.

A/Professor Jennifer Kelly
 Principal Supervisor

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ABBREVIATIONS

ABI   Acquired Brain Injury

ACAT   Aged Care Assessment Team

GDP   Gross Domestic Product

MS   Multiple Sclerosis

NCSEM   National Centre for Social and Economic Modelling

NDIS   National Disability Insurance Scheme

YPIRAC   Younger People with a disability in Residential Aged Care

GLOSSARY OF TERMS

Benefit Finding: A sense-making strategy adopted by those affected by grief where a benefit is attributed to the loss to make sense of it and assist with the adjustment process.

Eco-mapping: A diagrammatic approach commonly used in Social Work practice to assist with grouping and understanding complex systems in an individual's life.

Grief: The emotional response to loss.

Meaning Making: A sense-making strategy adopted by those affected by grief where the individual is searching for a meaning to their loss.

Resilience: A stable trajectory of healthy functioning after a highly adverse event is experienced.

CHAPTER 1

INTRODUCTION

Introduction to the Research

The placement of younger people with a disability requiring high level care and support into residential aged care facilities is common practice in Australia. Such practice exists due to underfunding of the disability sector and as a consequence, reliance on inappropriate models of care and insufficient accommodation to meet the needs of individuals with a disability and complex care needs (Winkler, Farnworth, Sloan, Stringer, & Callaway, 2011). Younger people, for the purposes of this research, are defined as people over 18 years but younger than 65 years. Government policy defines the term 'younger people with a disability' in the health and disability sector and in the literature, as people under the age of 65 years with a disability (Australian Institute of Health and Welfare, 2012).

Demand for community-based support services far exceeds what the state-funded disability system can provide (Winkler, Farnworth, & Sloan, 2006). Additionally, younger people with a disability often live longer and as they age their care needs increase. Younger people with a disability who do not have family support, or have care needs that exceed what can be provided by informal carers within the home, often have no other choice but residential aged care placement

Residential aged care facilities are perceived as a 'safe' option for the provision of care for younger people with a disability who have high level needs

that require twenty-four hour care. However, this form of accommodation is a major concern as the care does not align with many aspects of the psycho-social needs of the younger person. The focus on only meeting the physical and nursing care needs of an individual, as is the case in this model of care, neglects the social, psychological and emotional needs of the younger person (Rissanen, Ehrlich, Kendall, & Muenchberger, 2013).

Social, emotional and psychological needs are equally important as physical care needs. Holistically addressing the complete needs of a younger person with a disability is known to enhance their life (Rissanen et al., 2013). Research confirms that where a person lives affects their health and the physical living environment is a key determinant of psychological well-being (Muenchberger, Ehrlich, Kendall, & Vit, 2012). However, residential aged care facilities fail to meet the psycho-social needs of a younger person with a disability (Rissanen et al., 2013). A lack of access to the external community, age-appropriate social relationships and purposeful and age-sensitive activities combined with a lack of choice about who and what to engage with all contribute to an environment that fails to meet the basic needs of a younger person with a disability (Winkler et al., 2011). Younger people with a disability should have access to funding and resources that ensure their individual care needs are met, along with their emotional, social and psychological needs, in the same way that other members of society have their needs met. People with disabilities should have choice surrounding their accommodation and the accommodation's limits upon care should not be a barrier or burden.

The resourcing of the disability sector in Australia is significantly poor in comparison to other developed nations. For example, Australia's financial

contribution to the disability sector is half what Norway, Sweden and Denmark allocate to fund disability services (Price Waterhouse Cooper, 2011). The lack of resourcing results in high numbers of younger people with a disability being placed in residential aged care facilities compared to what is observed in other countries such as Canada, the United States and the United Kingdom (Price Waterhouse Cooper, 2011). Current Australian data indicates there are more than 7000 younger people with a disability who currently reside in residential aged care facilities across the country (Commonwealth of Australia, 2015). However, these residential aged care facilities were established to support older people, such as those over 65 years of age, or 50 years if Aboriginal or Torres Strait Islander (The Aged Care Act, 1997) for the purpose of providing care and support during the end stage of their life. In Australia, the average age of a resident in an aged care facility is 84 years (Bigby, Webber, Bowers, & McKenzie-Green, 2008). Hence, the provision of care is focussed on those who are older, frail and ill, as opposed to being flexible in order to meet the needs of younger people with a disability.

Significance of the research

The key purpose of this study is to discover the experiences of younger people with a disability placed in residential aged care facilities. This research is significant because there is minimal in-depth research surrounding the real life experiences of young people living in aged care facilities. This research explores the psychosocial impacts of early-age placement in a residential aged care facility. It is intended that knowledge and perspectives arising from this research may assist health professionals, the disability sector and residential aged care providers to better understand and address the psycho-social care

needs of younger people requiring high level care. To date, very little qualitative research has previously been undertaken on this topic or with this group of people. Previous studies have predominantly utilised quantitative methodologies and have not focused on capturing the lived experience of the younger person with a disability living in a residential aged care facility. A review of the literature revealed that previous qualitative research on this topic is predominantly anecdotal, utilising surveys of residential aged care facility staff and family members, along with file reviews, as a means of data collection (Bigby et al., 2008; McMillan & Laurie, 2004; Weingarden & Graham, 1992; Winkler et al., 2006; Winkler, Farnworth, Sloan, & Brown, 2011). The voice of the person with a disability has been largely absent from research undertaken thus far. Literature, general discussion and anecdotal detail surrounding the inappropriateness of residential aged care placement for younger people with a disability, reinforces the need for exploration of this topic. Moreover, exploration of social isolation, deterioration of physical functioning and consequent social, emotional and psychological impacts is absent in previous qualitative studies.

Examining the impact of being placed in a residential aged care facility for younger people with a disability and their experience using a phenomenological approach will provide insight into the essence of the experience from the younger person's perspective. Phenomenology enables the researcher to explore the essence of the individual's experience and the meaning they derive. The lived experience is the key focus of this research, as previous studies have not approached the topic of younger people with a disability living in a residential aged care facility from this perspective. A qualitative approach enables the participants to focus on aspects of their lives in a residential aged

care facility that they consider important rather than being directed by what the researcher is striving to gain from the study (Liamputtong, 2013). The aim of this research was to gain a broader and deeper understanding of the experiences of younger people with a disability living in residential aged care facilities so that health professionals, aged care service providers and disability services might gain insight into the possible needs of this group and hence better plan service delivery that meets their needs.

The tradition of the informal care supplementing care that is not met by the government is no longer reliable as the number of informal carers is declining due to the ageing population, role changes for women and financial burdens associated with day-to-day living (Price Waterhouse Cooper, 2011). As such, there is already greater reliance on government funded support services to supplement family or community care as families and particularly ageing parents are unable to provide the support they have previously provided to people with a disability. An increase in the number of people with disabilities, whereby each week another five Australians sustain a spinal cord injury and ten to fifteen sustain a severe traumatic brain injury (Price Waterhouse Cooper, 2011) places increasing pressures on finite resources The continual increase in people with a disability creates increased expectation and pressure on state and federal governments to meet the need that informal carers are unable or no longer willing to provide. Ageing parents often have health issues of their own and are not able to be strong advocates for their children who require intensive resources to live in a community-based setting. Without strong advocacy and alternate care, many younger people with disability are at risk of placement in residential aged care facilities. For those younger people with a disability who

currently reside in residential aged care facilities, gaining a better understanding of their needs may assist to improve their quality of life and ensure that the environment adequately meets the psychological, emotional and social needs of younger residents.

Today, life-saving and sustaining advances in medical technology enable many people who might previously have died from disabilities and degenerative diseases to live longer. However, younger people with disabilities often have complex care and support needs that require specialist staff, equipment and an adapted environment to adequately meet their needs. Such needs are resource intensive, thus limiting the number of individuals who may receive the care and support they require in the community. With the implementation of the National Disability Insurance Scheme (NDIS) across the nation, this research into younger people with a disability is timely as findings may highlight the impact of placing younger people with a disability in residential aged care facilities. Research such as this can highlight the need to develop alternative models of care in order to offer younger people with a disability appropriate care and support options in their accommodation of choice.

Purpose of the research

Gaining an understanding of the experience of a younger person with a disability placed in a residential aged care facility will provide greater insight into the needs of this under-represented group. Additionally, without empirical evidence, questions surrounding the appropriateness of such placements remain unaddressed and unanswered. The purpose of this study is to explore how the younger person with a disability who is placed in a residential aged

care facility has their emotional, social, and psychological needs met within the residential aged care environment. Additionally, this study proposes to discover what strategies the younger person has applied to address any unmet needs and to adjust to the residential aged care environment.

Structure of the thesis

This thesis contains five chapters. The first chapter (Chapter 1) provides an introduction and overview of the topic to be researched. This chapter also highlights the purposes and significance of exploring the experiences of younger people with a disability being admitted to a residential aged care facility. Chapter 2 reviews the literature and research conducted to date on this topic. There is considerable research available on older people moving into residential aged care facilities and the issues affecting their adjustment to this environment. However, there is very limited qualitative research literature on the experience of younger people with a disability in residential aged care facilities.

Chapter 3 outlines the design of the study and explains the qualitative methodology selected for this research. This chapter explains the use of purposive sampling to recruit participants and semi-structured interviews to elicit and explore the experiences of the participants. Participants included in this study were from regional and metropolitan areas of Australia. All of the participants had decision making capacity and the cognitive ability and language skills to participate in an in-depth interview. The study does not focus upon one type of disability or chronic illness as the aim of the study was to explore the experience for the individual regardless of their disability.

Chapter 4 presents the data and findings from the in-depth interviews. This chapter explains the emergence and identification of themes and sub-themes that arise in the interpretation of the data. The final chapter, Chapter 5, includes the analysis of the data and combines the findings with the literature previously presented about this topic. Chapter 5 also proposes future strategies to enhance the experiences of younger people with a disability living in residential aged care facilities and presents the limitations of this study. Finally, Chapter 5 includes future recommendations. Future recommendations include options for further research as well as strategies to improve supporting younger people with a disability and the need for improved accommodation choices.

CHAPTER 2

LITERATURE REVIEW

Introduction

Younger people with a disability and significant care needs are sometimes placed in residential aged care facilities because there are insufficient resources to support them in the larger community or within a residence of choice. Technological and medical advances in health care enable people with both congenital and acquired disabilities, to live longer but ageing carers may struggle to find sufficient supplementary disability care in the community. As the younger person's care needs increase beyond the family's and community services' abilities, residential aged care may be the only viable option to meet the care needs of individuals due to the lack of targeted and appropriate community-based disability support. To date, the majority of research undertaken on the topic of younger people entering residential aged care has focused on younger residents with a specific diagnosis, such as acquired brain injury (McLean & Kopping, 2010; McMillan & Laurie, 2004; Winkler et al., 2011;). Research has predominantly been quantitative, utilising surveys and file reviews as a means of data collection. Of the qualitative research available, the focus has been on anecdotal evidence from staff of the facilities or family members, with limited exploration of the psychosocial impact of being placed in a residential aged care facility. Very little qualitative research has involved the exploration of the experiences of younger residents using a phenomenological approach.

Governments are aware of this gap in community services for younger people with a disability. For instance, two decades ago *The Aged Care Act 1997 (Commonwealth)* made the provision for people under the age of 65 to enter a residential aged care facility if they require the care and support provided and where no alternative is available. Twenty-six percent of Younger People with a disability in Residential Aged Care (YPIRAC) service users reported the unavailability of appropriate alternate accommodation as the major reason for them remaining in residential aged care and a further four percent indicated inappropriate disability services prevented them from living in a more appropriate setting (Australian Institute of Health & Welfare, 2012). A study of YPIRAC participants in Victoria found thirty-six percent of the younger people in residential aged care have the highest level of support needs, requiring twenty-four hour per day care and support (Winkler, Sloan, & Callaway, 2007).

Australian context

At present, government disability policy in Australia is not reflected in governmental practice despite Australia ratifying the *United Nations Convention on the Rights of Persons with Disabilities* on 17th July 2008. Article 19 of this convention, titled 'Living independently and being included in the community', states that people with a disability should have the "opportunity to choose their residence and where and with whom they live on an equal basis with others, and not be obliged to live in particular living arrangements" (United Nations, 2007). This perspective was reflected in a 2005 *Senate Inquiry into Aged Care in Australia* which concluded that the placement of younger people with disabilities into residential aged care facilities was detrimental to meeting the needs of the individual and should be viewed as a "last resort", not a first option

as is often the case (Hansard Report, 2005). However, the most recent

government data, from the Productivity Commissions Report on Government

Services, states that during 2013 - 2014 there were 7194 people aged less than

65 years of age living in residential aged care facilities in Australia

(Commonwealth of Australia, 2015). The greatest proportion of these (43%)

reside in New South Wales, Victoria (24%) and Queensland (20%)

(Commonwealth of Australia, 2015). Of these nearly 7200 younger persons,

90% are aged between 50 and 64 years (Commonwealth of Australia, 2015).

Most people under 50 years living in aged care facilities, age range is between

40 to 49 (Winkler et al., 2011). Government agencies providing aged care

services such as the Aged Care Assessment Team (ACAT) and Department of

Human Services, consider the minimum age of eligibility to aged care as 65

years. Of note, 59% of admissions of younger people into residential aged care

facilities occur directly from hospital (Winkler et al., 2011).

The placement of younger people with a disability into residential aged care

is not unique to Australia. This is the experience in many Western nations,

particularly for younger people with an acquired brain injury (ABI). However, the

research available suggests that the prevalence of younger people in residential

aged care accommodation in Australia is far greater than other countries. In

Australia, the occurrence is estimated to be 31/100 000 (Winkler et al., 2011).

By contrast, Belgium has an estimated rate of 9/100 000 younger people with

an ABI in residential care (Lannoo, Larmuseau, Van Hoorde, & Eyssen, 2008).

The prevalence of people under 65 years in residential aged care in Ontario,

Canada is 23/100 000 (Winkler et al., 2011). In a Scottish study, the rate of

occurrence in the Glasgow region for young people with ABI was identified as

10/100 000 (McMillan & Laurie, 2004). The lower rates of prevalence in other countries is attributed to the development of more suitable housing and support models of care in those nations (Winkler et al., 2011). Australia also has a lower level of disability related expenditure than other countries, particularly European nations such as Denmark, Sweden and Norway, who spend double the share of Gross Domestic Product (GDP) on long term care for those under 65 years (Price Waterhouse Cooper, 2011).

Younger people in residential aged care in Australia are most likely to have suffered a catastrophic injury or have a progressive neurological disease (Commonwealth of Australia, 2015). Most are likely to have an acquired brain injury (Winkler et al., 2011). Winkler et al. (2011) estimates the percentage of people with an acquired brain injury to be 61%, followed by those with Multiple Sclerosis at 14%. Other diagnoses include, but are not limited to, Spinal Cord Injury, Intellectual Disability, Huntington's Disease, Motor Neurone Disease and Mental Illness (Commonwealth of Australia, 2015).

Economic impacts of living longer with disability

Technological and medical advances in health care ensure more people who acquire disabilities will live longer despite disability (Watt & Konnert, 2007) but funding to maintain the required level of lifelong health and personal care for these younger people is not allocated to ensure their placement in the community. Accordingly, an outcome of longer life expectancy for a younger person with significant disability and concomitant care needs is that their longevity will relegate them to living a greater proportion of their lives in care, compared to an older person (Australian Institute of Health & Welfare, 2012).

The National Centre for Social and Economic Modeling, [NCSEM], (2005) reports the number of people with severe profound disability will increase by an estimated 160% between 2003 and 2031. Concurrent to this is the prediction that the number of carers aged over 65 years will grow by 110% for the same time period (NCSEM, 2005). Consequently, policy makers and service providers in Australia are facing significant issues with the increase in people requiring care and a decline in those able to provide informal care (Eley, Boyes, Young, & Hegney, 2009). This disparity in people needing care and people able to provide care will place pressure on existing services to fill the gaps. Furthermore, although many ageing carers may wish to continue to be a primary caregiver to a family member with a disability for as long as possible, there is not the capacity of community service providers to support this by supplementation of care to meet the need and demand (Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2014).

Residential aged care facilities are not designed to accommodate younger people with disability. The primary purpose of aged care facilities is to provide short-term accommodation and end of life care to older people (Winkler et al., 2006). The average age of residents in aged care facilities is 84.3 years and the average length of stay in a facility, for older people, is 2.7 years (Bigby et al., 2008). As such aged care environments do not adequately meet the needs of younger people with complex care needs whose life expectancy may be twenty plus years as opposed to three years. Of significance, residential aged care facilities are not designed or resourced to support young people in areas other than meeting their physical care needs (Winkler et al., 2011). Shortfalls in the residential aged care model as a viable option for younger people includes the

lack of specialist, technical and clinical support; poor provision of personalised equipment and aides; and lack of staff trained to provide ongoing specialist care. Additionally, there is limited or non-existent community inclusion for the younger resident; and lack of age appropriate recreational and social activities (Dearn, 2011).

Social Isolation

The inability of aged care facilities to support the younger residents' continued participation in activities and to actively access the larger community, both internal and external to the facility, may be a contributing factor to the sense of social isolation many younger residents use to describe the residential aged care experience (Perrson & Ostwald, 2009). Additionally, regimentation of lifestyle, reduced participation in decision making, and limitations on continuing relationships with friends and family, have been concerns identified in the current research (Perrson & Ostwald, 2009; Winkler et al., 2006; Watt & Konnert, 2007).

The experience of social isolation in younger residents in aged care facilities features prominently in the literature. For example, a 2006 study by Winkler et al. whereby Directors of Nursing at residential aged care facilities in Victoria were surveyed found that the 330 younger people in these facilities experienced high levels of social isolation. Of note, 44% of the 330 younger people received a visit from a friend less than once per year or never. The study also found 34% almost never left the facility to access the community or participate in community-based activities such as shopping or visiting friends and family (Winkler et al., 2006).

Similarly, a small mixed method study by Persson and Ostwald (2009) involving younger residents in eight nursing homes in Texas, in the United States of America, found 48% of the participants spent most of their time alone or watching television. Less than half of the participants went outdoors or participated in exercise or sports. This research used focus groups, individual interviews and data collected from the resident's charts, and found that the participants identified the environment and the lack of age appropriate activities as major contributors to their sense of isolation (Perrson & Ostwald, 2009). A Canadian study involving 43 young adults in a Calgary aged care facility, concluded that residential care placed young individuals at risk of reduced social support, thereby affecting the quality of life scores they were measuring in their study (Watt & Konnert, 2007). Additionally, participants of the Calgary study rated the sub-components of social and community belonging as low, indicating that disconnectedness from social contacts including friends, family and community was a major concern. Watt and Konnert's study also revealed 37% of young people reported leaving the facility less than once per month and a similar number (34.9%) reported not having a close person to whom they would confide in a time of need.

The issue of significant social isolation experienced by younger people in residential aged care facilities is further highlighted when compared with the experiences of younger people who have an acquired brain injury and live in shared supported accommodation in the community (Winkler, Farnworth, Sloan, Brown, & Callaway, 2010). Questionnaires from 128 younger people and 34 managers from shared supported accommodation services in Victoria were analysed. Managers reported that nearly half, (41%) of the residents, received a

visit from a family member at least weekly. Community access was higher with 93% of participants accessing community at least daily and 77% participating in age-appropriate activities more often than monthly (Winkler et al., 2010).

The Victorian Younger People in Residential Aged Care (YPIRAC) Initiative commenced in 2006 and was a Victorian government strategy implemented to reduce the number of younger people with a disability residing in residential aged care facilities. A Residential Aged Care Exit Group was formed whereby 58 people living in residential aged care facilities were provided with support to live in alternate accommodation. An evaluation of support provided to live in alternative accommodation was undertaken by the Summer Foundation and findings revealed increased community access, more frequency of social contact and more enriched lives when supported to live in age-appropriate environments (Winkler, Holgate, Sloan, & Callaway, 2012). Furthermore, the participants of this initiative spent less time in bed and accessed the outdoor environment more often than what they had when living in a residential aged care facility (Winkler et al., 2012).

Health & support needs

Aged care facilities were not developed, designed or structured to manage younger people who may present with a range of mental health, physical or emotional and behavioural problems and so may struggle to adequately meet the needs of this group of residents (Price Waterhouse Cooper & Summer Foundation, 2013). In 2011 a study in the USA concluded that 50% of aged care facilities had Medicaid funded residents who were younger than 65 years and had a mental disorder and more than 75% of facilities had at least one

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resident aged under 65 years being prescribed an antipsychotic medication (Simon, Lipson, & Stone, 2011). Simon et al. (2011) suggested that most aged care facilities in America lacked trained mental health professionals and if mental health treatment is provided in an aged care facility, it is limited to medication therapy rather than a more holistic therapeutic program.

The physical environment of residential aged facilities can also compromise the physical health of younger people due to its lack of focus on resident's physical activity and the potential to foster institutionally acquired infections (Winkler, Sloan, Callaway, & Truscott, 2008). Pressure injuries, urinary tract infections, spasticity/contractures are not uncommon (Winkler et al., 2008). Further, younger people are considered to be highly susceptible to secondary conditions such as respiratory tract infections that can lead to critical illness and even premature death (Dearn, 2011). The 2008 study by Winkler et al. involving younger people in an aged care facility in Tasmania, found that nine of the 14 participants in this study had developed an illness or infection in the previous 12 months, with the most common being chest infection. Similarly, the renowned study by Weingarden and Graham in 1992 identified high rates of hospital readmissions for younger people in residential aged care with spinal cord injury, due to urinary tract infections. The high incidence of hospital admissions was linked to the prevalent use of indwelling catheters in aged care facilities (Weingarden & Graham, 1992). Death is not uncommon in people under the age of 50 years who live in an aged care facility with an average of 45 people "permanently discharged" each year (Dearn, 2011). Winkler, Farnworth, Sloan, Stringer and Callaway (2011) estimate the average rate of death of younger people in aged care facilities in Australia is 21.4 per year. For example, there

were 32 deaths in Victoria of people under 50 years in 2008 - 2009 in Commonwealth funded residential aged care (Dearn, 2011). Although not all deaths of younger people are attributable to the care provided in a residential aged care facility, Dearn (2011) notes that some of the reportable deaths are preventable and indicative of high susceptibility to secondary conditions.

Residential aged care facilities are not focussed upon sustaining or developing the physical functioning of younger residents with a disability (Winkler et al., 2011). A deterioration in physical functioning results from an inability to perform activities of daily living at an optimum level and highlights the incongruence between individual needs and the environment in which younger people live (Sloan, Callaway, Winkler, McKinley, & Ziino, 2012). Insufficient and inadequate staffing resources, regimentation of lifestyle and perceived risk to the resident and hence to the facility for negligence claims all contribute to declining ability to perform physical activities (Sloan et al., 2012). However, Dearn (2011) claims the lack of equipment such as wheelchairs and other personalised specialist equipment contributes to the decline in ability of younger people to maintain a level of independence within a facility.

Funding for equipment and care in aged care facilities is also skewed towards high dependency care needs rather than independence and functional development. The availability of appropriate and sufficient equipment is the facility's responsibility. However, the equipment needs for aged care residents compared to the needs of younger people located in an aged care facility is significantly different. Furthermore, aged care facilities are ineligible for government funded equipment programs that would suit the needs of younger residents. Although some State disability programs will consider equipment

requests, personalised specialist equipment and aides can be extremely costly and as such are not a high priority for funding allocation in an aged care facility.

The aged care funding model in Australia is based upon aged care facilities being paid for the level of care the resident requires. Maximum funding is allocated to care for residents who are more dependent and who need continual care. Winkler et al's. 2011 study of younger people leaving residential aged care and being re-established in the community, found that younger residents in residential care were not being toileted, despite being continent on entering the facility. Instead, incontinence was promoted and residents were expected to use incontinence aids, in the same way as the older residents. Additionally, Winkler et al's. study (2011) revealed that transition back to the community resulted in significant gains being made in mobility for many people with an acquired brain injury. Other functional improvements for deinstitutionalisation identified in this study included speech development and unassisted feeding. Winkler et al's. study reaffirms the proposition that community living with a focus upon independence and developing functional competence is optimal for younger people with a significant disability. But is also highlights the need to be aware of the de-conditioning and reduced independence that may threaten successful transitioning to the community for those already in residential aged care facilities, should funding be made available to support them outside a residential environment.

Emotional impact of residential aged care placement

Persson and Ostwald (2009) identified complex emotional experiences, such as feelings of sadness and depression, as one of the concerns raised by

the participants in their study. Findings suggest such emotional responses may be attributed to the physical environment, limited staff resources and staff training, as well as the adjustment to a change in the younger person's health as a result of illness or trauma (Perrson & Ostwald, 2009). Furthermore, some of the participants indicated feelings of entrapment and being *held captive* as they could see no means of being able to leave the facility (Perrson & Ostwald, 2009).

The negative impact of aged care residential accommodation upon the emotional health of younger people is supported by a study of younger adults living in residential aged care in Belgium (Lannoo et al., 2008). Lannoo et al.'s study found that younger people with an ABI in aged care accommodation displayed more behavioural (41% versus 24%) and emotional problems (49% versus 21%) than those who resided in community care (Lannoo et al., 2008). This qualitative study with a sample of 889 young people in aged care and 506 in community care concluded that staff of aged care facilities experienced difficulties in caring for younger people and the lack of caring skills may contribute to the emotional and behavioural problems exhibited (Lannoo et al., 2008). Additionally, findings from Lannoo et al's. study also revealed that social isolation, the physical environment, the lack of meaningful and stimulating age-appropriate activities, staff training and the lack of support structures could not be discounted as contributing factors.

Similarly, Winkler et al's. 2011 study suggested that challenging behaviours in younger people with an ABI may dissipate if they reside in appropriate living environments. Winkler et al's. study followed seven younger people with an ABI who moved from a residential aged care facility to a community setting.

Findings clearly indicated a link between the exacerbation of challenging behaviours to factors such as loneliness, boredom, lack of choice and control and emotional distress. Additionally, Winkler et al. found that appropriate resources and services to address severe behavioural issues are not available in aged care facilities. Furthermore, Winkler et al. determined that staff in aged care facilities do not have sufficient training nor possess the skills required to manage challenging behaviours in younger people with an ABI. Moreover, there are inadequate staffing ratios and consistency with staffing allocation to ensure the implementation of behavioural programs (Winkler et al., 2011).

Lack of access to emotional support and an age-appropriate environment was linked to depression in the 2005 *Senate Inquiry into Aged Care in Australia.* The Inquiry Report cites submissions that highlighted that an individual's depression was exacerbated by the environment of the aged care facility. Additionally, exacerbation of depression was linked to younger people being overwhelmingly surrounded by large numbers of older co-residents with cognitive impairment, and that they were witnessing deaths of their co-residents with little or no support provided to adjust to these factors (Senate Committee Report, 2005).

Adjustment of older people to residential aged care placement

Considerable research has been conducted on how older people adjust to placement in a residential aged care facility. Loss of independence, loss of autonomy, and difficulty maintaining meaningful relationships have been identified as significant aspects of moving into a residential aged care facility (Brownie, Horstmanshof, & Garbutt, 2014; Rodgers, Welford, Murphy, &

Frauenlob, 2012; Walker & Paliadelis, 2016). Walker and Paliadelis (2016) examined the experiences of older people living in residential aged care using a phenomenological approach. The major findings of Walker and Paliadelis' study were that the loss of home life that results from moving into a residential aged care facility reduced the older persons' sense of autonomy and independence. The grief they experienced from these losses was countered with the 'resigned acceptance' that their physical needs dictated the need to move into an environment in which they would receive appropriate care.

Factors that facilitate adjustment to residential care placement have been the focus of recent research (Brownie, et al., 2014; Johnson & Bibbo, 2014; Tuominen, Leino-Kilpi, & Suhonen, 2016). Input into the decision-making process that happens around moving into residential care, preservation of autonomy through adoption of a person-centred care approach and retention of meaningful social relationships have been found to be key factors in the transition to long-term care (Brownie et al., 2014). For those older people where these elements were absent, greater rates of sadness, depression and anger were identified (Fraher & Coffey, 2011). Additionally, loneliness and social isolation is more likely to be experienced in higher rates by those who are separated or isolated from family and friends following placement in a residential aged care facility (Brownie et al., 2014). Maintaining important relationships is critical to residents adjusting to the residential aged care environment.

Personal resilience was identified by Brandburg, Symes, Mastel-Smith, Hersch and Walsh (2012) as a significant strategy to facilitate the transition to residential aged care life. In this context, resilience is defined as the individual's

ability to adapt to traumatic or stressful life challenges. Participants in Brandburg et al.'s qualitative study cited the personal belief that a residential aged care facility was the better place to live given the level of care they required. Participants believed that the move to a residential aged care facility was necessary to avoid being a burden to family members, due to the level of care they required. Additionally, those participants who did not have family to assist in their care identified that prior to moving to a residential aged care facility they struggled to care for themselves adequately (Brandburg et al., 2012). The use of such facilitative strategies by the participants demonstrates attributes of resiliency. Brandburg et al's. study also identified significant losses experienced by the participants including loss of privacy, possessions and hobbies.

Grief and loss

In consideration of the losses experienced by those moving into residential aged care placement, grief and loss as it relates to adverse life events requires exploration. Grief and loss is not only related to death and dying but may be attributed to any significant life event that falls outside the realm of 'normal' (Murray, 2001). Loss experienced by people with a disability may be both physical and psychosocial. Physical loss is associated with a change in health status such as what occurs when an individual acquires a disability or chronic illness. Psychosocial loss is less tangible and occurs when individuals experience life events such as divorce, retirement, unemployment and illness (Goldsworthy, 2005). Grief differs to loss as it is the emotional response that arises due to loss (Goldsworthy, 2005).

Grief may manifest in a variety and combination of emotions such as anger, frustration, sadness, guilt, despair and helplessness (Raphael, 1984). Grief reactions are experienced by those who perceive that something of value is lost to them (Murray, 2001). Each person's experience of grief and loss will be individualised, dependent on the type of loss experienced, the importance the person placed upon that loss and the resources the individual draws upon to manage the ensuing grief (Goldsworthy, 2005). The use of strategies to manage grief and loss ensures the majority of individuals will not have difficulty in adjustment, thus demonstrating resilience (Bonanno, 2004).

Resilience

The way in which grief and loss is experienced is highly individualised. Grief and loss theory recognises grieving is not a staged process but more about oscillation between grief and engagement in life (Bonanno, 2004). Individuals will utilise coping strategies in which to maintain an equilibrium and the adoption of such strategies has become known as resilience (Bonanno, 2004). Southwick, Bonanno, Masten, Panter-Brick and Yehuda (2014), report resilience is best described as being a constant trajectory of robust functioning after a significant adverse event. Therefore, resilience is characterised by the ability to adjust to a situation and employing a number of factors that impact on adjustment. Sense making (or making sense of the loss) is one such concept that allows meaning to be reconstructed following a loss (Neimeyer, 2006). Meaning Making and Benefit Finding are sense-making processes adopted by those affected by grief and loss to facilitate incorporation of the grief into their life (Neimeyer, 2006). Sense-making in grief and loss theory has been widely accepted and used by Social Workers for decades as it recognises the

uniqueness of the individual and that loss will be interpreted differently by each individual (Goldsworthy, 2005). By focusing on the individual, meaning can be sought around the individual experience. Such a concept fits well with a phenomenological perspective, where emphasis is on the individual participant and the meaning they make of the lived experience.

Grief and loss theory accepts that individuals experiencing loss will demonstrate resilience towards their loss and that 'meaning making' and 'benefit finding' are strategies adopted to manage adjustment to loss (Neimeyer, 2006). Further, when applied in a health context, such as disability, 'meaning making' suggests the individual is searching for a meaning to their loss (Neimeyer, 2006). Additionally, Neimeyer (2006) purports that when an individual is having difficulty making sense of a loss, 'benefit finding' may be applied as part of the sense-making process. 'Benefit finding' is a strategy applied to manage grief, where a benefit is attributed to the loss to make sense of it and to assist with the adjustment process (Bonanno et al., 2014).

Conclusion

Despite medical advances and increased life sustaining measures for those born with significant disability or who suffer catastrophic injury, choices, appropriate care and sufficient support services in the accommodation of choice continues to be under-resourced in Australia. The disparity between Australian government policy and funding has resulted in large numbers of younger people with a disability being placed in residential aged care facilities due to lack of more appropriate options. Ageing carers, most often parents, has added to the demand and need for increased services to be available for the support of

younger people with a disability in the community. Demand for care services outweighs supply, resulting in those with the highest level of care requirements most often being placed in residential aged care facilities as the only available option. Australia is not unique in this approach to disability care but Australia lacks infrastructure that other Western countries afford. Larger numbers of younger people with a disability, in Australia, will be placed in residential aged care facilities than in other developed countries. Inappropriate placement of younger people with a disability is largely due to less government funding allocated to disability care compared to countries such as Sweden, Norway and Denmark.

 Younger people with a disability placed in residential aged care facilities experience a range of psychosocial challenges such as loneliness, social isolation, limited access to the community and reduced interaction with family and friends (Winkler et al., 2011). Furthermore, physiological factors such as respiratory tract infections, pressure injuries and urinary tract infections are common and significantly more prevalent in younger people with a disability living in residential aged care facilities than for those in community-based accommodation (Winkler et al., 2008).

Limited research on the topic of younger people with a disability placed in residential aged care facilities is a major concern. In particular, the lack of qualitative research available provided the impetus to conduct this study as current literature relates to older persons placed in residential aged care facilities. Research on the transition to residential aged care for older people identified that psychosocial elements such as social isolation, loneliness and

loss of autonomy impacts on adjustment to residential aged care placement and a similar finding may exist for younger people.

This chapter explored the available literature surrounding the challenges and realities of having a disability, being under 65 years and requiring high level care in Australia. The literature reviewed provides an understanding of the psychosocial impacts of placing younger people with a disability in residential aged care facilities and highlights the inappropriateness of such placements. The following chapter, Chapter 3, presents the methodology employed to conduct this study into the experiences of younger people with a disability residing in an aged care facility.

CHAPTER 3
METHODOLOGY

Introduction

This chapter outlines the methodological approach employed to explore the experiences of younger people with a disability who reside in residential aged care facilities. Recruitment of participants, data collection strategies and ethical considerations and processes utilised for data analysis and methods to ensure rigour and credibility are outlined and discussed. The first section of this chapter examines the significance of employing a qualitative approach to explore this topic. Additionally, the relationship between the experiences of younger people admitted to residential aged care and the methodology is addressed.

Gaining an understanding of the experience of a younger person with a disability placed in a residential aged care facility using qualitative research was considered necessary in order to provide greater insight for health care workers into the impact of such placements. Further, the use of residential aged care facilities for younger people with disabilities warrants qualitative exploration because there is little qualitative findings available to address the inadequate provision of service and care. Therefore, phenomenology will be employed as the methodological approach to explore the lived experience of a cohort of individuals placed in residential aged care facilities in Australia.

Qualitative research

This research is based on securing an understanding of the experience of individuals and therefore lends itself to a qualitative research design. Qualitative

research aims to explore human understanding and make sense of the world (Welch, 2011). Qualitative research is based on the principle of valuing the viewpoint of the participant and presenting their experience according to their perceptions (Welch, 2011). The core value of qualitative research is the ability to present the story that is told to the researcher and is most suited to hearing the stories of those most marginalized in society (Liamputtong, 2013). Younger people with a disability placed in residential aged care facilities are marginalised as they often have little or no choice than to be placed in such an environment. As such, choosing a methodology to complement the topic is essential.

Methodology is the philosophical and ethical approach a particular research project adopts, when attempting to develop knowledge about an issue or topic (Carpenter, 2010). Therefore, this qualitative research aims to explore the experiences of younger people with a disability placed in residential aged care, using a phenomenological approach. Phenomenology is considered most beneficial for this research because it enables the exploration of the lived experience of younger people placed in aged care facilities. Additionally, phenomenology is most suited to this research because it explores the essence of the individual's experience, enabling the researcher to understand the meaning the individual makes of the experience. Overall, phenomenology provides a detailed perspective and insight into the participant's 'lived view' of the experience (Liamputtong, 2013).

Phenomenology

Phenomenology emerged from philosophy and was developed as an interpretive science as a means of understanding and describing human

behaviour and the constructs individuals create of their individual experiences (Titchen & Hobson, 2011). The phenomenological researcher promotes the placement of the experience within everyday life by having participants describe the meanings they attain from such experiences (Titchen & Hobson, 2011). Description is a fundamental characteristic of phenomenology and the crucial means for communicating the experience (Welch, 2011).

There are two key approaches to phenomenology, descriptive phenomenology and interpretive or hermeneutic phenomenology (Liamputtong, 2013). Descriptive phenomenology is based on the work of Edward Husserl, who is considered the founder of phenomenology, and whose approach was to focus on detailed descriptions of specific experiences (Titchen & Hobson, 2011). Husserl's descriptive phenomenology contrasts interpretive phenomenology or hermeneutic phenomenologists, designed by Heidegger and Gadamer. Interpretive phenomenology focuses on describing the meanings individuals make of those experiences (Carpenter, 2010). The work of Husserl's student, Heidegger, is based on the belief that individuals are not separated from their world but immersed in their world (Titchen & Hobson, 2011).

Although there are two differing approaches to phenomenological research, they share the concepts of intentionality, essence and life-world between them (Welch, 2011). Intentionality refers to human consciousness and is how an experience is perceived or how the meaning is created from an experience (Welch, 2011). Essence relates to the common understanding we share in relation to a phenomena. Liamputtong (2013) describes essence as the phenomenon that is reflective of the general experience of people as opposed to an individual's experience. An individual's experience will differ considerably

from another's however, there will be aspects of the experience that they will share and it is these views that are the essence. Life-world refers to the world of lived experience (Welch, 2011). The life-world concept requires reflection of the experience, by the participant, in order to understand what has occurred (Welch, 2011).

Husserl's descriptive approach includes the concept of bracketing whereby the researcher "brackets" their experience and knowledge. Bracketing is the process a researcher uses to suspend all preconceived notions in order to become fully immersed in the life of the participant, thus being able to fully understand the lived experience of the participant (Carpenter, 2010). Bracketing originates from the mathematical concept of bracketing, where parts of equations are separated from each other, to allow a particular part to be the focus in isolation (Hamill & Sinclair, 2010). Bracketing sets aside beliefs, ideas, judgements, biases, and personal experiences in an effort to ensure the researcher listens and describes the essence of the phenomena being described by the participant without influencing the participant's understanding of the experience (Carpenter, 2010). This ensures that the data collected is not shaped by the researcher's assumptions, suspending any judgements and preconceived ideas.

In contrast to Husserl, Heidegger's approach is based on the belief that it is impossible for a researcher to bracket what is known or what has been experienced (Liamputtong, 2013). Therefore, research that employs interpretive phenomenology is presented from the perspective that the researcher is unable to bracket previous experiences, and exposure to the research topic.

This study will employ interpretive phenomenology in order to explore the lived experience of participants living in residential aged care facilities. Interpretive phenomenology is most suited as bracketing previous experiences and exposure to this topic is not possible. The key objective of this research is to explore this topic from a qualitative perspective because previous studies have not addressed the essences of individual's in any significant depth. Overall, interpretive phenomenology is ideal because participants will be encouraged to describe their lived experience in the context of their daily life which is the core focus of this research.

Participants

Six to eight participants, both male and female, will be sought as participants for this study in order to obtain rich data surrounding this topic. Participants may have a range of complex care needs that has necessitated placement in residential aged care. However, this study will not focus on people with specific disabilities or chronic illness because the aim is to explore the experience for the individual regardless of their disability. Additionally, previous research has focused on groups of younger people with specific disabilities such as acquired brain injury (ABI) but this study has a more broad-ranging perspective.

Participants will be aged between 18 and 65 years. However, as a large proportion of younger people with a disability living in residential aged care facilities are aged between 50 and 64 years, the participants will more than likely be within this age range. The overall aim of the research will be to include people from a range of ages and gender. Participants must be a permanent

resident of an aged care facility in Australia and a mixture of participants from metropolitan and regional facilities are to be recruited.

It will be essential that participants are able to converse in English due to the lack of availability and access to face-to-face interpreter services in regional areas of Australia. Participants will need to be able to communicate verbally or via assistive device in order to participate in an in-depth interview. Additionally, participants will need to possess a level of cognition that allows them to provide informed consent to participate, be independently interviewed and respond appropriately to semi-structured questions.

Recruitment

Purposive snowball sampling will be used to recruit participants for this study. Purposive sampling seeks out participants who will be able to provide detailed information about a specific topic (Carpenter, 2010). Purposive sampling is considered most relevant to this study because the focus is on a very specific group of individuals and their experiences. Therefore, purposive sampling will be utilised to include participants of varied ages, a balance of male and female, with a range of disabilities and from both metropolitan and regional areas of Australia. The strategy of snowballing will be used in order to assist the recruitment of participants. Snowballing involves asking original participants to identify others they believe would meet the inclusion criteria (Liamputtong, 2013).

Participants will be invited to participate in the study using purposive snowballing, whereby the directors of organisations such Disability Services Queensland, Young Care, Multiple Sclerosis Queensland, disability advocacy

services, hospital social workers and residential aged care service providers will be approached in order to identify potential participants for the study. Initial contact will be made to organisations by telephone. Permission regarding an organisation's willingness to assist with the recruitment of participants will be determined at the time of the telephone call.

The organisations that identify having suitable clients that may be willing to participate in this study will be mailed the Participant Information Sheet (see Appendix 1), detailing the purpose and relevance of the study, how the interviews will be structured, time commitment of the participants and how the results will be used. The organisation will be asked to forward the Information Sheet to the individual they believe meets the eligibility criteria. The researcher will reinforce to the Director of the organisation the importance of not coercing or requesting anyone to participate in the study.

The Information Sheet advises potential participants that they can contact the researcher directly if they are interested in participating or would like further information and questions answered before consenting to participate. Potential participants can contact the researcher via telephone or email, to indicate their interest in being a participant. Only the researcher will be involved in the recruitment of the participants, with the assistance of the key organisations identified above.

Once the participant has indicated their interest in being involved in the study, they will be asked to complete a consent form (see Appendix 2). Those participants who are unable to physically sign may have a suitable person sign on their behalf, providing they can validate their consent to participate. Consent

from participants will be obtained prior to interviews being conducted and participants are fully aware that they may withdraw from the study at any time, prior to data analysis commencing, without repercussion or the need for an explanation.

Data collection methods

The data collection method for this study will include one-to-one, in-depth interviewing in order to capture and describe the phenomena being experienced (Patton, 2002). One-to-one interviews as a method of data collection are commonly used in phenomenological research as opposed to focus groups or questionnaires because they enable the participant's experience to emerge without interference from others (Liamputtong, 2013).

In-depth interviewing will be the key method of data collection for this research. Face- to- face and one- to-one interviews will enable the researcher to develop a rapport with the participants. Building a rapport with the participant is important in order to facilitate data gathering about the individual experiences of participants (Liamputtong, 2013). One or two interviews will be undertaken for a period of 30 to 40 minutes but the duration of the interviews and numbers of interviews will depend on the fatigue levels of the participant. Interviews will be scheduled at a time convenient to the participant and the residential facility, to ensure there is no disruption to the participant's routine or other commitments they may have. Interviews will ideally take place outside the residential facility, for example in a nearby park, library or other public place close to the facility. The meeting place will be dependent on the participant being able to access the community and that privacy is maintained during the interview.

Further, semi-structured questions will be used to assist participants to accurately describe their experience to gather rich data (see Appendix 3). Semi-structured questions are useful because while giving some direction to the interview, they allow participants the opportunity to elaborate on particular areas that are important to the individual (Carpenter, 2010).

Interviews will be audio recorded and transcribed by the researcher. Transcribing will be undertaken by the researcher as close as possible following the interview. Additionally, field notes, in the form of a written journal, will be kept by the researcher and notes will be recorded immediately following the interviews. Maintaining a journal will capture nuances such as non-verbal behaviour and changes in tone and expressions. The purpose of such observation assists with checking for consistency between what the participant is stating and their non-verbal behaviour and changes in tone and expressions.

Data analysis is how a researcher understands the data that has been collected. The purpose of data analysis in qualitative research is to identify common themes and key concepts that emerge from the interviews. Data analysis for phenomenological studies is recommended to commence at the outset of the research (Liamputtong, 2013). Commencing data analysis at the beginning of the study allows the researcher to improve strategies for collecting data and managing data (Liamputtong, 2013).

Data management is the organisation of the data collected in preparation for analysis and during the process of analysis (Berg, 2007). Data management enables the large volume of raw data collected during interviews to be simplified and for key themes to emerge. To achieve this, the audio recorded interviews

will be transcribed by the researcher and field notes edited and summarised, in preparation for the data analysis stage. Initial impressions and thoughts will be manually recorded to assist with thematic analysis.

Manual thematic analysis will be undertaken by the researcher. This is a data analysis method commonly applied in qualitative research to identify patterns, and emerging themes (Liamputtong, 2013). Thematic analysis requires reading the transcribed interviews multiple times to find repeated themes. Coding is a most important element of this process and is the starting point for data analysis. Colour coding will be employed to enable common statements and comments to emerge from the transcriptions. An initial set of themes will be developed, based on key frequent comments, statements and descriptions from each participant that emerged from the interviews.

Once the major themes are identified, eco mapping will be undertaken. Eco mapping is a diagrammatic approach commonly used in Social Work practice to assist with grouping and understanding complex social systems in an individual's life. Eco mapping enables the Social Work practitioner and their client to visually understand the connections an individual has to their environment (Hartman, 1978). Although not usually utilised for research analysis purposes, eco mapping will be applied to the analysis process as it can provide a visual picture of the complexity of the participant's situation, allowing the researcher to identify the major themes and sub-themes for each of the participants. Eco mapping also facilitates the identification and emergence of sub-themes. Therefore, the researcher will move between the transcribed interviews and eco map (see Appendix 4) to analyse the data and bring clarity

to each of the themes to understand the impact of each theme on the participant.

Ethics

Research ethics set out the rules in which research is to be conducted to ensure the benefits of the research outweigh the associated risks (Liamputtong, 2013). The ethical principles of beneficence, respecting autonomy, non-maleficence and justice are the key principles to be adhered to in order to conduct ethical research (Ramcharan, 2010). These principles ensure the welfare of the participant is always paramount and that the good outweighs the bad in terms of outcomes of the research (Ramcharan, 2010). All individuals must be fully informed of all aspects of the study in order to provide informed consent to participate in the research. Therefore, the consent process includes informing the participants as to how the research will be conducted, the purpose of the research and how the findings will be used.

Potential participants will be informed they can withdraw from the research at any time without adverse effects prior to data analysis. Withdrawal after data analysis has commenced is not possible because analysis commences at the time of data collection and transcribing of audio recordings. It would be impossible to then extract an individual's data without impacting on the entire research. Any information collected about the participant who withdraws from the research will be destroyed should they choose to discontinue.

To protect the participant's identity, participants will be provided with and referred to using a pseudonym. Pseudonyms are usually formed by the researcher and allocated to the participant (Liamputtong, 2013). The researcher

will be the only person who is aware of the true identity of each participant. Participants will only be referred to using their pseudonym for the duration of the research and in relation to any publications. Pseudonyms will also be allocated for the name of the residential facility and the town or city in which it is located, further ensuring the participants cannot be identified. Allocating pseudonyms is an important aspect of ensuring confidentiality and privacy for the participants and the care facilities located in regional areas of the state as opposed to participants and facilities in large cities.

Storage of data is a significant ethical matter as data collected needs to be stored using a method that ensures confidentiality is maintained. Data storage for this study will include the use of password protected computers, computer files and locked filing cabinets. Access to these will be limited to the researcher to ensure the confidentiality of data. Data collected for this research will be retained for the requisite five years, in accordance with section 601.2/C124 and 601.2/C125 of the Queensland State Archives University Sector Retention and Disposal Schedule.

Ensuring the well-being of the participants throughout the research is vital. In particular, the emotional and psychological well-being of the participant is paramount to ensure that conducting the research in no way harms the young person. Exploring life events may elicit emotional reactions, both during and following the interview. Emotional reactions would possibly not be anticipated prior to participation in this study. Participants experiencing any emotional or psychological distress will be provided with counseling should they indicate the need to speak to someone. The Participant Information Sheet includes contact details for Lifeline telephone counselling should immediate support be required.

Additionally, participants may access a private Accredited Mental Health Social Worker who may provide either, onsite, off-site or telephone counselling through this Medicare funded program. Information is included in the Participant Information Sheet and a brochure (see Appendix 4) on how to access this service will be provided to participants.

Ethical clearance was obtained from the University of Southern Queensland Human Research Ethics Committee (see Appendix 5). Furthermore, this study will adhere to the Australian Association of Social Workers Code of Ethics as the researcher is a member of this professional association. In particular, section 5.5.2 of the Australian Association of Social Workers Code of Ethics (2010) specifies ethical responsibilities for Social Workers engaged in research, in addition to adherence to the general provisions of the Code.

Rigour and credibility

Rigour refers to the quality of the research and the trustworthiness of the research in terms of how the research was conducted (Liamputtong, 2013). Rigour is a similar concept to that of reliability and validity in quantitative research, ensuring credibility, authenticity, transferability, dependability and confirmability of the research (Liamputtong, 2013). A number of strategies will be incorporated into the research design of this study to ensure rigour and credibility of the research.

Credibility and authenticity will be employed through the use of purposive sampling of participants, which requires participants to have knowledge and experience surrounding the topic (Liamputtong, 2013). Purposive sampling will be achieved by participants meeting the inclusion criteria set out earlier.

Presenting the individual participant's experiences as accurately as possible will further contribute to the credibility and authenticity of the research. Prolonged engagement with participants is an additional strategy that will be utilised in this research to demonstrate credibility. Developing a good relationship between the participants and the researcher, over a period of time, assists to reduce bias from deception and achieve consistency in the data being collected (Carpenter, 2010; Liamputtong, 2013).

Other strategies employed to promote credibility is the use of verbatim quotations made by the participants. Such use ensures the intended meanings are captured by the researcher. Using the words of the participant precludes misinterpretation by the researcher and misrepresentation of the participant's words thus contributing to credibility.

Transferability relates to generalisations of the findings that may be applied to other contexts outside which the research is set (Liamputtong, 2013). As previously mentioned, purposive sampling will be used as a strategy to help identify participants and this strategy helps to ensure transferability because there is an evidence trail of potential participants. Additionally, thick description will be used whereby the research setting, the participants and the methods used to undertake the research are described in detail. A field journal and the audio recording of interviews will assist with transferability as the notes and recordings can be recalled to verify the data collected (Liamputtong, 2013).

Outcome of recruitment

This study sought to recruit six to eight participants using purposive snowball sampling. However, recruiting participants proved to be challenging due to

factors that limited the inclusion of suitable participants. The requirement for participants to have high level cognition and language skills was a major barrier. However the key barrier that limited recruitment was difficulty accessing potential participants via key organisations. People contacted at organisations were reluctant to be involved in the study and failed to disclose having suitable young people with disabilities. Although some service providers initially indicated suitable young people lived in the facility, the facility failed to return phone calls or commit to enquiring whether the person was willing to participate in the study. Therefore, only four participants were recruited for this study from regional residential aged care facilities. The table below outlines details of each participant.

Table 1. Participants

NAME	AGE	TIME IN FACILITY	REASON FOR PLACEMENT
Rachel	61	15 years	Multiple Sclerosis
Fay	46	10 months	Multiple Sclerosis
Brian	59	12 months	Hit and run accident – spinal injury
Bronwyn	52	2 years	Motor vehicle accident – acquired brain injury

Conclusion

   This research will employ a phenomenological methodology to explore the experiences of younger people with a disability placed in residential aged care. Phenomenology is most suited to this research as this approach will enable the

focus to be on the participant's experiences and what is important and significant to them while living in this environment.

Data collection will be via semi-structured interviews. The audio-recorded interviews will be transcribed by the researcher and the data will be manually analysed using credible strategies. Many ethical considerations are factored into the research due to the potential level of vulnerability of this particular group. Although the research is considered low risk, psychological, social and time imposition risks have been minimised using a number of different strategies. Strategies include the use of pseudonyms for both the participant and the residential facility in order to protect their true identity and maintain confidentiality. The following chapter discusses the findings that emerged from data collection and presents these findings using themes and sub-themes.

CHAPTER 4
PRESENTATION OF FINDINGS

Introduction

This chapter presents the key findings from the semi-structured interviews and unveils the essence of the experiences of four people who are younger, have a disability and live in a residential aged care facility. The four participants, aged between 43 and 63 years, lived in residential aged care facilities across Australia.

The data was analysed using eco-mapping and thematic analysis. Eco-mapping enabled links to be made between emerging patterns themes to be identified. Eco-mapping is commonly used in the domain of Social Work to assist social workers group the multifaceted relationships, systems or events of a person to facilitate a deeper understanding of the complexities of an individuals' life (Hartmann, 1978).). As such, eco-mapping enabled data to be grouped using a diagrammatic approach that assisted with identifying patterns as to the complexities associated with younger people placed in residential aged care facilities. The eco-mapping process was invaluable to the emergence of the major themes and sub-themes (see Appendix 6) in addition to thematic analysis. Thematic analysis was deemed best suited to this phenomenological study because it facilitates identification of common patterns that emerge from the participants' comments (Liamputtong, 2010, 2013). Thematic analysis involved reading and re-reading the transcripts in order to make sense of what the participants said to find repeated patterns of meaning. As such, thematic analysis is a process requiring the researcher to become immersed in the data,

by carefully reading each transcribed interview multiple times in order to identify common aspects of the experience. Additionally, a manual coding process was employed in the form of colour coding to categorise the repeated patterns. The repeated patterns became the major themes and sub-themes. Two distinct themes that emerged from the data were:

1. Loss,

2. Resilience

The first major theme, *Loss,* proved to be significant as all participants described aspects of their lives that had been 'lost' due to being placed in a residential aged care facility. The major theme of Loss included four subthemes. The other major theme, *Resilience*, related to the participants' experiences of adjusting and coping with the losses and the associated grief which are described using two sub-themes. The findings revealed that the four participants adopted strategies to adjust to the losses they experienced as a result of placement in a residential aged care facility. The strategies used by the four participants to adapt to their loss guided the emergence of the minor themes. The figure below (Figure 1), illustrates the two major themes and associated sub-themes that emerged from the data which are explored and explained throughout the remainder of this thesis.

Figure 1: Major Themes
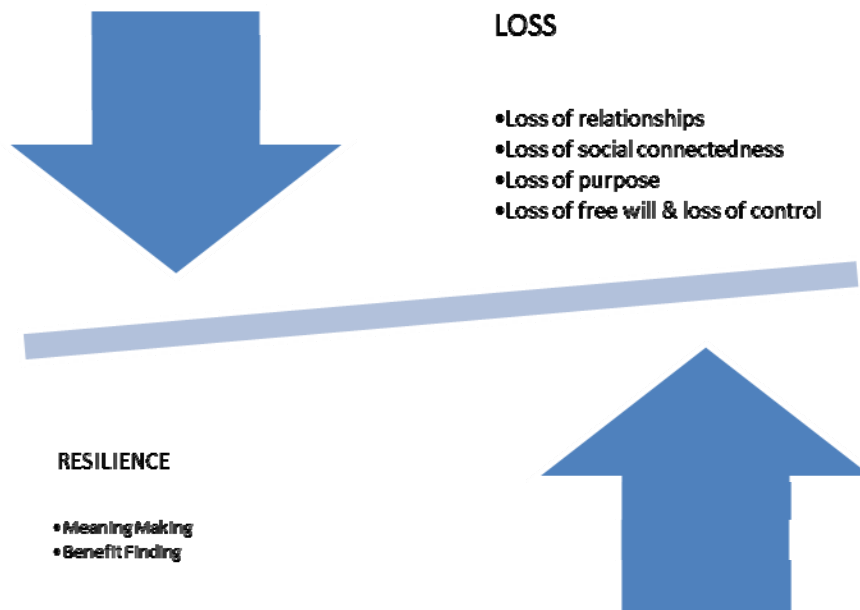
LOSS

Loss was the major theme to emerge from the data due to the significant and frequent responses by the participants that related to the concept of loss. Not only had the participants experienced physical and functional loss associated with the use of their body but they also experienced multiple psycho-social losses, before and after the onset of their disability or illness. Moreover, an altered health status and subsequent decreased physical functioning resulted in the participants requiring care that was only available to them in a residential aged care facility. For all four participants, the move to a residential aged care facility was not by choice but necessitated by the level of care they required.

All participants endured multiple losses to their personhood in terms of physical and psycho-social loss. All of the participants claimed their identities were completely changed due to the loss of physical function and altered body image, a stark comparison to their previous lives. For example, Rachel described no longer being able to read due to her deteriorating vision. She said,

"*one of the things I miss is reading. I loved to read*". Deterioration in physical functioning and the uncertainty this created further added to Fay's sense of loss as she stated,

> *I've noticed another thing, the condition's deteriorating. So the latest thing I've had an optical neuritis thing happening, which is normal with MS. So that's just another thing I'm dealing with.*

Further, all participants claimed they had experienced psycho-social losses and changes to role identity. For instance, Fay said that her "*sense of motherhood changed*" due to having to relinquish her role identity as a mother, as a result of her illness. Additionally, Fay's move into a residential aged care facility significantly impacted on her relationship with her children. Fay was moved into an aged care facility, away from her young children. The geographical location impacted on her children's ability to visit, despite the facility being chosen in the town where her father and step-mother reside. The loss that Fay encountered due to the need to access twenty-four hour care meant that she "*missed the last five years of my children's lives*". Fay's illness necessitated her living apart from her children in order for her to access services and support. Prior to moving into a residential aged care facility, Fay lived in a regional town but had to move to a larger metropoloitan city in order to access appropriate care. This forced her to leave the care of her children to her ex-husband, all of whom were located two hours away from the large metropolitan city.

Similarly, Rachel experienced family and relationship changes resulting in her inability to identity as a wife. Although Rachel is married, her disease and disability necessitated her being relocated a long distance from her family

home. After being relocated, Rachel perceived she could not continue as a wife or lover in any physical or emotional context. Rachel's disconnect with her identity and role as a wife is due to her distance from her former home. Rachel was only able to return to the family home each month, for three or four days and having limited contact with her husband in between return visits. The forced separation created by the location of the residential aged care facility has impacted on the quality of the relationship she has with her husband.

Loss of relationships

Separation from family due to the high level of disability and care needs of the participants was one of the most significant losses experienced. All participants lost access to their community support and relationships due to placement in a residential aged care facility. The need to be located away from support networks resulted in grief and loss for three of the four participants. Fay, Rachel and Bronwyn described the significant loss they experienced as a consequence of being physically separated by distance from their families. For instance, Rachel was placed in a facility that is 100 kilometres from the family home because there were no closer suitable facilities. Rachel described the inability to access care and support services, which forced the move to residential aged care, stating,

> *We lived so far out; too far out for a Blue Nurse to visit. My husband had to have some support to care for me. You couldn't expect one person to do that 24 hours. So I ended up here.*

Similarly, Bronwyn was placed in a facility approximately 400 kilometres away from her community, friends and home due to the lack of appropriate high

level care closer to home. Further, both of Bronwyn's sons live in a remote location and the distance between Bronwyn and one son is 900 kilometres. As such, Bronwyn experienced significant loss due to physical and emotional separation from her family and friends and the support they provided. The distance also created a loss of contact with friends as the distance caused visits from friends to be sporadic and uncertain. The uncertainty created by not knowing when Bronwyn would receive a visitor was evident when she stated,

> *I'm stuck here and there's no one. When I get visitors I couldn't tell you when I'm going to get a visitor. My cousin's supposed to be coming to see me this week. I don't know whether he will or not.*

Therefore, the participants experienced significant loss due to physical, social and emotional separation from family and friends. Moreover, the absence of suitable high-level community-based care for the participants, in rural and regional areas emerged from the data as a major factor that resulted in them needing to move into full-time care outside their community of support. The geographical location of the facility added a further sense of loss for three of the four participants, as the distance from their community, family and friends caused them to experience loss in terms of social interactions.

Loss of social connectedness

The participants' experience of loss of previous social support networks was compounded by the lack of age-appropriate companions in the facility. As such, the participants' social isolation was amplified by the inability to form new relationships in the residential aged care environment. Rachel reported that in the 15 years she lived in the residential aged care facility, "*I've really only had*

one close friend here. I think a lot of them are here just for respite, so they come and go". The lack of opportunity to connect with like-minded people of similar age was experienced by all of the participants as other residents in the facilities were predominantly over 80 years.

All four participants reported dissatisfaction with the lack of regular contact with people the same age. Contact with people of a similar age was limited to intermittent visitors, strangers or staff. This lack of social connectedness with peers resulted in loneliness, social disconnect and a sense of not belonging. This was very significant for Fay and Bronwyn. Fay revealed she was frustrated by the loss of contact with people her own age and stated, "*I need to get out to see people my age and have contact with people*". Fay added, "*I'm lonely cos I'm not surrounded by anyone my age. I'm surrounded by other women but then they are a whole generation different*".

Similarly Bronwyn noted, "*I haven't got anyone my age to talk to. They are all old*". Thereby, Bronwyn spent long periods of time alone, often in her room, with her only interaction being with staff or the occasional visitor. Brian also experienced a sense of loss, being the youngest resident in the residential aged care facility. He mentioned there had been "*a younger woman who had resided in the facility but she recently moved out*". When asked if he was missing her he replied "*oh yeah, yeah, yeah. Someone to talk to, cos she was about five or six years younger than I. But my conversation around my age is with the staff*".

Being surrounded by people that were not of a similar age heightened the sense of loss the participants' experienced in relation to their previous lives. Fay grieved her previous life because it impacted on her sense of belonging and

self- identity. Fay was aware she did not fit in with the other residents as they were older. Fay revealed, "*that's why I got upset the other day because I said I just don't know where I fit. You know it's like I don't fit in. I'm not that old; another generation. I don't fit*". Additionally, Fay's sense of belonging was challenged because she is older than many of the staff. She described this saying, "*there's young staff and so I'm older than them so it's sort of feeling like between a rock and a hard place*". The loss of contact or the ability to communicate with people of a similar age reminded Fay of the loss of conversation and friendships and further contributed to the sense of loneliness. She explained, "*yeah I'm feeling very lonely here and they're not my peers, as friendly as they are. They're not my peers*".

The participants' feelings of social isolation were further highlighted by being surrounded by residents who had dementia. Three participants identified that residents with dementia contributed to their general lack of interaction with the other residents. Being unable to maintain meaningful relationships or conversations was viewed negatively and the participants viewed this as adding to their sense of isolation. Three participants claimed that the decreased cognitive functioning of some residents often resulted in repetitive conversations. Fay said, "*there's a lovely lady here, Harriet but I hear the same story over and over. She's got a bit of dementia*".

Similarly, Bronwyn and Rachel revealed that being surrounded by residents with cognitive impairment impacted on their social interaction. Both Bronwyn and Rachel were located in areas where the co-residents had cognitive impairment. Rachel reported she avoided engaging with other residents saying, "*I don't want to get too involved*". Bronwyn described her co-residents as, "*older*

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with dementia". For this reason, Bronwyn chose not to participate in organised group activities and avoided spending time engaging with other residents. Bronwyn reported that she avoided the residents' lounge, preferring to spend time alone either in her room or in the garden. As a result, Bronwyn's social interaction with others was limited to the staff and resulted in social isolation and loneliness.

Rachel also felt a loss of privacy by being surrounded by residents with dementia. Rachel claimed residents with dementia were intrusive, entering her room without permission, "*quite often at night I can be in my room and they come along, the demented ones, and they just walk in. They start talking*", said Rachel. This further added to Rachel's experience of isolation as even her room was not a private space.

In contrast, the issue of being surrounded by co-residents with dementia did not emerge as significant for Brian. Residents with cognitive impairment were in another wing of the facility and Brian was not exposed to disinhibited and intrusive behaviours like the other participants. Therefore, Brian experienced a different level and depth of engagement with other residents, in comparison to the other three participants. As a result, Brian had less sense of social isolation than the other participants. He felt that being surrounded by other people met his needs for social contact and engagement. Interestingly and conversely, Brain experienced a higher level of social interaction within the aged care facility, compared to his previous life. Previously, Brian had experienced social isolation in his home and he perceived he benefitted from the engagement in the residential aged care facility. When explaining this Brian stated,

Just having people around you. Someone to talk to. Cos I was finding it difficult especially when mum moved into a nursing home and my sister started her new job, so she was more restricted. I was finding I was, as I said to you, very isolated. Here I've got people to talk to. Here you've got people around you all the time so you're not just sitting around thinking.

Social isolation was not only associated with lack of visitors or stimulating interaction with like-minded people. Excessive time alone was identified as a contributing factor to the sense of loneliness experienced by three of the four participants. Rachel, Bronwyn and Fay all reported spending considerable time alone despite being surrounded by people in the environment in which they live. Fay described having spent the entire ten months of her time in the facility predominantly in her room, reading and watching movies or television. Fay believed the increased time to think about her situation had a negative impact on her emotional state, claiming,

So I'm a bit of a hermit and know I tend to implode. You know I just read but I've found… um that that isn't satisfying anymore and so I… uh… really crave contact with people but then I find that contact with older people… it's not …..

Another factor that highlighted the age difference between the participants and the other residents of the facilities was the issue of fellow residents dying. Death created further loss for the participants as all of the participants revealed that residents' dying was a negative aspect of living in a residential aged care facility. Both Fay and Brian had experienced the death of a resident to whom they were close and where a friendship had developed. This resulted in further grief and loss as Brian explained,

The only sad part about it is you make friends and then they pass away. So since I've been here there's been roughly four people pass away that I was fairly close to. You make a friendship and then you wake up one morning

and they are gone. And it's hard to imagine but you know it's kind of coming. And like I've said to a couple of people, probably that's the scary thing about coming into here is that. But I've just had to adjust to it.

Therefore, time spent alone, limited regular visitors and the lack of stimulating interaction with other residents, as well as the impact the move into residential aged care had on existing relationships, were all aspects contributing to the sense of social isolation and loss of identity. Younger people with a disability living in residential aged care facilities and their experience of loss of social connectedness leading to social isolation, features heavily in the literature (Perrson & Ostwald, 2009; Winkler et al., 2006; Watt & Konnert, 2007). Compounding the sense of social isolation for the participants was the limited experience of access to the community and their inability to identify with having any purpose in their lives.

Loss of purpose

All four participants in this study indicated that they experienced a loss of purpose in their lives as a result of their move into a residential aged care facility. All of the participants claimed they were no longer able to add to the community, society and its economy. Brian described the impact his health status had on his ability to maintain employment when he said,

After I had the accident I basically never got back to work. After a year off we tried to do where they get you to work part-time and work your way up. But I just couldn't. More to do with the pain than anything. So I just had to give it away. That was when I retired. Then I ended up at home for that two years, marooned.

This sense of disconnect with the age of other residential aged care residents was also highlighted by the lack of age-appropriate activities available

in the aged care facility. The experience of a lack of age-appropriate activities caused participants to spend long periods of time alone and added to their perceived lack of purpose. The lack of purposeful and interesting activities led participants to be bored and grieve the activities and interests they held prior to their move into a residential aged care facility. For instance, Rachel claimed, "*I used to like cooking but I'm not able to do that here*".

Lack of stimulation and loss of control and independence in relation to their environment also reminded some of the participants' of their worsening disability. Bronwyn relayed how she was bored because the only activity she could participate in was music therapy. Aside from this weekly activity, Bronwyn stated, "*I normally just get up and spend the day outside*". Rachel also spoke of a lack of stimulating activities as a key reason for causing her to spend considerable time alone, mostly in her room. Rachel claimed the major adjustment she had to make after she moved into residential care was, "*being on my own and being bored*". Fay, also, had not participated in any organised activities within the facility, and spent the majority of her time alone in her room. This had proven to be frustrating for Fay but she explained how the solitude she experienced has caused her to try and socialise with other residents as she said,

> *Over the year I've really stuck to myself. Always alone in my room either reading or watching a DVD. Now it's like you know, I sort of am starting to force myself to talk to people. Like at meal times I talk but I'm starting to put a bomb under me.*

Although Fay was not interested in the activities offered within the facility, she did participate in some external outings. However her physical limitations

prevented her from undertaking a number of outings. Positively, there had been

recent attempts made to improve her situation, as she explained,

The lady who works here who's in charge of getting out to do things, she's trying to involve me in doing things so I go out and do and so she's trying to get me moving and she's suggested that I go out for the bus trips whenever they do bus trips. And so they have a whole safety thing trialling me getting on the bus, you know, in the wheelchair. Getting the wheelchair on the bus and what to do.

Access to the community, from within the residential aged care facility, was

a challenge identified by all of the participants. Further, the lack of community

access also contributed to the participants' experience of social isolation and

loss of social connectedness. The inability to easily access the community was

linked to the participants experiencing a lack of control over this significant

aspect of their lives. Participants also encountered a loss of choice about when

and if they could leave the facility independently. For safety reasons, Fay,

Bronwyn and Rachel were not permitted to access the community

unaccompanied. This resulted in the participants being dependent on either

staff or their visitors to assist them to access the community and even the

exterior of the facility. Rachel stated, "*if you want to go out for a walk, it's a big

challenge*". The participants were no longer able to choose what level of risk

they were prepared to accept in life. Fay reported, "*I've been told I'm not

allowed to go out by myself because of my balance and whatever. I need the

security of having someone with me*". This resulted in a loss of freedom and

independence for Fay, and further isolated her from the wider community. The

loss of control resulted in being dependent on others to experience the

outdoors.

A lack of visitors resulted in the participants experiencing being almost entirely dependent on staff members for conversation and interaction. Bronwyn revealed that her limited access to interacting socially with others resulted in further feelings of loss of social contact and normal interaction with others. Bronwyn stated, "*I'd like to be more sociable but you can't always get out*". Rachel reported that one of the major challenges she experienced in residential aged care was, "*not being able to get out anymore. It can be very frustrating. It's like an army manoeuvre to do something*". Bronwyn echoed this experience when she replied that the biggest loss she experienced in moving into a residential aged care facility were the restrictions on choice and resulting in social isolation, adding,

> *Not being able to get out anymore. I used to spend a lot of time on the beach up at M. I lived down at W Beach and I had my little car and used to get into that and go somewhere.*

Not all participants felt the same level of restriction in participating in activities inside and outside the facility. Brian had embraced a number of activities on offer within the facility and on organised excursions outside the facility. He viewed these as opportunities to explore new interests he had not previously experienced and he retained some sense of control over his environment. Interestingly, Brian's facility had a larger range of activities available to residents than the other participants' facilities. Additionally, the residents had input into the planning of activities and a social calendar was developed for each month that included a range of weekly activities. Figure 2 (below) is an example of the monthly activities calendar for July 2016 and illustrates the choice and scope of possible participation by residents.

Figure 2: Monthly activities calendar Facility 4.

However, similar to Fay and Bronwyn, Brian's ability to access the community was restricted due to the high degree of planning required to mobilise him. The inability to make spontaneous decisions to participate in activities outside the facility led to Brian experiencing frustration as he stated,

Mum's gone over to visit her daughter and granddaughter (interstate); normally I would have gone too but I couldn't and I would need to get a plan to get things done. So that's something that I'm negative about.

Brian did not consider the limitation to accessing community activities as a negative aspect of his living environment because in a way, his status quo had not changed as unlike the others, prior to entering residential aged care Brian did not have ability to undertake community activities. Brian's only disquiet was the loss of spontaneity to choose an activity or join an activity due to the high degree of planning required for him to participate in some external events.

When the participants could access the community, this was viewed as a very positive experience however being unable to regularly participate heightened their feelings of loss. Participants were grateful to be taken out, for

instance Fay reflected positivity on the experience of being taken out by a staff
member when she stated,

> *Shelley, she's the Physio here, and she said I think you need to get out so*
> *she took me outside and had a coffee and it was just so wonderful to know*
> *there's a whole world out there, outside these walls.*

Overall, social isolation was experienced by participants due to the inability
to actively engage in facility-based age appropriate activities. Additionally, lack
of regular visitors combined with lack of accessibility to the community
contributed to a sense of being disconnected from society and heightened
feelings of loss. Furthermore, the inability to freely choose the activities and
social engagements available to the participants resulted in a loss of free will.

Loss of free will and loss of control

Free will is the ability to independently make decisions, determine choices
and to maintain self determination (Phemister, 2001). All four participants
described a loss of free will over aspects of their lives as a result of being
placed in a residential aged care facility. Many factors were identified by the
participants as being beyond their sphere of control. These included their input
into decision-making, and the routine and regimentation of residential aged care
placement which impacted on choices and options available to them.

Overwhelmingly, the loss of free will around decision making was
experienced by all four participants. Primarily, decision making input in relation
to the initial decision to move into a facility, and, the choice of facility where the
participants were placed, was removed. All four participants reported they did

not get to choose to move into a residential aged care facility. The literature clearly indicates that a key determinant of successful relocation to residential aged care is where the individual exerts control over the decision to move (Brownie et al., 2014). The physical care needs for all participants had taken away the choices available to them and dictated the need to receive a level of care that was unavailable to them in the community. For two of the participants (Fay and Rachel), the decision to move into residential aged care was made by family members and the participant's input into the decision was limited to commenting about the location of the facility. Rachel stated, "*here I am. It was a case of having to be somewhere*".

Brian and Bronwyn had all decision-making removed and were advised by hospital staff that they had to be placed in a residential aged care facility. They believed that they had no choice in the matter and both moved directly from hospital to residential aged care placement following lengthy hospital admissions. Brian reported that following his third or fourth admission to hospital due to falls at home, he was told by doctors, "*we'll have to put you somewhere*", effectively removing all decision-making from him.

The phrases '*be somewhere*' or '*put somewhere*' were used by both Brian and Rachel to describe their experience. Bronwyn recounted her lengthy stay in hospital waiting for a placement when she stated, "*I spent a long time in hospital waiting. It was about nine months, I think*". Similarly, Brian had a long wait in addition to no control over choosing to move into a residential aged care facility. Overall, the majority of participants had limited choice or options regarding their placement, particularly if they were discharged directly from hospital. Additionally, Brian felt a need to accept whatever placement was

offered to him as he had been told places were highly sought after, resulting in limited vacancies. He also attributed his unique care needs as being a major factor in limiting choice of placement. Brian explained, "*most of the time they wouldn't take blokes my size*".

Bronwyn was not involved in the decision-making around the choice of facility at all. She was located in a facility a significant distance from her family and friends and reported she had been given no opportunity to participate in that decision-making process. Bronwyn stated, "*that was all decided for me by the doctors*". As discussed earlier, the geographical location of the facility where Bronwyn was placed had created numerous challenges for her and an overall sense of powerlessness.

Routine and regimentation were a constant for all participants. The lack of influence over choices and how the participants lived contributed to their experience of loss of free will and lack of choice. Residential aged care facilities follow routines to maximise delivery of care for staff, largely due to the number of residents requiring care and assistance. For Fay, there was some scope for flexibility in the delivery of care; however this was not the case for the other participants. For instance, Fay explained how there were times when her MS takes over stating,

> *Like the other week I had a classic case of MS. It's like I'm an inflatable toy someone's pulled the stopper out, that's how you feel. Like all the air goes out. And so a couple of mornings they brought me breakfast. I've had it in my room and so they are very flexible.*

In contrast, Bronwyn described that she had no choice or flexibility surrounding when she was woken, showered or dressed, and so any sense of

free will and control over day to day decision-making was removed. Moreover, there was no sense of choice, continuity or clarity about the time tasks would be undertaken. The timing of tasks was based on staff availability, rather than Bronwyn's wishes and preferences. "*I don't get the choice to stay in bed*". Bronwyn's daily experience as a resident of an aged care facility is one of repetition, further reinforcing the loss of free will experienced daily. Bronwyn reported having the same routine each day stating,

I get up at about 7.30, 8 o'clock. They give me a shower and give me breakfast and then take me outside and I would usually go to sleep out there. I come back in after lunch. Then I have a nanny nap in the afternoon. (Long pause) Yeah, that's about it for the day. And that happens every day unless it's raining and they leave me in bed.

Previous life experiences and preferences also influence how favourably the participants viewed routine. While the regimentation of the routine in facilities was perceived negatively for the majority of the participants, Brian claimed maintaining a rigid schedule was beneficial to him when adjusting to the environment. As an ex-serviceman, Brian's previous life had been one of routine and accepting that the needs of the group and rules are viewed as important as the individual and choice is part of service life. Brian found maintaining this in his current living arrangements comforting and had aided to adjusting to his placement. Brian described this stating,

I'm used to set rules and restrictions cos in this area we've got over 40 people so 40 other people to think about other than yourself. That's why there are rules. For that many you've just got to learn to live within this environment. I've found it really easy so the regimentation didn't worry me.

The combination of changed location in addition to the impact of disease and disability emphasised the sense of loss. Decreased physical functioning, as a

result of their medical conditions, impacted on the sense of loss of free will for three of the participants. The three participants described the experience of loss of physical activity as an additional complexity to their already difficult adjustment to placement in a residential aged care facility. Fay described her experience stating, "*so it's a mixture of things. It's getting used to the condition and also getting used to being here*".

The lack of access to rehabilitation and ongoing physiotherapy had a significant negative impact on her. Bronwyn's physical functioning had significantly declined upon moving into the residential aged care facility. Over a five month period, Bronwyn had no access to a Physiotherapist as the staff Physiotherapist had resigned and was not replaced. Additionally, funding for Bronwyn to attend a community-based rehabilitation day centre had been withdrawn. Bronwyn explained,

> *They were sending me over to Rehab. I was doing physio twice a week there but they stopped the funding and I wasn't able to see that service. So yep I haven't been able to. And now the Physio here pulled out to get married and she hasn't come back so they haven't had anyone to walk me for five months.*

Bronwyn experienced further loss to her function and independence since admission to the facility. In describing her physical deterioration as a result of no longer receiving rehabilitation or physiotherapy input, Bronwyn claimed, "*I was walking sixty-nine steps and I could move a bit better in bed than what I can now*". Bronwyn advised she is now unable to walk at all and requires two staff to reposition her in the bed as she is unable to do this independently. In describing the impact that the lack of rehabilitation had on her physical functioning Bronwyn despondently claimed that she saw her life going "*nowhere fast*".

Additionally, Bronwyn said that although her present life goal is "*just to walk again*", she had no idea how this would be achieved; further evidence that her sense of loss was overwhelming and outside her realm of control.

Similarly, the inability to manage and control the progressive nature of a chronic disease was a challenge for Fay and Rachel, both of whom have Multiple Sclerosis (MS). Fay and Rachel spoke at length about this lack of control and a need to constantly adjust to changes in their physical functioning. Fay reported,

> *Yeah I've noticed another thing, the condition's deteriorating so the latest thing I've had an optical neuritis thing happening, which is normal with MS. That's the normal sort of thing. Yeah so that's another thing I'm just dealing with now.*

All participants described the significant impact of not maintaining activity had upon their experience of loss of control of their lives. The participants became dependent on others for care well before that would be considered developmentally appropriate for their ages. Additionally, hopes and dreams of possible future travel, employment, life stages, choices and new experiences were abandoned by the participants.

The experience of loss of a previous lifestyle was particularly evident for Bronwyn when describing her life prior to the accident. Bronwyn's disability prevents her from engaging in age-appropriate hopes and dreams for the future. Bronwyn described herself as having been a '*free spirit'*, spending much of her adult life travelling around Northern Australia and working on properties. In describing this loss, Bronwyn spoke with sadness and a sense of hopelessness stating, "*if I hadn't had the accident I'd be able to work and travel about visiting*

friends. Yeah, I've got friends up in the Territory and work up there and cousins down at C".

Further, the participants' loss of control was also attributed to no longer having someone they could depend on for support. For example, Fay had undergone divorce and physical separation from her ex-husband and was reliant upon him to take over the role of sole parent when she became ill. In summarising the loss of control associated with her placement in a residential aged care facility, Fay described her experience as, "*I've always been someone fairly in control all my life. You know, I did this, I did that and then feeling like your whole life has been taken out of your hands*".

Summary of loss

Loss was one of two key findings to emerge from the data. Most significantly, the loss of relationships with family and friends was experienced by all participants as a result of living in a residential aged care facility. Living in an aged care facility impacted on the support available to the participants and contributed to a sense of social isolation, loneliness and social disconnect. Lack of free will largely contributed to the loss experienced by the participants. For instance, not only had decision-making about being placed in a residential aged care facility been removed, but the ability to control day-to-day aspects of their lives was also lost. To redress the lack of control experienced by the participants as a result of loss strategies of resilience were adopted in order to maintain the equilibrium.

RESILIENCE

Bonanno initially described resilience in 2004 as the ability to adjust to an adverse event in a functional way. Resilience emerged from the data as a major theme because the participants demonstrated the adoption of coping strategies, meaning making and benefit finding, to adjust to Loss. These two strategies (meaning making and benefit finding) are commonly associated with resilience. The sub-themes of meaning making and benefit finding reflect resilient thinking and were utilised extensively by the participants as a means of adjusting to the losses associated with placement in a residential aged care facility.

Meaning Making

All four participants found meaning in being placed in a residential aged care facility by using a variety of strategies. One of the strategies used was to find benefit in being in the aged care facility as it ensured that their physical care needs were met. There was also an indication that participants were trying to make positive meaning out of their situation. The participants described experiencing a sense of safety by living in the facility, due to having staff available to attend to their needs. Fay stated, "*I'm in a place where I'm safe. I'm cared for where it matters*".

All the participants have high care needs which could not be met in the community, without 24-hour live-in care. The reason they were placed in residential aged care was that this level of care was not financially or physically available to them at home. All of the participants in this study required assistance with activities of daily living such as showering, toileting and dressing. Two of the participants, Fay and Brian, could feed themselves.

Bronwyn and Rachel required assistance with cutting up food, however once this was done, they were able to feed themselves. Bronwyn described her care needs as follows,

> *When they come in to toilet me they have two people, they roll me. I can't roll by myself. And I can't sit up by myself. The only way I can sit up is if I push the bed right up and then let it go back.*

Therefore, the participants rationalised that in order for their high-level care needs to be met, they needed to move to an environment that provided that level of care. Such rationalisation was the same for all the participants and was one of the strategies they had adopted to adjust to the move. The sense of safety and security created by the environment in which they lived, was for Fay, Brian and Rachel a positive aspect of the environment in which they now reside. All participants believed they were in the best place possible for them due to their high risk of falling. Brian stated, "*when I had my third fall and we talked about it, to me it* (moving into a residential aged care facility) *was the best thing to do*". Fay mentioned having recently been offered accommodation with other MS sufferers but she had refused stating "*I think I'm actually more comfortable here and I don't know if me being in a house would have really been helping me at all*".

Additionally, the fact that their individual care needs could be met by the residential aged care facility was perceived as a means of relieving the burden of care that would otherwise have been placed on the participant's family members, had they remained living in the community. All the participants perceived that their placement in a residential facility had ensured that their family and friends had not been burdened with their care. As such, the

participants demonstrated meaning making out of their experience and despite the loss accepted being placed in a residential aged care facility. Brian revealed that his family were not in a position that they were able to support him living in the community as his care needs increased following repeated falls. Brian stated,

> My older brother was here but he moved up north with his family. And that's why I decided not to go home, back being on my own again. So I couldn't drive anymore because of the falls and also you know, basically I was stuck. Mum couldn't, it was hard for mum to come over if I needed help, and again with my sister, her work, she became second in charge and her workload increased so she couldn't get away as much.

All four participants believed the most appropriate environment for them to live was in a facility. Rachel claimed, "*well it just got too much for me* (at home), *and to survive I suppose and had to have someone look after me. So I ended up here*". Therefore, of note, although residing in an aged care facility, they were afforded an environment of safety and security. For instance, despite Fay identifying benefits in the environment in which she now lives, she described feeling somewhat conflicted by this. This was apparent when Fay stated,

> I feel so decadent you know. I don't cook and I don't clean and I don't wash and it's like, um I feel like this is ridiculous at 46. I'm conscious of the fact I don't want to get used to this environment.

Brian, however, described this as a positive aspect of living in the facility, adopting the process of benefit finding to highlight the positive aspects of his living environment. Brian stated,

> It's good you get three good meals a day and you don't have to worry. When I lived alone, I would usually cook enough for the whole week. And sometimes you'd cook it and by the time you've finished you don't feel like eating it. So here you have that and you don't have to worry about other things like rego, insurance, and you know rates.

The adoption of meaning making strategies to enhance resilience was utilised by all the participants. Having care needs met in a safe environment was a perceived benefit but having their views reshaped about their perceptions of older people was another. Brian drew meaning from his placement by reflecting upon how the experience was reshaping his perceptions about older people. Brian emphasised this many times during the interview, explaining how this served a purpose and assisted him to adjust to the residential aged care environment. Further, Brian described how he felt many of the older residents were more active than him and that older people generally are more active than ever before. He stated,

I wasn't really sure how I would fit in with the age difference but as I said, age is not a big thing now. You know, because there are people who come in here who are in their seventies and eighties and still full of life.

Brian also described his feelings about being surrounded by older people, stating,

It doesn't really matter how old people are. A lot of them, a lot of people now are much younger on their outlook on life. Cos when I was in my twenties, you would always see someone in their sixties or seventies was old and there's a lot of people here a lot older and more active than what I am.

Brian demonstrated meaning making when describing his altered perceptions about older people. This positive reframing assisted him to adjust to living in an environment surrounded by much older people. Additionally, Brian's perceptions of having developed friendships with staff, who were much closer in age to himself, was a further means for him to adapt to living in a residential aged care facility.

The perception that friendships had developed with the staff from the facility was experienced by all four participants. The participants cited friendships with facility staff as being helpful to them and providing them with an opportunity to have contact with younger people, which they desired and missed. Each participant spoke of having formed stronger relationships with staff, compared to other residents. Bronwyn reported, "*they* (the staff) *are the only young ones to talk to*". Similarly, Brian said, "*the staff here are around my age so that helps as well. I guess they're the people you connect with because of the age thing*". Fay also noted, "*that's why I think I've gravitated towards carers here because they're younger and not an old person*".

Bronwyn also reported having developed a close friendship with the head nurse saying, "*she takes me out about every three weeks for half the day. She takes me to the shopping centres and we have lunch or morning tea. Do a bit of shopping*". The perception that a staff member is a friend and someone to engage with socially provided Bronwyn with age-appropriate engagement and access to the wider community. When Bronwyn described the time when she had been taken outside the facility with the staff member, it was the only time during the interview that she spoke enthusiastically and positively.

Having developed friendships with staff members from the facilities in which they resided, afforded the participants the opportunity for peer contact and a sense of social connectedness with those of a similar age. Furthermore, the participants believed that their presence also benefitted the older aged care residents positively and this provided them with meaning and understanding.

Benefit Finding

Two participants, Brian and Fay, described having integrated positivity into the lives of other older residents as well as staff in the facility. On entering residential aged care, Brian and Fay's role identity changed and emphasised a sense of purpose through providing benefit and personal meaning and happiness to others. Both Brian and Fay spoke of the positive impact that they made as younger residents in the facility. Further, Brian and Fay believed they brought new perspectives to the residents which gave them a sense of purpose as a resident. Fay stated, "*yeah 'cos I'll talk to them and they really enjoy having a younger person here I think*". Additionally, Fay perceived her presence had a positive impact on the staff, "*the young carers they love it there's someone younger here*", thereby further demonstrating benefit finding in her living environment.

Brian found benefits in giving by sharing skills with other residents. For example, Brian described sharing his skills in scrapbooking and card making with the other residents and the fact he conducted workshops within the facility. Additionally, Brian described facilitating some activities and providing enjoyment to residents on the weekends, when there would not usually be organised activities available to the residents. Being able to contribute to the facility provided Brian with a sense of purpose. Additionally, Brian believed this was viewed very favourably by the residents and provided him with a role that was valued and useful. Brian claimed,

> *With my age, I do help with activities so we do have bingo in here three times a week. And on the long weekends I'll run a bingo on a Saturday or Sunday. So that's some of the things I do. And I've run a couple of scrapbooking days as well as just making cards.*

Placement in residential aged care was not entirely negative because being in facilities such as the one Brian was located also provided opportunities for some of the participants to live differently. For example, Brian perceived being placed in a residential aged care facility had provided opportunities and experiences that he would not have had in the community. Brian viewed the opportunity to be involved in new activities as a very positive aspect of his placement and it provided him with a means of filling his time with interesting and purposeful activities. Therefore, Brian's experience of benefit finding was a coping strategy and assisted him with successfully adjusting to his placement. Brian described this when he said,

One of the things I've taken up here is doing the birthday cards. I make a design and give them to the residents. As I've said, I've taken up scrapbooking. Something my younger sister was doing a long time ago and I thought, oh well, it's something. So that keeps me occupied and gets me away twice a month.

Brian's experience of residential aged care contrasted sharply with that of Bronwyn. Bronwyn did not identify any positive aspects in her experience of residential aged care placement. For the other participants, identifying positive aspects of their lives provided them with a coping strategy and they could draw on these to rationalise why the move to a residential aged care facility had been necessary.

The concept of benefit finding is often utilised by people with a chronic illness, whereby an individual will redirect their focus to those and compare themselves to those that they consider are in a worse situation. Rachel and Fay provided an example of this when they described other residents within their

respective facilities who they felt were "*worse off than me*". Fay elaborated on this in describing a fellow resident stating,

> *Ah one good thing that's been good is in here the people are in a way worst situation so that in a way that ……. Like this guy here (indicating a fellow resident close by), Craig, he's got Parkinsons Plus. It's a lot worst. And so talking to him he used to be, it's so sad, he was an ambassador, so he's travelled all around the world. It's almost nasty but it's actually also it's good for me to look at that and think right, you know what, I'm not alone. It's strengthening in a way to see that there's other people dealing with things.*

Moos and Holahan (2007) have labelled this 'positive reappraisal' as it refers to times when an individual with a chronic disease or disability will compare and consider themselves luckier than another individual who also has a chronic illness or disability. Positive reappraisal is a resilience- enhancing strategy and was utilised by all the participants as a means of benefit finding.

Summary of resilience

Resilience was the second key theme to emerge from the data. Resilience is the ability to adjust to loss and restore the equilibrium in the face of an adverse event (Bonanno, 2004). People who adjust well to loss, do so by adopting resilience-enhancing techniques to aid adjustment. Resilience-enhancing techniques, such as benefit finding and meaning making were adopted by the participants of this study as a means of facilitating their adjustment to placement in a residential aged care facility. Benefits identified by the participants included their presence providing a positive impact for the older residents and the staff. Additionally, Brian adopted benefit finding in sharing his card making and scrapbooking making skills with the other residents of the facility in which he resided. Meaning making was the other resilience enhancing strategy utilised.

An example of meaning making is in the way all four participants justified their placement in a residential aged care facility as the environment met their physical care needs.

Conclusion

An analysis of the data found that the participants experienced significant loss. Loss was experienced from a number of perspectives beyond the physical loss of function. The participants experienced loss on multiple levels – biological, functional, social, physical and psychological. The level of disability experienced by the participants led to their placement in an aged care facility. The degree of loss experienced by the participants was significant and compounded by the environment that was now their home.

The participants' sense of loss of community that was associated with loss of social supports and connectedness was strong in several domains and this was highlighted particularly for those participants who were geographically located a long distance from family and friends. The loss of previous and family/friend relationships was particularly significant and was exacerbated by an inability to make new social and meaningful close connections with either people of similar age, interests and lack of access to a community external to the aged care facility. Loss of future hopes and dreams and an inability to plan, make choices or control daily activities or to participate in purposeful activities was also highlighted.

It was clear that some strategies were employed by at least some of the four participants to manage their adjustment to the losses. Thereby, the participants exercised their resilience in the face of loss in order to accept the environment

in which they now lived. Utilising a grief and loss framework, the sub-themes of meaning making and benefit finding presented as strategies employed to adjust and cope with placement by some participants and in some cases, positive appraisal was used to favourably compare their own function and illness with others as a way to cope. Overall, the participants were actively engaged in re-negotiating their sense of identity, role and purpose within the aged care facility as an unconscious way to integrate their multiple losses into their new life.

The following chapter, Chapter 5, includes an analysis of the findings in alignment with the literature. In particular, this final chapter will discuss the use of resilience as a strategy used by younger people with a disability to adjust to living in residential aged care facilities. The chapter concludes with examining implications for practice, identifying limitations and proposing recommendations. .

CHAPTER 5

ANALYSIS OF FINDINGS AND DISCUSSION

Introduction

This study aimed to explore the experiences of younger people who were placed in residential aged care facilities. A phenomenological approach was used to gain insight into the lived experience of the four participants included in this study. The participants included four individuals with a disability who live in residential aged care facilities. Although the small number of participants produced rich data and insights, findings are not able to be generalised.

Findings from this study highlighted that significant loss is experienced by younger people with a disability placed in a residential aged care facility. An additional finding was that in managing loss, the participants adopted resilience enhancing strategies to adjust to the impact residential aged care placement had on various aspects of their lives. The loss that the participants experienced related to psychosocial changes - in particular, the loss of surroundings, friends and family, decision-making and control.

All the participants experienced loss but interestingly, they did not outwardly appear to grieve their loss but adopted strategies aligned with resilience to accept the changes associated with living in a residential aged care facility. Therefore, this final chapter will analyse the findings in line with Bonanno (2004) who challenges traditional and contemporary theories of grief and loss. Bonanno's work is noteworthy and relevant because it proposes that some

individuals do not experience grief in relation to loss because individuals develop resilience to the loss.

In addition to presenting the analysis of the findings, this chapter will compare and contrast the findings with the literature. Finally, this chapter will examine and outline the limitations of this study and present recommendations from this research, including future possible research, and provide a conclusion to this study.

Analysis of findings and discussion

The intent of this study was to explore the experiences of four younger people with a disability living in residential aged care. The major theme that emerged from the data was loss therefore analysis of the data focused on exploring the many aspects of loss that the participants experienced. However, it is important to demarcate that the purpose of exploring loss was not to examine whether the participants experienced grief as a result of their loss. Grief and grief responses to loss are most often individualised experiences and exploring responses to grief was not the intent of this research. Moreover, the theme of loss was multi-faceted which reinforces the significant emphasis and depth to discussing loss.

. The way one person responds to loss will differ greatly from another person, despite experiencing the same type of adverse event. This study found the experiences of younger people with a disability residing in a residential aged care facility are similar in many ways to those of older people transferred to and living in a comparable environment. The participants of this study experienced loss of role, identity and loss of purpose. Additionally, the participants

experienced loss of personal identity due to the loss of relationships with family and friends that resulted in social isolation and consequently a loss of social connectedness.

Loss of personhood and identity

The participants of this study experienced changes to their role in life whereby their role was diminished because of being placed in a residential aged care facility. The participants' change to role identity related to them being no longer employed and as such, no longer contributing to society through a productive working life. Further, the three female participants, identified a change in their role status from wife and mother, to aged care facility resident. The female participants were no longer able to perform the tasks associated with nurturing and caring for family members, and instead, they required the care that they had previously provided to others.

The sense of loss surrounding their loss of identity and personhood was significant and was compounded by the lack of interesting and purposeful age-appropriate activities available to them in the residential aged care facility. These findings concerning loss of identity and personhood are indicative of those identified by Winkler et al. (2008) who found that the primary losses experienced by younger people with a disability living in residential aged care facilities included loss of home maintainer, caregiver, friend and family member. Life roles were also altered as a result of placement in a residential aged care facility, as the participants were unable to perform basic tasks such as cooking and cleaning. The experience of having an undefined role and purpose impacted significantly on the participants and was countered with a need to find meaning and a sense of belonging within the residential aged care environment.

A sense of belonging relates to purpose and identity and is a measure of quality of life (Barringham & Barringham, 2002). The participants of this study experienced disengagement from their community, their family and friends and the other residents of the facility, affecting their sense of belonging. The displacement experienced by the participants, resulted in loss of previous friendships, relationships, and social connectedness. Emotional disconnect was also a result of lack of contact with peers within the residential aged care facility. The participants claimed that being surrounded by older people, some of whom had dementia, impacted on their ability to create a sense of belonging within the facility. The capacity to develop new friendships in the residential aged care environment was extremely limited and the participants identified with the staff of the facility for social relationships and interactions rather than the other residents. Relying on staff for interactions further emphasised the difference between the participants and the other residents and reinforced they did not belong. Bigby et al. (2008) identified a primary concern for residential aged care providers included the inability of younger people with a disability to 'fit' into the resident community. The reasons for this identified by Bigby et al. was age and the differing interests between younger and older residents. Therefore, this study aligns with findings from previous research whereby often the only commonality between residents within an aged care facility is the need to receive supported care.

The inability of the participants to readily access the community, beyond the confines of the residential facility, further reinforced the lack of belonging to and connection with the wider environment. This finding of being unable to access

the community is indicative of Watt and Konnert's (2007) and Winkler et al's. (2011) research which found a lack of social and community belonging were highlighted as negative impacts of placement within a residential aged care facility. The lack of social and community belonging was compounded by an inability to access the community as well as a lack of regular visits from family and friends, as was evidenced in this study. Not only were the participants of this study disconnected from family and friends by geographical distance but they were unable to participate in social activities outside the facility. Brownie et al. (2014) revealed that retaining meaningful social relations was a key factor in older people adjusting to residential aged care placement. Similarly, Brownie et al. found that where the only available care option for younger people with a disability was to be placed in a residential aged care facility, the facility should be geographically located in their community to maintain existing social and support networks.

Furthermore, all the participants in this study described access to the community as a major challenge to living in a residential aged care facility, and as heightening their sense of social exclusion. All participants believed that increased community access would be beneficial to their emotional and social well-being. Consistent with findings from previous studies is the notion that social inclusion is considered as important an aspect to younger people with a disability as the provision of support services and assisted devices to aid their physical functioning (Commonwealth of Australia, 2015; Dearn, 2011; Persson & Ostwald, 2009; Winkler et al., 2006; Winkler et al., 2011). The Community Affairs Reference Committee Report (2015) states that regardless of their disability, all people need to feel connected to the broader community

in which they live, through purposeful interactions with others. Additionally, the Community Affairs Report found that most younger people residing in residential aged care facilities have a desire to participate in education, employment and social and recreational activities however their living environment is a major barrier to this as it does not provide support structures to enable this (Commonwealth of Australia, 2015). Therefore, overcoming structural barriers requires ingenuity and commitment on behalf of government, and residential aged care and disability service providers. Of note, Winkler et al. (2011) found that younger people who transitioned from a residential aged care facility back into the community had significantly increased opportunities to access community activities. Winkler's finding highlights the point that the individual's disability is not necessarily a barrier to community connectedness but it is the residential aged care environment.

Despite accepting that their placement in a residential aged care facility met the participants high level physical care needs, the participants of this study articulated their feelings of loss and how they perceived their lives could be improved within the residential aged care facility. The ability to easily access the community, to participate in age-appropriate and purposeful activities and to retain social and family relationships or have the opportunity to develop new ones were all identified by the participants as ways that their lives within a residential aged care facility could be improved. The participant's suggestions are reflective of the findings by Persson et al. (2009) who indicated that maintaining social relationships, purposeful activities and a less regimented routine would support younger people with a disability to adapt to living in a residential aged care environment. Maintaining social relationships would

ensure that younger people with a disability in residential aged care facilities are not unseen and unheard.

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Unseen and unheard

Younger people with a disability in residential aged care facilities are marginalised as they are hidden from society and as such, are unseen and unheard. Marginalisation was apparent for the participants because they were not included in the majority of decision-making regarding their placement into a residential aged care facility. Despite possessing decision-making capacity, the participants of this study had little or no involvement in the decision to move into a residential aged care facility. Exclusion from decision making regarding being placed in a residential aged care facility is reflective of individuals needing to enter residential aged care directly from hospital.

Furthermore, the participants were eliminated from the choice in the location of the facility and lack of consideration was given to the relocation causing disengagement from their respective communities. People with a disability are considered to be amongst the most marginalised in society (Winkler et al., 2011) and the lack of involvement in decisions is reflective of the participants being marginalised.

Furthermore, decision making regarding day to day living within the residential aged care environment was also identified as a challenge for the participants of this study. Strict routines and inflexibility by staff was identified by two of the participants as being a negative aspect of the residential aged care environment. Previous studies have revealed that the greater control older people have in the decision making process to enter residential aged care, the

more likelihood of a successful transition (Brownie et al., 2014; Johnson et al., 2014; Rodgers et al., 2012; Tuominen et al., 2016).

Resilience as a strategy to adapting to a challenging environment

The participants of this study did not choose to live in a residential aged care environment but resigned themselves to accept such a placement in the belief they had no other option. Due to a lack of other accommodation options and support, the participants of this study had to accept being placed into residential aged care. All the participants demonstrated aspects of resigned acceptance, using meaning making and benefit finding strategies. Persson and Ostwald's (2009) study concluded a similar finding to this research in that, the participants of that study resigned themselves to accept living in a residential aged care facility due to there being no viable alternatives for care. The participants accepted the residential aged care facility was an environment in which they were safe and well cared for.

Therefore, the participants used a number of resilience strategies to manage their adjustment to residential aged care in order to redefine themselves, cope and 'fit in' to the space they now lived. For example, Brian perceived that he brought pleasure to the older residents and the staff due to being younger. Brian's meaning making and benefit finding was evident by being helpful, teaching the other residents new skills in craft and co-ordinating activities to support the staff.

Adopting sense-making strategies to enhance resilience has allowed the participants of this study to adapt to life in the residential aged care environment. Not wishing to be a burden to family due to their high level care

needs and the acknowledgement that they had health conditions that would result in continuing physical deterioration, were all benefit finding strategies utilised by the participants. The participants' justified their placement in a residential aged care facility as being the most appropriate environment in which to have their needs met. The participants also believed that the residential aged care facility provided a safe and secure environment that could not be replicated in community-based living.

Resilience was demonstrated by the participants of this study in relation to their chronic health conditions and their awareness that continuing physical deterioration would be a result of the disease process. Resigned acceptance was adopted by the participants who perceived they were powerless to alter this and therefore accepted it as inevitable. Resigned acceptance was also combined with meaning making and benefit finding strategies to manage these continuing losses. The participants compared their own physical functioning with those of co-residents, determining that others were more debilitated or "worse off", thus demonstrating how meaning making and benefit finding were applied.

Watt et al. (2007) identified that younger people with a disability who are placed in residential aged care facilities develop resilience. Watt et al. believed 'realistic optimism', where younger residents 'made the best of it', was applied. Similarly, resilience has been identified in the literature as a strategy used by older people transitioning to residential aged care placement. Brandburg et al. (2012) identified personal resilience as the fundamental strategy adopted by older people to facilitate transition into residential aged care. It is reasonable to surmise that resilience is a strategy many residents utilise to adapt to the

change associated with residential aged care placement no matter what their age.

Understanding the adaptive processes used by younger people with a disability to adjust to placement in a residential aged care will better aid staff, family and friends to support the younger person manage the grief and loss they may experience. Building resilience supports the individual in a strengths-based approach to managing loss (Southwick et al., 2014) and is a positive means of addressing loss in an environment such as a residential aged care facility.

Not a 'last resort' option

The findings of this study reinforce the inappropriateness of placing younger people with a disability in residential aged care facilities. The impact of such placements was evident in the experiences described by the participants of this study. Significant losses contributed to social isolation, loss of relationships, boredom and a sense of not belonging. The participants of this study had no input into whether or not they were placed in a residential aged care facility and alternative options for supported care in the community were not explored. The discord between Australian government policy and meeting the obligations set out in the United Nations Declaration on the Rights of Disabled Persons is evident.   Principle 9 of the Declaration states that people with a disability should reside in accommodation that promotes community participation and is the least restrictive environment possible for promoting community life (United Nations, 2007).

The lack of appropriate accommodation options for younger people with a disability and high level support needs, with residential aged care facilities

filling the gap, is discussed extensively in the literature (Commonwealth of Australia, 2015) and while not favoured is considered acceptable practice. This is despite the wide acknowledgement and the numerous studies that have demonstrated that such placements are inappropriate and negatively impact on quality of life and other psychosocial aspects of the lives of those affected (Persson and Ostwald, 2009; Watt and Kannert, 2007; Winkler, et al., 2006).

This study further reinforces that this practice continues, with alternative options for care in the community not been explored for the participants of this study. None of the participants in this study expressed a desire to move from their current accommodation and all accepted this was the most suitable environment to meet their needs. However, the participants had not had been provided with alternative accommodation and support options. Only one of the participants had been provided with an opportunity to explore alternative community-based accommodation options since being placed into a residential aged care facility. None of the available options were deemed suitable to meet her unique care needs and were therefore discounted.

Little progress has been made in the decade and a half since Australian research commenced exploring the practice of placing younger people with a disability into residential aged care facilities. There are in fact more younger people with a disability recorded as residing in residential aged care facilities in 2013 – 2014 [7194] (Commonwealth of Australia, 2015) compared to the number in 2012 [6000] (Australian Institute of Health and Welfare, 2012), overall an increase of approximately 1,200. Furthermore, the roll-out of the National Disability Insurance Scheme (NDIS), which was lauded as the saving grace for younger people with a disability currently residing in residential aged care

facilities, has failed to meet the needs of this vulnerable group. The Summer Foundation reports admissions to residential aged care facilities have increased by twenty percent in two of the three NDIS trial sites (Summer Foundation, 2017).

Limitations of the study

The key limitation of this study was the lack of generalisability as this is a qualitative study with only a small number of participants. Qualitative research is synonymous with a small cohort which means that the findings are limited to the participants included in the study, as opposed to the general population (Liamputtong, 2013). However, recruitment of participants was challenging as the inclusion factors limited people being able to participate in the study. For instance, participants required a high level of cognition and language skills to participate in the in-depth interview. Most younger people with a disability who reside in residential aged care facilities have brain injuries. Brain injuries may impact significantly on cognitive functioning and speech (McDonald, Togher, & Code, 2016), thus limiting the ability to participate and leading to participant exclusion from the study.

Another limitation to this study was the difficulty in accessing younger people admitted to aged care facilities. Recruitment of participants was problematic and a major limitation of this study. Recruitment relied on purposive snowball sampling which was contingent on engaging key stakeholders of organisations to suggest potential participants. Obtaining buy-in from some key organisations was difficult as some facilities refused access to potential participants.

Gender balance was also a limitation of this study as there was only one male participant. Despite significant efforts to try to recruit an additional male participant, this was not possible therefore gender comparisons have not been made in the conclusion to this study. Of note, attracting more male participants was difficult because many of the potential male participants had brain injuries and lacked the cognition and language skills to participate. A further limitation was the lack of culturally diverse participants. It is noted that there is an absence of participants from different cultures but this study was conducted in a regional area where there is no access to interpreters.

Future Recommendations

Improving the accommodation and support options available to younger people with a disability is a key recommendation from this study. Residential aged care facilities should not be the only option for younger people with high level care needs. As the 2005 Senate Enquiry into Aged Care in Australia declared, younger people in aged care facilities needs to be a "last resort". All other avenues for providing care in the community should be explored before the placement of younger people into residential aged care facilities. The introduction of the National Disability Insurance Scheme (NDIS) is an opportunity for all younger people with a disability to have input into decisions around their support and care needs and how they are best met. Additionally, the opportunity for those younger people currently residing in residential aged care facilities to explore alternative accommodation options is warranted as part of the scheme.

Decision making around the options of care available should always involve the younger person where they have decision making capacity. For those younger people with a disability who have no other option but to enter residential aged care facilities the recommendation is that decision making is promoted and encouraged as part of the decision making process. All four participants of this study acknowledged that decisions such as the geographical location of the facility would have benefited from their input to ensure existing relationships with family and friends were maintained.

In relation to decision making input of the younger person, health professionals require education around the issue of consent and decision making capability. This study recommends raising the awareness amongst health professionals of the impact of removing or not involving people in the decision making concerning their placement. Furthermore, providing education is highly recommended sounding the different needs of younger people with a disability. Health professionals need to advocate for younger people being able to make decisions regarding the most suitable options to meet their needs thereby upholding he rights and wishes of the younger person.

There is a significant need to increase the number of facilities that can provide high level care to enable people, young or old, to remain as close as possible to their family and community. Support and services need to be more readily available so that individuals do not to relocate to larger centres.

Another recommendation is that where residential aged care is the only available option for a younger person with a disability, lobbying of government to provide funding to facilities for age appropriate activities and support to access community-based activities is necessary. Coupled to this is the need to

facilitate access to volunteer work, education and training opportunities, centre-based day respite facilities and supported employment would address many of the psychosocial needs of younger residents and provide a sense of participation in purposeful and interesting activities.

Finally, it is highly recommended that further qualitative research is conducted on younger people with a disability placed in residential aged care facilities. To date, limited research has been undertaken and there exists a plethora of information that is unknown about this group of people. Additionally, researching staff of residential aged care facilities to determine their perceptions of younger people being admitted to aged care facilities would assist with identify the needs of staff caring for younger people and determining education and skills required to ensure appropriate care is provided.

Conclusion

Research by Bonanno over two decades ago found that some people are more resilient to loss than others (2004). Enhancing resilience in individuals experiencing adverse life experiences is a concept accepted within grief and loss theory and Bonanno (2004) believes that individuals use a variety of coping strategies to avoid adverse grief reactions. When reviewing the characteristics of those who are more resilient to loss, Neimeyer (2006) notes that individuals who cope well with adjusting to loss use one or both thought processes, meaning making and benefit finding.

All participants in this study demonstrated resilience evidenced by utilising sense-making processes when experiencing loss. The participants balanced their losses with meaning making and benefit finding to enable them to adjust to

the environment in which they resided. This finding reflects previous research on resilience and chronic disease and disability, whereby meaning making and benefit finding are applied in order to manage adjustment to changes (Moos & Holahan, 2007). Building resilience in young people with a disability may assist managing the impact of a disability or chronic illness in addition to the loss of independence as the individual ages or enters a residential aged care facility.

The transition into a residential aged care facility impacts significantly on the lives of those requiring the high level care offered by this environment. The losses for older people include loss of home, loss of independence, loss of autonomy and loss of connectedness (Brownie et al., 2014). Walker and Paliadelis' (2016) phenomenological study of older people's experiences of living in a residential aged care facility in Australia, found a loss of autonomy and decision making, the importance of meaningful relationships being maintained, and participant's acceptance of their situation, as the most significant aspects associated with moving into residential aged care facilities. Similarly, a 2014 study by Brownie et al., identified a number of key determinants to older persons having a positive experience when relocating to an aged care facility. For instance, the person having some control over the decision to move to an aged care facility is essential. Additionally, it was important for autonomy to be preserved and being able to retain meaningful relationships.

This study into younger people being admitted to residential aged care reinforces the need to examine alternative models of care for younger people with a disability who require high level care. Alternative care settings need to be developed to provide holistic care including meeting social, emotional and

psychological needs of the younger resident. It is important to note that younger people with a disability living in a residential aged care facility may remain as residents for many years, despite being more susceptible to health issues and often experiencing chronic disease. In conclusion, this study has highlighted the need for Australia to adopt contemporary structures to ensure younger people with disabilities live longer with health and wellbeing needs suitably addressed.

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Participant Information Sheet.

Participant Information for USQ Research Project Interview

Project Details

Title of Project: The lived experience of younger people with a disability living in residential aged care facilities: A phenomenological study

Human Research Ethics Approval Number: H16REA018

Research Team Contact Details

Principal Investigator Details

Mrs Melissa D'Or
Email: Melissa.D'Or@usq.edu.au
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Supervisor Details

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Email: Jennifer.Kelly@usq.edu.au
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Description

This project is being undertaken as part of a Masters of Science (Research) Project. The researcher is a Social Worker with a Bachelor of Social Work from James Cook University.

The purpose of this project is to explore the experiences of younger people with a disability who live in a residential aged care facility. In particular, this study would like to explore the psychosocial impacts that may relate to living in this environment. The study is based on collecting individual stories from the perspective of the person living in residential aged care.

The research team requests your assistance because it is important to understand the psychological, social, emotional, cultural and spiritual needs of younger people with a disability and whether they are being met in a residential aged care environment. Additionally, understanding what strategies have been used to adjust to the environment will assist in determining how suitable such placements are for younger people. The individual stories collected in this study will inform how younger people with a disability experience such a placement. This will contribute to an understanding of how the quality of life for younger people with a disability in aged care facilities may be improved.

Participation

Your participation will involve a one-to-one interview that will take approximately 45 minutes of your time. It is also possible to have two shorter interviews if this is necessary or if you would prefer.

The interview will take place at a time and venue that is convenient to you. Ideally, it would be good if we could agree to a place outside the facility such as a library or park but a quiet area in the facility is also possible. The location of the interview is dependent on whether you are able to easily access the

community in a safe and risk-free way. You may wish to bring a family or staff member with you should you feel necessary.

If the interview takes place with the residential facility, it will be necessary to gain the consent of the facility director or manager for this to occur. If this is the case, a private area within the facility would need to be identified such as your own room, an interview room or an office. This is to ensure your privacy.

Questions will include 'How has your life changed since moving into a residential aged care facility' and 'what has been the biggest impact on your life as a result of moving into residential aged care'.

The interview will be audio recorded. This is to ensure that the researcher captures everything you say. This will later be transcribed by the researcher and you will have the opportunity to read the transcript to ensure that what you have said is consistent with what has been written. The researcher will also keep a field journal and notes will be recorded in this immediately following the interview. Keeping notes is done to capture important aspects such as non-verbal communication and changes in your tone and expression. Because the research is based on an indepth interview, you will need to be able to communicate verbally or via assistive device in order, to participate.

Your participation in this project is entirely voluntary. If you are interested in taking part in this research please contact the Principal Researcher (Melissa D'Or) directly by phone or email (Melissa's details are at the top of the first page). If you do not wish to take part you are not obliged to do anything further. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage prior to data analysis commencing. You may also request that any data collected about you be destroyed. If you do wish to withdraw from this project or withdraw data collected about you, please contact the Research Team (contact details at the top of this form).

Your decision whether you take part, do not take part, or to take part and then withdraw, will in no way impact your current or future relationship with the University of Southern Queensland.

Expected Benefits

It is expected that this project will not directly or immediately benefit you as you are already residing in a facility. However, this may benefit younger people with a disability in the future where such stories are used to inform how the quality of life of younger people placed in residential aged care facilities may be improved.

Risks

There are minimal risks associated with your participation in this project. These may include feelings of discomfort or distress when reflecting on the impact of the placement and how your life has changed since you have moved into residential care.

Sometimes thinking about the sorts of issues raised in the interview can create some uncomfortable or distressing feelings. If you need to talk to someone about this immediately after the interview, or at a later time, please contact Lifeline on 13 11 14. You may also wish to consider consulting your General Practitioner (GP) for referral to an Accredited Mental Health Social Worker providing services privately under Medicare. An information brochure on this service is attached.

Privacy and Confidentiality

All comments and responses will be treated confidentially unless required by law.

- You will have the opportunity to verify your comments and provide a response prior to the finalisation of the study.
- A summary of the results will be made available to all participants at the conclusion of the study.
- The recording will not be used for any other purposes than those stated.
- The researcher is the only person to have access to the recording and the researcher will be conducting their own transcribing of the recording.
- The data collected may be used by the researcher for further studies related to this one, or by other researchers who are interested in this topic.

Any data collected as a part of this project will be stored securely, in password protected files, in password protected computers and locked filing cabinets, as per University of Southern Queensland's Research Data Management policy.

Consent to Participate

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate in this project. Please return your signed consent form to a member of the Research Team prior to participating in your interview. If you are physically unable to sign you may have someone sign on your behalf providing you are able to validate that you have provided consent to your involvement in the project.

Questions or Further Information about the Project

Please refer to the Research Team Contact Details at the top of the form to have any questions answered or to request further information about this project.

Concerns or Complaints Regarding the Conduct of the Project

If you have any concerns or complaints about the ethical conduct of the project you may contact the University of Southern Queensland Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au. The Ethics Coordinator is not connected with the research project and can facilitate a resolution to your concern in an unbiased manner.

Thank you for taking the time to help with this research project. Please keep this sheet for your information.

Consent Form.

University of Southern Queensland

Consent Form for USQ Research Project Interview

Project Details	
Title of Project:	The lived experience of younger people with a disability living in residential aged care facilities: A phenomenological study
Human Research Ethics Approval Number:	H16REA018

Research Team Contact Details	

Principal Investigator Details

Mrs Melissa D'Or
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Mobile: 0405 901 742

Supervisor Details

Associate Professor Jennifer Kelly
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Telephone: (07) 3470 4230
Mobile: 0418 745 113

Statement of Consent	

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.

- Have had any questions answered to your satisfaction.

- Understand that if you have any additional questions you can contact the research team.

- Understand that the interview will be audio recorded.

- Understand that you will be provided with a copy of the transcript of the interview for your perusal and endorsement prior to inclusion of this data in the project.

- Understand that you are free to withdraw at any time, without comment or penalty.

- Understand that the findings and method may be used in the future for further studies related to this topic, or by other researchers who may wish to conduct a similar or related study.

- Understand that you can contact the University of Southern Queensland Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au if you do have any concern or complaint about the ethical conduct of this project.

- Are over 18 years of age.

- Agree to participate in the project.

Participant Name	
Participant Signature	
Date	

Please return this sheet to a Research Team member prior to undertaking the interview.

Page 1 of 1

Semi-Structured Interview Questions.

Can you tell me about the circumstances that led to you being placed in a residential aged care facility?

What involvement did you have in planning your move to residential aged care? For instance, did you have a pre-entry visit? Did you receive reading material or did someone come to chat to you about the facility?
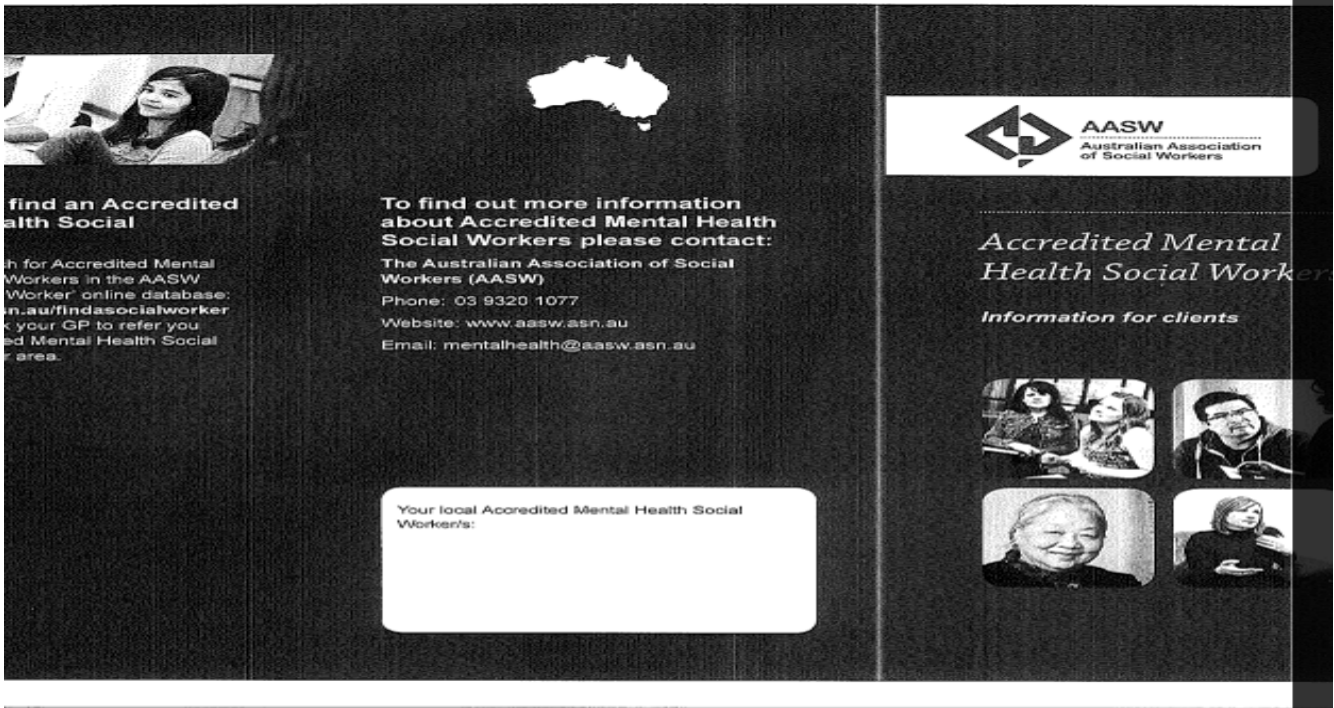
What has been the most significant change that has had the biggest impact on your life as a result of moving into residential aged care?

Can you describe for me what you do and who you see in a typical week?

Can you describe for me whether your life has changed since moving into a residential aged care facility?

If you could 'turn back time' what things could be done differently?

AASW Brochure.

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When should I see an Accredited Mental Health Social Worker?

An Accredited Mental Health Social Worker can help you when you experience difficulties that have an impact on your ability to manage the demands of day-to-day life. For example, when you:

- persistently experience low mood or anxiety;
- have a relationship breakdown;
- experience family, friend or workplace conflict;
- need assistance to re-engage in the workforce after an accident;
- feel socially isolated
- are diagnosed with or suspect you have a mental health disorder

What can an Accredited Mental Health Social Worker do?

Accredited Mental Health Social Workers understand mental health issues and disorders. They have the training, skills and expertise to assess your situation and to offer effective treatment to you or someone you know. Some of the treatments provided under Medicare include:

- Cognitive Behavioural Therapy
- Interpersonal Therapy
- Relaxation training
- Parenting training
- Interpersonal skills training

Other therapies that can be provided are:

- Relationship counselling
- Family therapy
- Bereavement counselling
- Psychotherapy

Accredited Mental Health Social Workers can also work as a team with other health professionals from whom you are receiving treatment and support.

Medicare Registered Providers

AASW Accredited Mental Health Social Workers are registered providers with Medicare.

Will my information be kept confidential?

Accredited Mental Health Social Workers are bound by a code of ethics, which includes maintaining confidentiality about what you discuss with them. However, there may be exceptional circumstances where an Accredited Mental Health Social Worker may need to discuss your information with others, such as when there is concern about your safety. You can talk to your local Accredited Mental Health Social Worker about the situations in which your information might be shared.

How do I receive a Medicare rebate?

To receive a Medicare rebate when seeing an Accredited Mental Health Social Worker:

1. Make an appointment to see your GP, paediatrician or psychiatrist
2. Take this brochure with you and ask your GP for a mental health care plan and a referral letter, or
3. If you are being referred by your psychiatrist or paediatrician, just ask for a referral letter.

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HREC Approval Letter.

OFFICE OF RESEARCH
Human Research Ethics Committee
PHONE +61 7 4687 5703| FAX +61 7 4631 5555
EMAIL ethics@usq.edu.au

UNIVERSITY
OF SOUTHERN
QUEENSLAND
AUSTRALIA

11 April 2016

Mrs Melissa D'Or
6 Red Ash Tce
Poona Qld 4650

Dear Melissa

The USQ Human Research Ethics Committee has recently reviewed your responses to the conditions placed upon the ethical approval for the project outlined below. Your proposal is now deemed to meet the requirements of the *National Statement on Ethical Conduct in Human Research (2007)* and full ethical approval has been granted.

Approval No.	**H16REA018**
Project Title	The lived experience of younger people with a disability living in residential aged care facilities: A phenomenological study
Approval date	11 April 2016
Expiry date	11 April 2019
HREC Decision	**Approved**

The standard conditions of this approval are:

(a)   conduct the project strictly in accordance with the proposal submitted and granted ethics approval, including any amendments made to the proposal required by the HREC

(b)   advise (email: ethics@usq.edu.au) immediately of any complaints or other issues in relation to the project which may warrant review of the ethical

Eco-map.