BEHIND CLOSED DOORS

Exploring Ways to Support Partnered Baby Boomers' Coupledom in Residential Aged Care Settings

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Abstract

A third of Australians living in residential aged care facilities are married or partnered, however, institutional interference in residents' relationships is not uncommon. Practices in some establishments include keeping residents' doors open; staff entering without knocking, ignoring 'do not disturb' signs, and gossiping about residents. Partners are variously accommodated in separate beds, separate rooms or separate wings of a facility. Many are not permitted to enter care together. Such conditions make it challenging for couples to maintain their relationships. To date, insufficient research has focused on supporting older couples' relationships subsequent to one or both partners being admitted into care. From July 2018, a public policy of consumer-directed residential aged care will take effect, developed in anticipation of the post-war 'baby boom' cohort becoming aged care consumers. This thesis reports on a study that explored the needs of Baby Boomers as aged care consumers, given that they represent almost a quarter of Australia's population. The aims of this study were to identify (1) which aspects of Baby Boomers' intimate relationships they considered essential to their wellbeing; and (2) practical measures that need to be implemented to support those valued relationship elements in residential aged care settings.

To address these aims, a predominantly qualitative, three-part mixed methods study was designed. It adopted an interpretivist-constructivist perspective, drawing on grounded theory and phenomenology. The findings indicated that, in practice, a broad policy focus on 'person-centred' aged care did not adequately address the needs of couples as they envisaged them. Instead, this thesis argues that, in the case of partnered residents, what is called for is an industry-wide 'couple-centred' model of aged care.

Conclusions drawn were that: (1) ageist attitudes to older adults' intimate and/or sexual relationships are pervasive at every tier of the aged care system; (2) the sector is failing the needs of many older couples; (3) these issues are not unique to Australia; (4) partnered Baby Boomers' needs are unlikely to be met by current aged care policies and practices; and (5) Baby Boomers' are already exploring alternatives to current models of residential aged care. These issues have wide-reaching implications at a societal level, for public institutions, the aged care sector as a whole and Baby Boomers themselves.

List of Publications

The following peer-reviewed research publications include components which stem from work completed towards this thesis:

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Certification of Dissertation

I certify that the substance of this dissertation has not already been submitted for any degree and is not currently being submitted for any other degree or qualification.

I certify that any help received in preparing this dissertation and all sources used have been acknowledged in this dissertation.

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Signature of Candidate Date

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Signature of Supervisor Date

Amy Lykins [redacted] 9.4.18

Signature of Supervisor Date

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To the hundreds of partnered Baby Boomers who participated in the online survey, a big thank you! This project is about you, informed by you, for you. What a privilege for me to gain a glimpse into your lives. It was truly heart-warming to read some of your answers. I hope this study makes a positive difference to your futures in some (preferably significant) way.

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Preface

This dissertation was inspired and motivated by my experience as a sex therapist. In discussions with clients and colleagues it became evident that not only do some older adults remain sexually active but they also display the same diverse range of sexual proclivities that one might expect in younger age groups. These included accounts of septuagenarian and octogenarian swinging and engaging in polyamory, BDSM[1] and fetish play. This was even more striking since the dominant perception of older people in Australian society is of them as post-sexual. Indeed, the very notion of mature age sexuality is apt to cause discomfort or even disgust, particularly amongst younger people. Older individuals perceived to be involved in amorous activities are often stigmatised as somehow 'deviant'. Such perceptions are evident in a range of contexts including derogatory greeting cards, jokes and clichéd media representations.

[1] The acronym BDSM refers to bondage and discipline, dominance and submission and sadomasochism

And when we get behind closed doors
Then she lets her hair hang down
And she makes me glad that I'm a man
Oh, no one knows what goes on behind closed doors

– Kenny O'Dell, *Behind Closed Doors*, 1973

Chapter 1. Introduction

1.1. Introduction

This dissertation explores the phenomenon of partnered individuals and couples (as dyadic units) in Australian residential aged care facilities from three perspectives: those of (1) individuals working in the aged care sector; (2) government legislation and policy; and (3) prospective aged care residents born between 1946 and 1965 (herein referred to as Baby Boomers[2]) who self-identified as being partnered. This study is novel for four reasons: it is the first to adopt a macro, meso and micro perspective to study the phenomenon of partnered aged care residents; it sought the views of a generational cohort prior to entering care; the information sought specifically targeted intimate partners, a group not represented in aged care policy; and it contributed a theorisation of the environmental influences on partnered residents in RACFs.

This chapter will outline the general background and context for the research, provide a description of the research problem and identify gaps in the literature. It will then describe the aim and scope of the project and provide an overview of each chapter, including a brief description of the research methodology and the theoretical frameworks used.

1.2. Contextual information

In approaching this study, I was informed and influenced by my background as both an architect and later, a sex therapist. At first glance, these may seem like disparate occupations whereas, in fact, there are common threads that connect them. Both roles required me to observe and actively listen to clients and advocate on their behalves. Over the course of my career(s) my focus has shifted back and forth between the perspectives of institutions and people's domestic lives. The relationship between these informs this research.

[2] The Australian Bureau of Statistics' definition of Baby Boomers, i.e. those born 1946 to 1965, has been used for this study.

The era in which I undertook my architectural education was, in hindsight, highly progressive. At that time, visionaries in the School of Architecture at the University of Sydney emphasised social justice issues. While a student, I was frequently charged with designing projects for the most underprivileged in society, such as orphaned and homeless children. As this thesis illustrates, institutionalised people are rarely given a voice in the building design process because they are not the ones who commission or pay for the buildings they subsequently occupy. During my studies, it was emphasised that architects have an obligation to actively consult with the end-users of their creations and advocate for their needs if occupants are to have an environment conducive to good life quality. However, as an employee architect, I later discovered that this moral stance was difficult to maintain without the support of employers and/or clients, especially when designing institutional buildings. I soon gained an understanding that institutional environments were invariably shaped by political and commercial decisions rather than directly responding to occupants' needs, as is evident in this study's findings.

Furthermore, during my architectural education I was influenced by a course unit called Man-Environment Studies [sic] (see Rapoport, 2016), which incorporated theory from sociology, social psychology, political science, architecture and urban planning. I became aware that the sensory and spatial attributes of buildings had a role to play in contributing to, or detracting from, building users' wellbeing. Scholars in the field of Environment, Behaviour and Society (EBS) (Rapoport, 1982; Moore, 2004; Seamon, 1979) posited that human behaviour, whether adaptive or maladaptive, was not simply a product of the social environment. Physical environments were also thought to exert an influence. During the writing of this dissertation, I found myself once again drawing on this work when exploring notions of personal space and the influence of sensory stimuli on aged care residents.

I spent much of my architectural career designing houses for couples and exploring what 'home' meant for them. Designing someone's home is a very intimate activity. It requires that clients reveal what they value, how they like to live, and their attitudes to those they share their home with. I frequently found myself playing the role of interpreter to help partners understand each other's perspectives. Sometimes it was the first time that my clients had discussed what it meant for them to live together and

what they enjoyed or found challenging about that. Finding the ideal balance of togetherness and time alone was subtly different for each dyad, a point that I draw attention to in this manuscript.

Similarly, as a sex therapist, I was in the privileged position of listening to partnered individual's intimate needs and aspirations, their challenges and their joys in relation to this largely private aspect of their lives. Once again, I acted as interpreter and guide to help them understand their individual and joint needs. When counselling couples, I realised that I was dealing with three entities, the third being their relational unit which had its own needs in addition to those of each individual partner. In this second career, it became increasingly evident that many older couples still valued the sexual aspect of their relationship and that this was often the glue that kept them together. It was their sexual relationship that transformed cohabitation from a purely social and practical arrangement to a more intimately connected and mutually rewarding state of being.

During this period, I was told a story about an older married couple that deeply moved me. Aged in their 70s, they lived in a nearby residential aged care facility. Although they shared a bedroom they were placed in single beds on opposite sides of the room. The husband, who had mild dementia, apparently used to cry himself to sleep every night because he longed to hold his wife. The couple repeatedly asked to have their beds pushed together, however the staff refused. In response, the wife arranged for them to be relocated to a new facility where they *could* sleep together. In that story, the seeds for this study were sown.

1.2.1. An overview of ageing and aged care in Australia

One in seven (3.7 million) Australians are aged 65 years or over (herein referred to as older Australians or older adults). The greatest number of older Australians reside in New South Wales (33%) and Victoria (24%) and are more likely to live in coastal regional areas than the general population (Australian Institute of Health and Welfare [AIHW], 2017d). However, per capita, Tasmania and South Australia have the highest proportion of older adults (Australian Bureau of Statistics [ABS], 2016).

While many older adults prefer to remain independent and age in their own homes (Folts & Muir, 2002; Millane, 2015), approximately 6% of older Australians (224,000 people) live in residential aged care facilities (RACFs) at any given time (AIHW, 2017d). This statistic offers one impression of the extent of the phenomenon of older Australians living in residential aged care. However, Australia's death statistics provide a clearer picture. Reports for the period 2004 to 2005 (Broad et al., 2013) and 2010 to 2011 (AIHW, 2015c) indicated that the proportion of older Australians dying annually in RACFs was 33% (Broad et al., 2013) and 43% (AIHW, 2015c) respectively. Furthermore, a study of 36 nations (Broad et al., 2013) found that Australia ranked third highest, after Iceland and New Zealand, in terms of institutionalised death in RACFs in the over 65 age group. Figure 1.1 illustrates the geographical distribution of older Australians living in residential aged care facilities (RACFs).

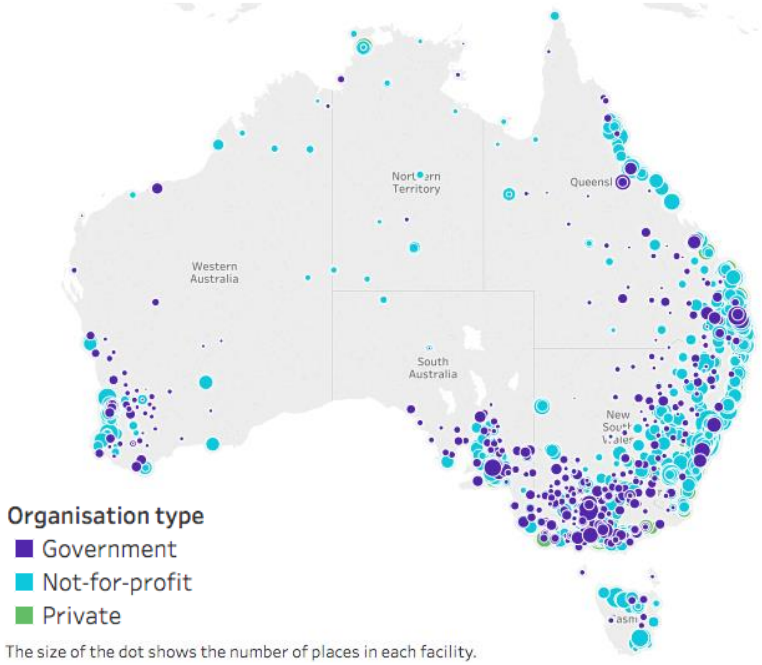

Figure 1.1. Geographical distribution of Australian aged care residents (AIHW, 2017c)

This dissertation reports only on Australian government funded RACFs, as defined by the *Aged Care Act 1997* (Cth). This thesis does not address retirement villages, assisted living or other privately funded congregate living arrangements used by older Australians. Until recently, Australian RACFs were typically referred to as nursing homes (or high care) and hostels (or low care) whereas, in other countries, different terminology is used, such as rest homes (in New Zealand) and long-term care (in the

United States). Services provided by Australian RACFs include assistance with daily living and 24-hour clinical care for people who would otherwise struggle to live independently.

Australian RACFs are funded by a mix of federal government contributions and means-tested fees paid by service users. Such facilities may be operated by not-for-profit organisations, commercial companies or state governments (primarily in Victoria and New South Wales). Not-for-profit (religious, community and charitable) organisations manage 55% of Australia's residential aged care services (AIHW, 2017c). This means that a significant number of Australians in RACFs are subject to the religious moral codes of these organisations to varying degrees whether they are adherents to the religions concerned or not. Commercially driven RACFs, on the other hand, tend to be larger in scale, often accommodating 100 or more residents, and are more often located in urban areas (AIHW, 2017g). These facilities can feel less homelike than smaller scale operations.

The target population for aged care services is people 65 years and over and indigenous Australians aged 50 or over (AIHW, 2017f). However, most people entering RACFs are aged 85 or more (AIHW, 2017a). It is important to understand that RACFs are no longer a lifestyle choice. Entry into residential aged care is based on need and placement in a RACF invariably occurs once all other choices have been exhausted. People commonly transition into residential aged care due to chronic health conditions, the most common being dementia (15%); musculoskeletal disorders (8%), such as arthritis; injuries (8%) (usually fractures); cancer (8%); cerebrovascular disease (6%), primarily stroke; and nervous system disorders (6%), such as Parkinson's disease (AIHW, 2017d).

Prior to admission into a RACF, individuals are first assessed by an Aged Care Assessment Team (ACAT) comprised of health and allied health professionals. The ACAT assessment process is focused on the needs of individual clients rather than those of co-resident caregivers (unless the caregiver is also in need of aged care services). Once an ACAT assessment has been undertaken, the most common pathway is to first receive aged care services at home followed, later, by admission into a RACF. In the period 2014 to 2015, most people newly admitted into RACFs were living at

home in a private residence (86%) or retirement village (11%) immediately prior to the move. Of those, one in ten were living with a co-resident carer, usually a spouse or partner (AIHW, 2017d). However, in the same period, approximately a third of all Australian aged care residents were married or in de facto relationships (AIHW, 2015b). It is unknown how many individuals enter residential aged care with their partner, a problem identified in this research.

1.2.2. The Baby Boomer generation

Approximately 5.57 million Australians were born in the post-war 'baby boom' between 1946 and 1965 (ABS, 2015a), representing almost a quarter of Australia's population (ABS, 2015a). Referred to as Baby Boomers, they were the first generation to grow up with television and to experience the effects and after-effects of the 1960s Counter Culture and protest movements. Possibly as a result, this cohort values civil liberties and human rights (Pennay, Bongiorno, & Myers, 2018). Another historical influence on Baby Boomers was the so-called Sexual Revolution of the 1960s and 1970s, the pre-AIDS era where non-monogamous sexual activity was more commonplace (D'Emilio & Freedman, 1988 as cited in Carpenter, Nathanson & Kim, 2009; Markowski, Croake, & Keller, 1978). Life-course scholars report that earlier life stages influence people's experience of ageing (Suzman, 2009) and that past sexual experiences influence one's sexuality in later life (Minichiello, Plummer, & Seal, 1996). Extrapolating from this, Carpenter, Nathanson, and Kim (2009) predicted that the Baby Boomer cohort may have expectations of continuing sexual activity of various kinds, no matter their age or living environment.

Baby Boomers have experienced much social change in their lifetimes. Relationships and family life in this age group have changed dramatically (Cooney & Dunne, 2001). Since the 1970s, new relationship structures have emerged as socially acceptable alternatives to marriage in later life. With an increasing emphasis placed on relationship quality, lifelong marriages are no longer the norm (Edgar & Edgar, 2017). Baby Boomers are leading the trend to divorce, remarry and/or cohabit in later life (ABS, 2012; Brown & Lin, 2012; Brown & Wright, 2017; Reimondos, Evans, & Gray, 2011) and are increasingly seeking out more flexible relationship options that support personal autonomy and/or gender equity (Calasanti & Kiecolt, 2007).

Such social change has resulted in broken family ties and disruptions to social networks, with friends and relatives being less likely to live nearby (Brown, Lee, & Bulanda, 2006). For men, divorce in later life results in less contact with adult children (Kalmijn, 2013). Re-partnering further weakens the parent-child relationship (Kalmijn, 2013; Noël-Miller, 2013), reducing the likelihood of children becoming future caregivers (Lin, 2008). Close relationships between children and parents create support structures that can prevent or delay their parents' entry into RACFs (Gaugler et al., 2007; Noël-Miller, 2010; Miller & Weissert, 2000). However, research indicates that, in the event of a health crisis, many Baby Boomer couples may have fewer sources of non-institutional support in late life outside of their primary relationship (Brown, Lee, & Bulanda 2006; Brown & Wright, 2017; Silverstein & Giarrusso, 2010).

1.3. Statement of the research problem

To date there has been insufficient research attention given to how older Australian couples can best be supported to maintain their relationships if one or both partners are institutionalised in a residential aged care facility. Since the 1970s there have been calls to keep couples together and for aged care organisations to demonstrate respect for older couples' relationships by affording them privacy, providing double beds and supporting conjugal visits by non-resident partners. However, these issues continue more than 40 years later.

There is some expectation that the next generation of aged care residents (Baby Boomers) will be less tolerant of current institutional practices. In anticipation of the Baby Boomer cohort transitioning into RACFs, there has been a recent shift in government policy to consumer-directed residential aged care (KPMG, 2012). From July 2018, residential aged care organisations will be required to reorientate their models of service provision towards meeting the needs of individual service users. To satisfy consumer needs, the aged care sector will require an evidence base to draw on. Where partnered Baby Boomers are concerned, there has been limited research to date into the needs of this group. There has been a lack of focus on which aspects of their relationships they consider essential for their wellbeing.

1.3.1. A brief overview of the literature on the aged care challenges encountered by older couples

Partnered older adults generally prefer to care for each other at home for as long as possible (Charles & Sevak, 2005; Claes & Moore 2000; Harrefors, Sävenstedt, & Axelsson, 2009; Nihtilä, & Martikainen, 2008; Noël-Miller, 2010; Soodeen, Gregory & Bond, 2007). More importantly, couples perceive home as a place that includes one's partner (Harrefors, Sävenstedt, & Axelsson, 2009; Tilse, 1995). However, when care needs become more advanced, some partners do not wish to become a 'burden' and believe that separation and entry into residential aged care, while not desirable, is inevitable (Harrefors, Sävenstedt, & Axelsson, 2009).

In Australia and other Commonwealth nations, where one or both partners in a relationship have sufficient care needs to require residential aged care services, there are a few possible outcomes. Partners may either be admitted into a RACF together or they become 'involuntarily separated' (Carroll, 2015), that is, they are offered no alternative but to separate. Separation may be precipitated by partners being placed in separate RACFs (BBC News, 2017a; 2017b) or by one partner entering care alone (Shuttleworth, Russell, Weerakoon, & Dune, 2010; Witheroe, 2017). Alternatively, in cases where partners enter a facility together, organisational policies and/or building designs sometimes dictate that partners are accommodated in separate beds, separate rooms or separate buildings (Bauer et al., 2013; Bauer, McAuliffe, & Nay, 2007; Bouman, Arcelus, & Benbow, 2007), irrespective of whether they are married (Shuttleworth, Russell, Weerakoon, & Dune, 2010; Woodburn & Pearce, 2016). Furthermore, it is unusual to find double beds in RACFs (Bouman, Arcelus, & Benbow, 2007).

Placing a partner in care can result in feelings of guilt and/or failure (Ade-Ridder & Kaplan, 1993; Brubaker, 1986). Living in a RACF irrevocably alters both partners' ways of life, including their senses of intimacy and companionship, communication, and their established roles as part of a functioning couple (Ade-Ridder & Kaplan, 1993). Many strategies that couples use to maintain their 'relational culture' (Baxter & Montgomery, 1996) can suffer when partners have reduced contact and can no longer share established daily routines. Furthermore, precious time spent together can

be repeatedly interrupted in the semi-public setting of a residential aged care facility (Gladstone, 1995).

Being physically separated from a valued partner is a source of grief for many couples. Unlike death, grief over the loss of the other's physical presence is ongoing (Ade-Ridder & Kaplan, 1993; Tilse 1995). The partner who remains at home becomes a 'visitor' to the RACF (Ade-Ridder & Kaplan, 1993) and may no longer feel like a member of a couple (Kaplan, 2001). The loss of a full-time companion can result in loneliness and social isolation (Aartsen & Jylha, 2011; Gladstone, 1995; Lundh, Sandberg, & Nolan, 2000; Tilse, 1995; Victor & Bowling, 2012), which is further exacerbated by the time spent travelling to visit the partner (Braithwaite, 2002). There is a growing body of evidence that loneliness and social isolation are predictive of depression and early death in older adults (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015; Matthews et al., 2016) whereas relationships have a protective effect (Cacioppo, Capitanio, & Cacioppo, 2014; Cacioppo, Grippo, London, Goossens, & Cacioppo, 2015).

Privacy is an issue for partnered aged care residents (Bauer, 1999). Spatial and psychological tensions arise at the public-private interface in residents' rooms, especially in the case of sexually diverse residents (Hughes, 2004a; 2004b; 2008). Routine staff practices include keeping residents' doors open, entering rooms without knocking, ignoring 'do not disturb' signs, or gossiping about residents (Bauer et al., 2013). Whether in care together or living separately, surveillance and privacy intrusions make it difficult for couples to maintain their intimate relationships (Edwards, 2003; Kenner, 2008) since opportunities for physical intimacy depend on perceived privacy within the RACF (Hajjar & Kamel, 2004).

It is generally assumed by aged care staff that older adults 'do not', 'cannot' or 'should not' engage in sexually intimate moments in RACFs (Bauer et al., 2013; Hajjar & Kamel, 2004; Roach, 2004). From the limited research that exists, there is evidence that some aged care residents still feel the need to express their sexuality in a variety of ways including "companionship, intimacy, touching, hugging, flirting, grooming, attire, being able to share a bed…masturbation and intercourse" (Bauer et al. 2013, p. 305). Residents' ability to display affection is dependent on the culture within each

facility (McAuliffe, Bauer, & Nay, 2007; Nay & Gorman, 1999). Australian health and aged care services have little or no policy regarding residents' sexual expression (Kirkman, Kenny, & Fox, 2013) and there are reports from Australia and the United Kingdom that indicate a need for aged care providers to offer environments that facilitate residents' intimate relationships (Royal College of Nursing, 2011; Osborne, Barrett, Hetzel, Nankervis, & Smith, 2002).

1.3.2. Recent changes to aged care policy

Significant reforms to Australian aged care policy that "place consumers at the centre of their care" and "focus on giving people greater choice and flexibility" (Department of Health [DoH] 2017c, p. 4; 2017d) are due to take effect on 1 July 2018 (DoH, 2017c). Consumer-directed residential aged care will link funding to individual consumers rather than directing block funding to service providers. In principle, these policy reforms are intended to create a "market-based system…where the consumer drives quality" (DoH, 2017b [web page]), enabling service users to select services that best suit their needs. This policy shift to consumer-directed care "anticipates demand for more choice and control by the 'baby boomer' generation" (KPMG 2012, p. 21). However, for consumer-directed care to become a reality, it will require that the aged care sector listen and respond to consumers' needs. This study seeks to take advantage of this unique historical opportunity by comparing current policies and practices in residential aged care with the needs and expectations of the next generation of aged care residents (Baby Boomers).

1.3.3. Gaps in the literature

The literature reviewed in Chapter Two explores older adults' relationship structures, their intimate and sexual behaviours, the sexual history of Baby Boomers and extant literature on their anticipated aged care needs. It also investigates the topic of ageism and the current state of residential aged care in Australia, including policies and practices applied to partnered residents. What it reveals is that older couples' relationship needs in residential aged care settings are under-researched. Gaps in the literature illustrated the lack of evidence available to inform aged care policy and practice in relation to:

- the sexual and physical intimacy needs of older couples and the degree of importance they place on their relationships;
- Baby Boomers' sexual attitudes and preferences, the importance of their couple relationships, and how they differ from previous generations;
- implementing federal aged care legislation and policy in the case of partnered aged care residents;
- organisational policies for partnered residents in relation to facility planning, building design, staff training, management of residents' sexual behaviours and sexual health screening; and
- transparent consumer information on organisational approaches to intimate relationships that might assist consumers to make informed decisions when choosing a facility.

1.4. Aim and scope of this study

The aim of this study is to investigate what measures need to be taken to support partnered Baby Boomers to maintain valued aspects of their coupledom in residential aged care settings. Being focused on couples, this study is limited to partnered Baby Boomers, the next (prospective) generation of partnered Australian aged care residents. Baby Boomers were targeted for three reasons. Firstly, the aged care sector has traditionally been slow to implement change, meaning that knowledge translation of this research was unlikely to significantly benefit the current generation of aged care residents. Developing improved building stock, for instance, requires an extended lead time. Secondly, Baby Boomers have earned a reputation for being 'demanding' and are associated with challenging existing norms. I was interested to discover whether this reputation is deserved and the implications of this. Lastly, in order to explore innovative aged care initiatives, I was interested to hear from people who do not currently live in institutional environments and who have not yet had to adjust their expectations of life to conform with institutional life. Preliminary research indicated a reluctance to participate and/or a sense of compromised expression on the part of existing residents. For these reasons, older adults currently in residential aged care were not included in the study. Also, for practical purposes, participation in this study was limited to people currently living in Australia who speak English.

This study is directed towards couples in a general sense and, while people from sexually and linguistically diverse backgrounds are included, specific attention to the

particular needs of these groups is beyond the scope of this study. This study also does not attempt to analyse the pathways and prevalence of older couples that become involuntarily separated.

The research questions which this study seeks to address are:

1. Which aspects of their intimate relationships do partnered Baby Boomers value and wish to maintain as they age?
2. What are Baby Boomers' attitudes to residential aged care?
3. What are the challenges to maintaining intimate relationships in residential aged care settings?
4. What initiatives are necessary to support partnered Baby Boomers' coupledom in residential aged care settings?

1.5. Significance of the study

This study seeks to identify factors that positively and negatively influence the relationship quality of partnered aged care residents. On a practical level, this study seeks to provide guidance to aged care providers wishing to implement consumer-directed care by advancing knowledge on the relationship features that partnered Baby Boomers value and their attitudes to residential aged care services. This study also seeks to contribute to the development of a couple-centred approach to partnered aged care residents. Lastly, when considered alongside work done by others (as outlined in the Conclusions chapter), the recommendations in this study will have immediate practical applications for the aged care sector.

1.6. Overview of the study

This dissertation is divided into three parts. In Part I, I introduce the reader to the topic of the study this thesis reports on (Chapter 1), situate the current study within the literature (Chapter 2) and outline the research methodology (Chapter 3). Chapter 2 explores demographic trends and the features and structures of intimate relationships in later life for heterosexual and sexually diverse couples. It includes discussion on caring for a partner in later life and subsequently becoming separated. Older age sexuality is discussed in relation to physical and mental health, the Baby Boomer

generation and societal ageism. To complete the chapter, I provide a critical review of the historical context and current policies and practices in Australia's aged care system and situate couples in relation to federal legislation and policy. This review of the literature takes an interdisciplinary approach, drawing on scholarship from the social sciences, sociology, psychology, gerontology, sexology, public health, medicine, nursing and other disciplines. From the insights gained, Chapter 2 argues for the need to investigate how best to support the specific needs of couples in residential aged care settings. By adopting this perspective, gaps in the literature that were most pressing were identified, from which the four research questions were formulated. Chapter 3 presents the interpretive-constructivist theoretical framework adopted; aspects of the phenomenological and grounded theory methodologies applied, the (predominantly qualitative) mixed methods research design and the data collection methods (interviews, a historical review and a survey) used in this study.

In Part II (Chapters 4, 5, 6 and 7), I present results of data analysis for each of the four research questions. The findings presented relate to valued aspects of partnered Baby Boomers' intimate relationships (Chapter 4), Baby Boomers' attitudes to residential aged care (Chapter 5), the current challenges to maintaining intimate relationships in RACFs (Chapter 6) and initiatives to support partnered Baby Boomers in residential aged care (Chapter 7).

Part III consists of the Discussion (Chapter 8) and Conclusions (Chapter 9). Chapter 8 presents the key findings for each research question and further analyses them using the lens of ageism and theoretical constructs such as Terror Management Theory, Socio-Environmental Theory and the Person-Environment Congruence Model. To complete the chapter, I offer a new conceptual model developed from the data through which to view couple relationships in RACFs. Chapter 9 draws conclusions based on the study and makes practical recommendations for legislators, government, data collection agencies, education at tertiary and vocational levels, aged care organisations, architects and designers, the aged care workforce and Baby Boomers themselves. The wider implications of this study for researchers and the broader community are also noted. Lastly Chapter 9 concludes with the study limitations and an agenda for further research.

Chapter 2. Literature Review - Intimate Relationships in Later Life, Baby Boomers and Aged Care

2.1. Introduction

A substantial proportion of Australians aged over 65 become permanent residents in residential aged care facilities (RACFs), where they spend the final years of their lives (Broad et al., 2013). The problem identified in the background information in the previous chapter is that, although a third of aged care residents are married or in de facto relationships, the Australian residential aged care system tends to take a 'one size fits all' approach that makes little distinction between partnered and single residents. This can create unnecessary distress for older couples and their families. What follows is a review of the literature on older couples' relationships and their aged care options. It explores intimate relationships in later life, older-age sexuality, the sexual history of Baby Boomers, the concept of ageism, the current state of Australian aged care and Baby Boomers in the context of aged care services.

2.2. Later life relationships

2.2.1. Demographic trends for relationships

In order to design aged care services that cater to partnered Australians aged 65 and over, it is important to understand demographic trends in this age group. Available demographic data describing Australian relationship structures is predominantly quantitative, collected from large-scale national surveys and census data. In 2011, two thirds of people aged 65–74 years lived with a partner or spouse (Australian Institute of Family Studies, n.d.). In older age groups, marriage remains the dominant relationship structure. Older Australians are most likely to have had marriages of long duration, many in excess of 40 years and, due to men's increased life expectancies, marriages are now lasting longer in the over 75 age group (Australian Bureau of Statistics [ABS], 2009). Nevertheless, significant social change in Australia since the 1970s has seen new relationship structures emerge as socially acceptable alternatives to marriage in later life. It is now increasingly common for middle-aged and older

Australians to opt for cohabitation, especially among those who have re-partnered due to separation, divorce or the death of a partner (ABS, 2012). The Household, Income and Labour Dynamics in Australia (HILDA) survey, a longitudinal study of 17,000 Australians since 2001, revealed that 61% of Australians aged over 45 were married, 25% cohabited and 16% chose to maintain non-resident partnerships, with most of the latter group indicating no future plans to cohabit or marry (Reimondos, Evans, & Gray, 2011).

Despite these demographic trends, scholarship on relationship structures has tended to focus on marriage and cohabitation among younger and middle-aged adults. Of the research that has included adults aged 50 years and over, indications are that relationships and family life among this age group are changing most dramatically of all (Cooney & Dunne, 2001). With the increasing emphasis placed on relationship quality, lifelong marriages are no longer the norm (Edgar & Edgar, 2017). Baby Boomers (people born 1946-65) are leading the trend to divorce, remarry and/or cohabit in later life (ABS, 2012; Brown & Lin, 2012; Brown & Wright, 2017; Reimondos et al., 2011) and are increasingly seeking out more flexible relationship options that support personal autonomy and/or gender equity (Calasanti & Kiecolt, 2007). Among scholars adopting the life-course perspective, there is some expectation that cohabitation will feature strongly in the Baby Boomer cohort as they age (Cooney & Dunne, 2001; De Jong Gierveld, 2004; Silverstein & Giarrusso, 2010), a factor that has significance for aged care settings. This expectation is premised on Baby Boomers' greater history of cohabitation compared to previous generations.

These social changes have produced looser family ties and disrupted social networks, meaning friends and relatives are less likely to live in close proximity (Brown, Lee, & Bulanda, 2006). Divorce and repartnering in this age group has weakened parent-child relationships (Kalmijn, 2013; Noël-Miller, 2010), reducing the likelihood of children becoming future care-givers (Lin, 2008). Close relationships between children and parents can prevent or delay their parents' entry into nursing homes (Gaugler, Duval, Anderson, & Kane, 2007; Noël-Miller, 2010; Miller & Weissert, 2000). However, there are indications that, in the event of a health crisis, many Baby Boomer couples may have fewer sources of non-institutional support in late life outside of their primary

relationship (Brown, et al., 2006; Brown & Wright, 2017; Silverstein & Giarrusso, 2010).

2.2.2. Intimate relationships in later life

The literature on intimate relationships later in life constitutes a combination of quantitative and qualitative work undertaken using a combination of theoretical lenses, privileging the disciplines of psychology, sociology, family studies and gerontology. Evidence suggests that social relationships are crucial influences on health and wellbeing at all stages of life (Cohen, 2004; Umberson, Crosnoe, & Reczek, 2010; Uchino, 2006). For older couples, their primary relationship becomes increasingly important in later life (Antonucci, Akiyama, & Takahashi, 2004) and, consequently, the quality of their relationship has a profound influence on each partner's health and wellbeing.

Committed relationships are associated with reduced depression (Kim & McKenry, 2002; Lamb, Lee, & DeMaris, 2003; Meadows, McLanahan, & Brooks-Gunn, 2008; Stokes & Moorman, 2017). People in intimate relationships, whether married or unmarried, living together or apart, report higher levels of wellbeing than those who are not partnered (Kamp Dush & Amato, 2005; Ross, 1995; Waite, 2000; Waite & Gallagher, 2000), regardless of sexual orientation (Wienke & Hill, 2009). Likewise, satisfying relationships are linked to longer, healthier lives (Cohen, Doyle, Skoner, Rabin & Gwaltney, 1997; Robles, Slatcher, Trombello, & McGinn, 2014; Seeman, 1996; Ross, 1995; Troxel, 2010), emotional satisfaction (Brown & Kawamura, 2010), improved sleep (Prigerson, Maciejewski, & Rosenheck, 1999; Troxel, Robels, Hall & Buysse, 2007), fewer visits to the doctor (Prigerson, Maciejewski, & Rosenheck, 2000) and better physical and mental health (Levenson, Carstensen, & Gottman, 1993; Stokes & Moorman, 2017).

However, not all relationships are satisfying and there is a body of evidence that links unhappy relationships and negative partner behaviours with negative physical and mental health impacts (Bookwala, 2005; Hawkins & Booth, 2005; Parry & Shapiro, 1986). Relationship discord may result in compromised immune response (Kiecolt-Glaser, 1999), poor sleep (Brissette & Cohen, 2002), poorer health (Murphy, Glaser,

& Grundy, 1997; Seeman, 1996), depression (Beach, Fincham, & Katz, 1998) and premature death (Brown, Nesse, Vinokur, & Smith, 2003; Tower, Kasl, & Darefsky, 2002; Saz & Dewey, 2001).

2.2.2.1. Marriage and marriage-like relationships

Research suggests that marriage or marriage-like relationships significantly contribute to wellbeing in later life (Gray, De Vaus, Qu, & Stanton, 2011). Living together can also foster an older couple's sense of independence (Day & Day, 1993; Wenger, 1990) and provide emotional support, belonging and security (Gove, Briggs, Style & Hughes, 1990; Gray, et al., 2011; Kitson, Babri, Roach & Placidi, 1989). Marriage provides older couples with continuity and links to the past (Brubaker, 1990); financial support (Walker & Luszcz, 2009); a secure, predictable environment (Walker & Luszcz, 2009); a framework for their shared experience of day-to-day life (Berger & Kellner, 1974); a sense of identity within a socially defined role (Brubaker, 1990; Gubrium, 1976; Kamp Dush & Amato, 2005); a close relationship that is not easily substituted (Johnson, 1985); and the "first line of defence" against disability (Stoller, 1992, p. 49). These are all attributes that are likely to be disrupted if one or both partners are faced with relocating to a residential aged care facility (Tilse, 1995).

A body of epidemiological and health literature supports the view that, across cultures, marriage protects the health of intimate partners (Carr & Springer, 2010; Tatangelo, McCabe, Campbell, & Szoeke, 2017). However, there is some debate as to whether it is marriage *per se* or the quality of the relationship that matters most. Scholars adopting a life-course perspective suggest that marital history and relationship quality, rather than marital status or marriage duration, have the greatest influence on partners' health and wellbeing (Bookwala, 2005; Dupre & Meadows, 2007; Gallo, Troxel, Matthews, & Kuller 2003; Hughes & Waite, 2009; Walker & Luszcz, 2009; Williams, 2003; Zhang & Hayward, 2006).

Studies targeting older adults associate marriage with better health, fewer disabilities and increased life expectancy (Hughes & Waite, 2009; Manzoli, Villari, Pirone, & Boccia, 2007; Pienta, Hayward, & Jenkins, 2000; Rendall, Weden, Favreault, & Waldron, 2011). Irrespective of gender, those who marry and remain married show consistent health advantages (Hughes & Waite, 2009; Zhang & Hayward, 2006). One

interpretation is that relationship stressors have far greater impact than marital harmony (Rook, 1984) and that the health benefits associated with enduring marriages derive from the absence of distress caused by separation, divorce and widowhood (Williams & Umberson, 2004).

By comparison, later life de facto and same-sex cohabiting partnerships have received much less attention (Silverstein & Giarrusso, 2010; Brown & Wright, 2017). Some scholars view marriage and non-marital cohabitation as points on a continuum of social attachment, having similar benefits in terms of physical or mental health (Musick & Bumpass, 2012). It is the presence of a partner, the equity between partners and the quality of the social attachment, rather than marital status, that predicts health and wellbeing (Hagedoorn et al., 2006; Ross, 1995) and provides resilience to counteract negative impacts such as illness (Walker & Luszcz, 2009).

The limited research on older cohabiting couples suggests that cohabiters aged 50 or more are more likely to have been divorced or widowed. They report increased relationship quality (King & Scott, 2005) and more durable relationships (Brown & Wright, 2017; Brown, Bulanda, & Lee, 2012) than younger cohabiters. They also experience similar levels of emotional satisfaction, pleasure, openness and time spent together as married couples (Brown & Kawamura, 2010). Likewise, mortality rates in older cohabiting couples differ only slightly from married couples (Liu & Reczek, 2012). There is, nevertheless, scant research on how married and cohabiting couples negotiate the move into aged care environments, how many are supported to remain together, and the outcomes for partners in terms of health and wellbeing.

2.2.2.2. Same-sex couples

If aged care services are to cater to couples, they must accommodate sexual diversity (Barrett, Crameri, Lambourne, Latham, & Whyte, 2015; Barrett, Whyte, Comfort, Lyons, & Crameri, 2015), as is their legal obligation[3]. The scant literature on older same-sex couples includes a combination of demographic surveys, small interview collections and participant observation studies. These either took a health perspective

[3] As set out in the *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013.*

or applied gay liberationist, critical and queer lenses, which deconstructed heteronormative social policies and discriminatory practices. The 1980s and 1990s saw a spate of research into same-sex relationships, largely to understand the spread of HIV/AIDS (Power, 2011). Same-sex marriage debates post-1990 then provided a new stimulus for further research, including comparisons of same-sex partnerships with heterosexual relationships (Bonello & Cross, 2009; Jones, 2009). However, there is limited research that distinguishes same-sex couples by age, relationship duration or domestic arrangements (Bennett & Gates, 2004). What little there is predominantly involved participant self-reports (Bariola, Lyons, & Leonard, 2015; Pitts, Mitchell, Smith, & Patel, 2006; Perleszet al., 2006). Observational studies were rare (Gottman et al., 2003). Furthermore, there is a paucity of research into people aged over 65 with diverse sexual orientations, most of which has focused on aged care settings (Barrett, 2008; Barrett, Whyte et al., 2015; Chandler et al., 2005; Hughes, 2006; Phillips & Marks, 2006). In the United States, 25% of same-sex couples include one partner aged 55 or more and, in another 20%, both partners are over 55 (Bennett & Gates, 2004). There is speculation that, in Australia, under-reporting by older same-sex couples in census data means that the prevalence of such couples is unknown (ABS, 2013b), suggesting that there is a significant fear of discrimination amongst older gays and lesbians (Roy Morgan Research, 2015).

Unlike heterosexual couples, same-sex partners are more likely to live separately (Cahill, South & Spade, 2000; Rosenfeld, cited in Butler, 2004). They tend to maintain an active circle of friends in addition to their primary relationship (Blando, 2001; Lipman, 1986), often of the same sex and sexual orientation (Herdt, Beeler, & Rawls, 1997). Limited research suggests that lesbians are more likely to be partnered than gay men (Herdt et al., 1997) and that they enter into partnered relationships at similar rates to the heterosexual population whereas only half of gay men describe themselves as partnered (Hostetler & Cohler, 1997). However, there is a small body of literature that indicates that many same-sex couples choose to maintain committed long-term relationships (Connolly, 2005; Hostetler & Cohler, 1997; Peplau & Spalding, 2000; Porche & Purvin, 2008).

In comparisons between same-sex and heterosexual relationships, levels of relationship satisfaction were generally found to be similar (Kurdek & Schmitt, 1986;

Blumstein & Schwartz, 1983; Roisman, Clausell, Holland, Fortuna, & Elieff, 2008) although a few studies reported that same-sex couples in civil unions experience less conflict and higher quality relationships than their married counterparts (Balsam, Beauchaine, Rothblum, & Solomon, 2008; Gottman et al., 2003; Kurdek, 2004). Australian research found that same-sex couples aged over 40 who had formally registered their domestic partnerships and/or performed commitment ceremonies did not experience better mental health than peers who had not formalised their relationships (Bariola, Lyons, & Leonard, 2015). However, in the United States, the opposite was true (Riggle, Rostosky, & Horne, 2010).

Some scholars emphasise the similarities between same-sex and heterosexual cohabiting couples (Gottman et al., 2003; Kurdek 1998, 2004; Kurdek & Schmitt, 1986; Peplau & Cochran, 1990), especially in terms of the emotional qualities that lead to relationship satisfaction and stability (Gottman et al., 2003; Kurdek 1998; 2004; Kurdek & Schmitt, 1986; Peplau & Fingerhut, 2007). However, being "out" has also been posited as a predictor of relationship quality (Balsam et al., 2008; Knoble, & Linville, 2012) and cohabiting relationships may provide same-sex couples with an added buffer from the stress of discrimination and sexual prejudice (Cochran, 2001; Meyer, 2003).

Older same-sex relationships are less structured and less culturally scripted (Blando, 2001) than heterosexual relationships (Dune & Shuttleworth, 2009) and the division of labour between partners tends to be more egalitarian (Kurdek, 2006; Reczek & Umberson, 2012; Solomon, Rothblum, & Balsam, 2004; Sullivan, 2004). There can be more emphasis on affection than genital sex among lesbian couples (Averett, Yoon, & Jenkins, 2012; Blumstein & Schwartz, 1990; Peplau & Fingerhut, 2007; Slevin & Mowery, 2012). In long-term male homosexual couples, sexual non-monogamy is more of a feature (Bonello, 2009; Bonello & Cross, 2009; Cahill et al., 2000; Hostetler et al., 1997; Kurdek & Schmitt, 1986; Blasband & Peplau, 1985; Peplau & Fingerhut, 2007; Solomon et al., 2004).

Interestingly, whilst there is evidence of research having influenced public policy on issues specific to sexually diverse aged care residents (Harrison, 2006; Harrison & Irlam, 2010; Hughes, 2016), there is a lack of cross fertilisation of these initiatives to

the heterosexual aged care population, particularly couples. Research that examines the commonalities and distinctions between same-sex and heterosexual couples in aged care contexts is lacking.

2.2.2.3. Non-cohabiting partnerships

International interest in non-cohabiting relationship structures in later life, such as living-apart-together (LAT), has begun to emerge in the past two decades. LAT relationships are defined here as committed partnerships based on mutual love and attraction (Karlsson & Borell, 2002) where both partners have regular contact but choose to live separately (Levin & Trost, 1999). Studies have found that older adults who opt for LAT relationships do so for a variety of reasons, particularly if they have had previous co-residential relationships (de Jong Gierveld, 2004). While still desiring companionship, intimacy and emotional support (de Jong Gierveld & Peeters, 2003; Koren, 2015), these couples come with their own personal histories and disincentives to merging households.

The choice to live apart may be influenced by a desire for autonomy and independence (Davidson, 2002; Karlsson & Borell, 2002; Liefbroer, Poortman & Seltzer, 2015), which is of particular importance to older women not wishing to exchange gendered labour for intimacy (Karlsson & Borell, 2002; Levin, 2004). Other factors include incompatible personality traits between partners (de Jong Gierveld & Peeters, 2003); living with resident children (Levin & Trost, 1999; Phillips, Duncan, Roseneil, Carter, & Stoilova, 2013; Reimondos et al., 2011) or wishing to remain in one's home (de Jong Gierveld & Peeters, 2003; Phillips et al., 2013). Financial issues such as concern about losing a pension (de Jong Gierveld & Peeters, 2003) and protecting financial assets (Phillips et al., 2013; Upton-Davis & Carroll, 2017) also play a part. Some individuals are caring for a parent (Levin & Trost, 1999) or, alternatively, are actively avoiding care-giving responsibilities (Lewin, 2017) while, in other couples, one partner lives in an institution (Levin & Trost, 1999; Phillips et al., 2013).

Although the study by Phillips et al. (2013) touched on relationships where one partner is institutionalised, there is no research into the phenomenon of both LAT partners becoming aged care residents. Thus, the extent to which such partners continue to engage in LAT living arrangements within RACFs is unknown. Questions of whether

it is, or would be, their choice to reside together or separately, and the extent to which such arrangements are facilitated as a matter of choice or enforced upon couples by aged care institutions, requires further attention.

2.2.2.4. More diverse relationship structures

Relatively little is known about other later life relationships that apply to people who are dating (Alterovitz & Mendelsohn, 2009; Brown & Shinohara, 2013; Dickson, Hughes, & Walker, 2005; Malta, 2007; 2013; Malta, & Farquharson, 2014; McWilliams & Barrett, 2014), in open relationships (Finn & Malson, 2008; McLean, 2004; Rubin, Moors, Matsick, Ziegler, & Conley, 2014), in so called 'friends-with-benefits' relationships (Kirkman, 2015; Lehmiller, VanderDrift, & Kelly, 2011) or polyamorous arrangements (Wolfe, 2003). Nor is there much research on relationships involving bisexual individuals in later life (Dworkin, 2006; McLean, 2004; Witten, 2016), let alone such relationships in aged care settings (Chandler et al., 2005).

2.2.3. Caring for a partner in late life

The literature suggests that both heterosexual and same-sex partners prefer to provide care for each other in old age and resist placement in residential aged care, treating it as a last resort (Charles & Sevak, 2005; Claes & Moore 2000; Harrefors, Sävenstedt, & Axelsson, 2009; Nihtilä, & Martikainen, 2008; Noël-Miller, 2010; Soodeen, Gregory & Bond, 2007). Home is of special importance for older adults - as a resource - as a place that holds memories and a sense of identity (Rowles, 1983; Rubenstein, 1989; Davison, Kendig, Stephens & Merrill, 1993) that supports independence, autonomy and choice (Davison et al., 1993). Home is viewed as a base from which to interact with the outside world - a familiar space where relationships can be expressed privately, where self-respect is maintained and frailty can be concealed (Bowlby, Gregory & McKie, 1997; Davison et al., 1993; Willcocks, Peace & Kellaher, 1987).

One drawback of long-term heterosexual relationships in particular is the tendency for partners to lose the life skills common to older singles (Carr, Nesse, & Wortman, 2005; Gubrium, 1976) that may be important for older spouses who later become physically separated from an institutionalised partner (Tilse, 1995). While older adults generally find it more difficult to make new friends (Rook, 2009; Zettel & Rook, 2004), married

and cohabiting heterosexual couples are also more likely to have reduced contact with existing friends (Musick & Bumpass, 2012). Johnson (1985) reported that heterosexual couples are often more socially isolated than widows, tending to satisfy each other's needs with little help from others, although those in higher quality relationships usually have a supportive network of friends and family (Stokes & Moorman, 2017). Older couples are also more likely to become carers in later life (Vlachantoni, Evandrou, Falkingham, & Robards, 2013), causing reduced contact and activities outside the marriage (Day, 1985).

Illness in one partner can be a source of distress for the other (Hagedoorn et al., 2001; Druley, Stephens, Martire, Ennis, & Wojno, 2003). However longitudinal studies have shown that while particular types and durations of care can have adverse health outcomes, informal caring *per se* is not associated with decreased health or increased mortality for older carers (Jenkins, Kabeto & Langa, 2009; Vlachantoni et al., 2013). In fact, when compared to non-carers, a carer's likelihood of dying over the four or five years of duration of each study was significantly reduced (Brown et al., 2003; O'Reilly D, Connolly S, Rosato M, Patterson, 2008), despite higher stress levels (Fredman, Cauley, Hochberg, Ensrud, & Doros, 2010; Pinquart & Sörensen, 2003). Caring for a partner can be associated with fewer depressive symptoms (Keene & Prokos, 2008), except where partners have dementia (Pinquart & Sörensen, 2003). Little is known about options offered to couples by RACFs to facilitate them remaining together and to what degree they can maintain their caring relationship and recreate a sense of 'home' in residential aged care settings.

2.2.4. Becoming separated – placing a partner in residential aged care

Despite their best efforts, without sufficient additional support, sometimes partners feel they have no option but to place their partner in residential aged care even when they would prefer to stay together. This has been termed 'involuntary separation' (Carroll, 2015; Tilse, 1995). In Australia, no government body keeps statistics on how many couples become separated in this manner[4]. Similarly, research has tended to

[4] The author received correspondence from the Australian Institute of Health and Welfare, the Australian Bureau of Statistics and the Honourable Ken Wyatt, Minister of Aged Care that confirmed there is no data available on the number of aged care residents with spouses or de facto partners living elsewhere.

focus on the institutionalised partner, with scant literature on the dyadic experience once one or both parties enter residential aged care.

Non-institutionalised partners are variously referred to in the literature as 'spousal caregivers' (Ade-Ridder & Kaplan, 1993; King, Collins, Given, & Vredevoogd, 1991; Novak & Guest, 1992), 'community dwelling spouses' (Hunt, 2015; Kaplan, 2001), 'older carers' (McGarry & Arthur, 2001) and even 'married widows' (Braithwaite, 2002). Such terms construct partners as individuals, denying their 'couplehood' (Kaplan, 2001) and sanitise the intimate nature of their relationships. Additionally, terms such as 'informal caregivers' (McGarry & Arthur, 2001) and 'family caregivers' (George & Gwyther, 1986; Townsend, 1990) are applied equally to all family members, which again fails to acknowledge the intimate nature of the spousal/partner relationship. Furthermore, the care that older adults provide for their partners has been described as 'invisible' (McGarry & Arthur, 2001). The partner who remains at home becomes the 'forgotten client' due to the absence of policy and planning for their situation (Pratt, Schmall, Wright & Hare, 1987).

Placing a partner in care can result in feelings of sadness, anger, guilt and/or failure (Ade-Ridder & Kaplan, 1993; Brubaker, 1986; Hunt, 2015). Nursing home placement irrevocably alters both partners' way of life, their sense of intimacy and companionship, communication, social status, sense of identity and their established roles as part of a functioning couple (Ade-Ridder & Kaplan, 1993; Hunt, 2015). The literature refers to strategies that couples use to maintain their 'relational culture' (Baxter & Montgomery, 1996; Wood, 1982). This includes regular, repeated communication that reminds them of their shared history (Baxter, 2011), shared social networks and sharing tasks, among other things (Canary & Stafford, 1994; Stafford, 2011). Many of these strategies can suffer when partners have reduced contact and sharing established daily routines is no longer possible, in an environment cut off from friends, family and community. Furthermore, precious time spent together can be repeatedly interrupted in the semi-public setting of a RACF (Gladstone, 1995).

Unlike death, the loss of the partner's physical presence is ongoing (Ade-Ridder & Kaplan, 1993). For many, there is an ever-present grief due to the "incomplete but non voluntary and non reversible termination of a relationship" that "offers little

resolution" for either partner (Tilse 1995, p. 45). The partner who remains at home becomes a 'visitor' to RACFs (Ade-Ridder & Kaplan, 1993) and may no longer feel like a member of a couple (Kaplan, 2001). The loss of a full-time companion can result in loneliness (Aartsen & Jylha, 2011; Gladstone, 1995; Lundh, Sandberg, & Nolan, 2000; Tilse, 1995; Victor & Bowling, 2012) and social isolation, which is exacerbated by the time spent travelling to visit the partner (Braithwaite, 2002).

There is a growing body of evidence that loneliness and social isolation are predictive of depression and early death in older adults (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015; Matthews et al., 2016) whereas relationships have a protective effect (Cacioppo, Capitanio, & Cacioppo, 2014; Cacioppo, Grippo, London, Goossens, & Cacioppo, 2015). According to the literature, loneliness is a complex construct comprising three inter-related dimensions: (a) intimate (b) relational, and (c) collective loneliness (Hawkley, Browne, & Cacioppo, 2005; Hawkley, Gu, Luo, & Cacioppo., 2012). Intimate loneliness, also termed emotional loneliness, results from the absence of "a person one can rely on for emotional support during crises, who provides mutual assistance, and who affirms one's value as a person" (such as a partner) (Cacioppo et al. 2015, p. 240).

Loneliness and social isolation expose partners to a range of negative impacts on physical and mental health (Grenade & Boldy, 2008; Holt-Lunstad, Smith, & Layton, 2010; Lynch, 2000), including sleep problems, poor cardiovascular health, and elevated blood pressure, each of which carries long-term consequences for mortality risk (Cacioppo et al., 2002a; 2002b; Hawkley, Burleson, Berntson, & Cacioppo, 2003). Nonetheless there is no direct sociological research on partnered Baby Boomers' preferences (as prospective aged care residents) on issues such as couples being separated, processes that maintain or disrupt coupledom in RACFs, or ultimately whether current approaches will meet Baby Boomers' perceived needs.

2.2.5. Summary

The review of the literature on later life relationships indicates that the presence of a caring, supportive partner bestows significant benefits in terms of health and wellbeing in later life, irrespective of whether one is in a married, cohabiting or non-cohabiting

relationship and no matter the sexual orientation of the partners. While there is some evidence that the level of commitment and legal recognition of each relationship type may affect the degree of wellbeing that partners experience, it appears that it is the quality of the relationship and the corresponding level of relationship satisfaction that has a greater influence. It is also clear that while separating from an unhappy relationship may have benefits, the literature suggests that the unexpected and involuntary separation from a valued relationship due to a partner being institutionalised can cause significant distress that may impact upon the health of both partners for years to come. It would appear that for older couples in supportive relationships it is in the best interests of both parties for them to remain together wherever possible. What is not clear from the literature is how older couples can best be supported to maintain their relationships in the event that one or both partners are institutionalised.

The literature review here showed that there was a distinct lack of research on (1) how couples negotiate entry in RACFs; (2) ways in which the aged care system supports or disrupts partners' coupledom; and (3) to what degree couples can maintain established relationship roles once in care. Nor is there an evidence base on partnered Baby Boomers' attitudes to such matters. Furthermore, the work on sexually diverse aged care residents could potentially be extended to raise awareness of the needs of all partnered aged care residents, including heterosexual couples.

2.3. Later life sexuality

2.3.1. Established consideration of later life sexuality

The World Health Organization (2006, p. 5) broadly defines sexuality as:

> sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.

Many authors agree that sexuality remains an important part of life in old age (Ginsberg, Pomerantz, & Kramer-Feeley, 2005; Lenahan & Elwood, 2004; Salzman, 2006) and, while there is significant variation in older populations, sexual enjoyment

is impacted upon at least as much as by ill health, beliefs, attitudes, and poor relationships as by ageing bodies (Weeks, 2002). In fact, according to DeLamater and Koepsel (2015, p. 54), "there is little evidence that physical changes associated with ageing necessarily lead to reduced sexual activity".

Research on older adults' sexuality, sexual behaviour and sexual health has largely been viewed from biomedical and, more recently, biopsychosocial perspectives adopted within the biological sciences, psychiatry, psychology and sexology. Epidemiological data collected using large-scale (usually cross-sectional) population-based quantitative surveys have predominated. However, a growing body of qualitative sociological, feminist and gerontological scholarship (largely from a lifespan perspective) has been developing since the advent of Viagra in the late 1990s (e.g. Fileborn et al., 2015a; 2015b; Fileborn et al., 2017b; Tiefer, Hall & Tavris, 2002; DeLamater, 2012; Carpenter & DeLamater, 2012).

Sexual satisfaction has often been regarded as an important factor in cohabiting couples' relationship satisfaction and there are indications that partner support and relationship happiness increase sexual frequency and satisfaction in later life (DeLamater & Koepsel, 2015). There is also evidence that continued sexual activity and physical intimacy not only improve one's quality of life but may improve health and longevity (Gianotten, Whipple, & Owens, 2006; Gates & Whipple, 2003; Komisaruk & Whipple, 1995). As more people live longer and in better health, sexual satisfaction will probably continue to gain in importance for older couples (DeLamater & Koepsel, 2015). However, research into the sexuality of older adults, especially within intimate partnerships, is under-researched and reveals many gaps (Deacon, Minichiello, & Plummer, 1995). According to DeLamater (2012, p. 125), research into the sexual expression of healthy older adults is a "relatively neglected topic" with attention mostly focused on the more problematic aspects of sexual expression and behaviour (Satcher, 2001). Marshall (2011, p. 406) contends that "there is an important role for critical social studies to expose and expand the constructions of mid- and late-life sexuality currently promoted by biomedical and consumerist discourses".

Since the availability of Viagra in 1998, research into older adults' sexual functioning has increased dramatically (DeLamater, 2012). However, the bulk of this research

takes a biomedical perspective (Tiefer, 1996; 2007), concentrating mainly on sexual desire, intercourse and male erectile dysfunction, largely ignoring the perceived quality of sexual experiences (Laumann et al., 2006). In addition, research attention has predominantly been focused on individuals, resulting in a paucity of research into the experiences of couples and the role partnerships play in shaping the sexual experience (Aubin & Heiman, 2004; Das, Waite, & Laumann, 2012).

A range of factors appear to have contributed to the piecemeal approach to this topic, including societal stereotypes (Carpenter, Nathanson, & Kim, 2006; Fileborn et al., 2015a; Ivey, Wieling, & Harris, 2000) and pharmaceutical agendas (many authors declare an affiliation with a pharmaceutical company). Numbers of sexually active older adults may in fact be significantly larger than reported given that gerontological research has tended to be narrowly focused on heterosexual partnered activity, especially coitus (Fileborn et al., 2015b; Gott, Hinchliff, & Galena, 2004). There is much less published data on the sexual expression of older lesbian, gay, bisexual, and transgender and intersex (LGBTI) people (DeLamater, 2012). Non-coital activities, such as oral sex and masturbation (both solo and partnered), are neglected topics deserving more attention.

According to Laumann & Waite (2008, p. 2300), "despite increasing demand for clinical interventions in an aging population, epidemiological data on the subject are scarce". Much of the research into sexual dysfunction adopts a biomedical, hetero-normative approach which focuses on restoring penis-in-vagina sex by seeking to facilitate erections and remedy vaginal dryness (Fileborn et al., 2015b; Leiblum, Hayes, Wanser, & Nelson; Mamo & Fishman, 2001; Marshall, 2012; Sandberg, 2013a, 2013b). In fact, much of the discussion on sexual dysfunction happens without first establishing a baseline reference for healthy sexual functioning in older individuals.

The literature indicates that sexuality remains important throughout the entire life cycle (Carpenter & DeLamater, 2012; Das, Waite, & Laumann, 2012; Lenahan, Nusbaum, & Sadovsky, 2005; Masters & Johnson, 1966) and, given the right conditions, many people remain sexually active into their 70s, 80s, 90s and beyond (Bretschneider & McCoy, 1988; Ginsberg et al., 2005; Lenahan & Ellwood, 2004; Masters & Johnson, 1966; 1970). Ongoing sexual expression is a normal part of ageing

for many (Kinsey, Pomeroy, & Martin, 1948; Kinsey, 1953) and ageing may even have potential sexual benefits, such as the 'unleashing' of a woman's sexual response when pregnancy is no longer a risk (Masters & Johnson,1966). An important distinction that Schnarch (1997) makes is between 'genital prime' and 'sexual prime', suggesting that one's sexual peak has more to do with who one is as a person than the state of one's body.

Notable findings are that age-related physical changes do not necessarily reduce sexual function or enjoyment (Kinsey et al., 1948; Kinsey, 1953; Masters & Johnson, 1966; Meston, 1997) and that, the 'use it or lose it' principle may apply. For instance, in older men, decreased sexual activity may be a cause, not an effect, of decreased testosterone levels (The Endocrine Society, 2015).

Older adults have often been viewed as asexual, defined either as being sexually undesirable or lacking sexual desire (Bouman, Arcelus, & Benbow, 2006; Fileborn et al., 2015a; Gott & Hinchliff, 2003b; Hinchliff & Gott, 2008; Kessel, 2001; Minichiello, Plummer, & Seal, 1996; Weeks, 2002). The asexual stereotype has been linked to religious beliefs that sex is for procreation, making later-life sexuality a "perversion" (Hinchliff & Gott, 2011). A growing body of research on older adults' sexual behaviours and desires in later life challenges the asexual stereotype (Carpenter & DeLamater 2012, De Vries, O'Donnell, & Doll, 2010; Fisher, 2010; Gott & Hinchliff, 2003b; Hinchliff, Gott, & Ingelton, 2010; Laumann & Waite, 2008; Mercer et al., 2013; Minichiello, Plummer, & Loxton, 2004; Papaharitou et al., 2008). Various studies confirm older adults' continued desire to touch, hold hands, caress, embrace, hug and kiss (Bauer, Fetherstonhaugh, Tarzia, Nay, & Beattie, 2014; Bretschneider & McCoy, 1988; Ginsberg et al., 2005). Furthermore, people aged 75 to 102 report continuing sensuality and sexual pleasure (Bauer, McAuliffe, & Nay, 2007; Bretschneider & McCoy, 1988; Gott, 2005; Loe, 2004a; 2004b; Salzman, 2006; Suzman, 2009). Other known behaviours in older age groups include sexual thoughts, fantasies and erotic dreams (Fisher, 2010), masturbation, and oral, anal and vaginal intercourse (DeLamater, 2012).

In the past two decades, three large national population-based studies have contributed to our understanding of sexual expression in late life – (1) the *National Social Life,*

Health, and Aging Project (NSHAP) conducted in 2005-2006 which analysed sexual problems among people aged 57 to 85 in the United States (Laumann & Waite, 2008); (2) the *Third British National Survey of Sexual Attitudes and Lifestyles (Natsal-3)*, which surveyed 15,162 people aged 16 to 74 in 2010-2012 (Mercer et al. 2013); and (3) the *Australian Study of Health and Relationships*, which surveyed 20,094 people aged 16–69 years in 2013 (Rissel et al., 2014). Significant findings were that "sexual problems among older adults are not an inevitable consequence of aging, but instead are responses to the presence of stressors in multiple life domains" (Laumann & Waite, 2008, p. 2300), and that "older women's sexual health [is] more sensitive to their physical health than is true for men" (Laumann & Waite, 2008, p. 2300). Also, "sexual behaviour and relationships" are both key to wellbeing and subject to "social norms, attitudes, and health" (Mercer et al. 2013, p. 1781). While Natsal-3 reported that sexual frequency reduces over the life course, a significant proportion of Baby Boomers and the generation prior to them were found to still actively engage in vaginal intercourse, genital contact, oral sex and masturbation (Mercer et al. 2013).

Older women's sexuality, in particular, has been regarded as invisible and taboo (Hinchliff, 2014), based on normative assumptions of attractiveness and 'sexiness'. Various authors have challenged these assumptions (Fileborn et al., 2015a; 2015b; Hinchliff, 2014; Loe, 2004a). Many older women may in fact be sexually frustrated (Loe, 2004a; Masters & Johnson, 1966; Meston, 1997). Reasons most often cited by older women for the cessation of sexual activity are a partner's erectile dysfunction (Fileborn et al., 2015b; Kingsberg, 2002) or lack of an available partner (Masters & Johnson, 1966; Meston, 1997) since partnership drives partnered sexual activity (Palacios-Ceña et al., 2012).

The inference that older women's sexual desire declines with age has largely been based on comparisons between men's and women's coital frequency, which ignores non-coital activities (Fileborn et al., 2015b; Meston, 1997). Meston argues that "age-related changes in sexual activity may best be understood by examining change across a person's total lifespan rather than comparing incidence between genders" (Meston 1997, p. 286). Rather than discussing 'libido', sex researchers now refer to desire, which Levine (1992) defined as the interaction of three components: drive, beliefs/values, and motivation, a complex mix that most women do not understand

themselves (Meston, 1997). Meston (1997, p. 434) contends that if "a woman has lost some of her drive" but remains motivated to be intimate with her partner, then "despite having little physical cues or interest, she still enjoys the sexual experience". Hite's ground-breaking research in the 1970s revealed that women aged in their sixties and seventies not only had sexual desires but enjoyed practices such as masturbation and cunnilingus (Fileborn et al., 2015b; Hite, 1976), with some reporting that they took lovers to satisfy their needs (Hite, 1976).

Many sexual changes that can occur with age have traditionally been regarded as a normal part of ageing (Hinchliff & Gott, 2011) and have been attributed to age-related hormonal decline (Meston, 1997). Such changes include reduced vaginal lubrication, vaginal atrophy and thinning of the vaginal walls in women (Kingsberg, 2002; Meston, 1997; Salzman, 2006). In men, the most common changes are reduced sexual desire and the increased time and stimulation needed to achieve (softer) erections (Meston, 1997; Salzman, 2006). A growing number of authors attribute the cause of sexual problems to overall health and psychosocial factors, such as stress and relationship quality, rather than age (Weeks, 2002). Psychosocial factors, such as shame and embarrassment, have also been linked to older adults not seeking help for sexual problems (Hinchliff & Gott, 2011).

More recently, continued sexual activity has been linked to 'successful aging' (Hinchliff & Gott, 2011, Marshall, 2012). Cultural stereotypes of older women as "gray-haired, frail, and asexual have given way to images of strong, active, and sexual women" (Kingsberg, 2002, p. 431). The 'sexy oldie' or 'sexy senior' is a new norm that has recently emerged in the research literature. The 'sexy oldie' represents 'successful' ageing by maintaining a 'youthful' sexuality (Fileborn et al., 2015b; Hinchliff & Gott, 2008, Marshall; 2012; Sandberg, 2013a). The strongest predictors of sexual activity, sexual frequency and sexual enjoyment in later life are good physical and mental health (DeLamater, 2012; Delamater, Hyde, & Fong, 2008; DeLamater & Koepsel, 2015; Gott & Hinchliff, 2003a; Laumann et al., 2006, Lindau et al., 2007), having a partner (DeLamater & Koepsel, 2015; Gott & Hinchliff, 2003a; Karraker, DeLamater, & Schwartz, 2011), relationship duration (Stroope, McFarland, & Uecker, 2015), relationship quality and happiness (Call, Sprecher, & Schwartz, 1995; MacNeil & Byers, 2005; Sprecher, 2002), and a positive attitude towards sex

(Das et al., 2012; DeLamater, 2012; DeLamater & Koepsel, 2015; Gott & Hinchliff, 2003a).

Almost 40 years ago in Australia, the Whitlam government's *Royal Commission on Human Relationships* (Evatt, Arnott, & Deveson 1977, p. 8-9) stated:

> it should not be overlooked that sexual needs do not disappear with advancing age; they may change and they may give rise to problems which need consideration….We need to develop more realistic attitudes and understanding of the ageing person as a sexual person, and recognise that most aged persons are mature, responsible and capable of making decisions.

The dominance of biomedical and consumerist heteronormative studies means the literature has clear limitations, in that it does not consider older adults' perspectives on their rights to aged care provisions that consider their relationships and sexualities. There is clearly a need for sociological research to balance out the limits of the biological frame, including research on how aged care facilities currently attempt to facilitate and make room for the sexual needs of their residents, and the extent to which this will be wanted by the next incoming generation of (Baby Boomer) residents.

2.3.2. (Re)considering Baby Boomers' later life sexuality

In the 1960s and 1970s, Baby Boomers were exposed to a range of new ideas on alternate lifestyles. Some experimented with sexual non-conformity beyond the traditional monogamy model (Rubin, 1990; Rubin, 2001). The *American National Health and Social Life Survey* shows Baby Boomers have had more sexual partners than previous generations and their sexuality is less shaped by religious beliefs than previous generations (Waite, Laumann, Das, & Schumm, 2009). There is a growing body of work on Baby Boomer experimentation with open relationships, 'swinging', polyamory, BDSM and 'friends with benefits' type relationships (Jenks, 1998; Kirkman, 2012; Rubin, 1990; 2001; Wolfe, 2003).

Gerontological research from a life-course perspective indicates that earlier life stages influence people's experience of ageing (Suzman, 2009) and that one's sexual attitudes, identity and preferences are established in early adulthood and change minimally over the course of a lifetime (Das et al., 2012; Minichiello et al.,1996;

Suzman 2009). Some authors believe that because Baby Boomers were teens and young adults in the 1960s and 70s, in an era of increased sexual permissiveness (Das et al., 2012), a proportion of Baby Boomers (now aged 52-72) may have expectations of continuing sexual activity of various kinds, no matter their age (Carpenter et al., 2009; Das et al., 2012).

Baby Boomers have been described as a generation who, through sheer force of numbers, have successfully lobbied for change in every sphere of life (Leach, 2007; Pruchno, 2012). They are often seen as being self-absorbed and having a strong sense of entitlement (Hudson & Gonyea, 2012) and because they display different attitudes from previous generations (Fallon et al., 2004; Huber & Skidmore, 2003; Maples & Abney, 2006; Roth et al., 2012), there is speculation that old age will be the 'last frontier' of Baby Boomers' influence (Freedman, 1999; Hudson & Gonyea, 2012; Pruchno, 2012).

There is very little research that identifies the current sexual and intimacy needs of Baby Boomers, let alone their anticipated needs in aged care settings. The *Sex, Age and Me* study is the first large-scale population-based study to provide insight into the sexual relationships and sexual health needs of 2,119 Australians aged 60-94, most of whom were partnered (76%) and aged in their 60s (i.e. Baby Boomers). It revealed that many older Australians are still sexually active and consider sexual pleasure important (Fileborn, Hinchliff et al., 2017). However, less than half are sexually satisfied (46%) (Heywood et al., 2017). Many of the over 60s are forming new relationships late in life and either shirk safe sex (Vogel, 2010) or have limited understanding of the risks of contracting sexually transmissible infections (Fileborn, Hinchliff et al., 2017). This may partially explain the high rates of new HIV transmissions worldwide in the over 50 age group (Smith, Delpech, Brown, & Rice, 2010; Tavoschi et al., 2017).

2.3.3. Considering ageism

Many of the 'younger-old' in the *Sex, Age and Me* study had experienced ageism, which they associated with poorer mental health and wellbeing (Lyons, Alba et al., 2017). Ageism is a term coined by Butler in 1968 during the civil rights era of Baby

Boomers' youth. Thus, it is a concept that may be more familiar and understood by them than previous generations, in ways that could impact their thinking on sexual rights. Butler (1969) defined ageism as a combination of three connected elements: (1) prejudicial or derogatory attitudes towards older adults and ageing in general; (2) discriminatory practices against older adults; and (3) institutional practices and policies that perpetuate ageist stereotypes. People experience ageism by being judged as old, by being made aware of their age and by being judged according to how well they are ageing (Butler, 1975; Bytheway, 2005; Comfort, 1977). Some view ageism as "one of the most socially-condoned and institutionalized forms of prejudice, such that researchers may tend to overlook it" (Nelson 2005, p. 208; Nelson, 2002; Palmore, 1999) or even perpetuate it. For instance, labelling people as 'elderly', 'young-old', 'old-old' or 'frail old' rather than using descriptors such as 'over 60', 'over 75' and so on may signify researchers' value judgements (Bytheway, 2005).

A substantial body of literature on ageism has developed over the past 50 years, although there has been significantly less research on ageism compared to other forms of discrimination such as sexism and racism (Lloyd-Sherlock, Ebrahim, McKee, & Prince, 2016). Many have speculated on its origins – whether it be a (1) deep-seated terror of one's own ageing and death (Terror Management Theory) (Greenberg, Pyszczynski, & Solomon, 1986), also described as prejudice against our "feared future self" (Nelson, 2005); (2) culturally prescribed gradual marginalisation of older adults (the veneration to degradation thesis), which saw pre-industrial cultures leaving their old to die (Achenbaum 2015; Fischer, 1978; Macnicol, 2002); or an (3) 'economic burden' created by people living longer post retirement (Manicol, 2010).

Some authors suggest that age discrimination took hold in Western cultures during the Industrial Revolution, in an era where families needed to be more mobile and where working with heavy machinery was more suited to the young and the strong (Nelson 2005; Stearns, 1986). During this period, older adults were increasingly viewed as "non-contributing burdens on society" (Nelson 2005, p. 209). An alternative view of ageism has its seeds in childhood (Bodner, 2009), positing that the more children are told they are 'too young' to participate in activities, the more likely they are to age stereotype others (Giles & Reid, 2005).

Despite evidence to the contrary, common stereotypes held about older adults are that they are (1) lonely, with few friends and family; (2) moody; (3) rigid and unable to cope; (4) all alike; (5) sick and dependent; and (6) cognitively impaired (Butler, 1975; Cooley et al., 1998; Kite & Johnson, 1988; Officer et al., 2016; Sneed & Whitbourne, 2005; Whitbourne & Hulicka, 1990). Butler (2005, p. 85) wrote "[p]erhaps the ultimate manifestation of age prejudice is the extent to which older adults are considered incapable of intimate sexual experience". Another argument is that rendering old age as asexual reflects a desire to disempower the older generation by those younger than them (Gibson, 1992). This is reinforced in a contemporary culture where sex is associated with youthful sexual attractiveness, envisaged as the antithesis of the ageing body (Gott, 2005; Weeks, 1985).

Negative stereotypes about older adults are not only held by the general public but also by health professionals, including doctors, nurses and psychologists (Bouman & Arcelus, 2001; Sneed & Whitbourne, 2005), especially where older age sexuality is concerned (Fileborn, Lyons et al., 2017; Gott, Galena, Hinchliff, & Elford, 2004; Gott & Hinchliff, 2003a; Gott Hinchliff, & Galena, 2004). Research suggests that institutional ageism underlies some global health policies (Lloyd-Sherlock et al., 2016). There is evidence that age bias may compromise medical care (Bytheway, 1995; Hitchcock, 2015; McGuire, Klein, & Chen, 2008) and the delivery of aged care services (Butler, 2005). Many health practitioners assume that some health complaints reported by older adults are a normal part of ageing that does not require treatment (McGuire et al., 2008).

A recent Australian survey by The Benevolent Society (2017) identified aged care as the third most important arena in which to combat ageism, after the workplace and healthcare sector. Van den Hoonaard (2009) described Australia's aged care system as conservative, where ageism is rife and residents are frequently considered asexual, childlike and/or incompetent. There is a dearth of literature on ageism in the aged care sector and even less on how ageism impacts residents' sexual relationships (Cook, Schouten, Henrickson, & McDonald, 2017; Simpson, Horne, et al., 2017). Sexual ageism, or 'ageist erotophobia', restrict opportunities for residents to conduct consensual sexual relationships (Simpson, Brown Wilson et al., 2017; Simpson, Horne, et al., 2017). Furthermore, in spite of the ethical issues posed by researching

sexuality in aged care settings (Cook et al., 2017; Simpson, Brown Wilson et al., 2017) there is an identified need "for research to go beyond problem-spotting to unearth actual good practice – the good news stories that could be disseminated across the care sector" about sexually active older people (Simpson, Horne, et al. 2017, p. 259). Ethical challenges can be minimised by utilising the working knowledge of key informants to guide research (Cook et al., 2017; Simpson, Brown Wilson et al., 2017).

As a consequence of ageist thinking, Baby Boomers' retirement years are being viewed as a source of impending doom, termed 'apocalyptic demography' (Peterson, 1999), due to the expected increase in demand for social security payments that might overstretch government resources (Longino, 2005). Terms such as 'storm', 'flood', 'silver tsunami' and even 'boomergeddon' have been used to construct Boomers as problematic (Bristow, 2016; Longino, 2005; Phillipson, Leach, Money, & Biggs, 2008; Poole, 2014). However, it is possible that Baby Boomers have enough understanding of the concept of ageism to be more demanding about their rights and more willing to challenge discriminatory perspectives or provisions. More sociological research is needed to both understand how ageism might impact their sexual relationships in RACFs and identify initiatives that may support those relationships.

2.3.4. Summary

In summary, this literature survey particularly identified gaps around the current sexualities of Baby Boomers (particularly couples), their sexual attitudes and preferences, the importance (or not) of their couple relationships, including sensuality, sexuality, and intimacy, and how they differ from previous generations. It reveals that societal ageism is a widespread phenomenon which affects public policy and the health and aged care sectors. This may impact aged care services offered to Baby Boomers and their perspectives on such services. Furthermore, ageing Baby Boomers are being framed as a problem and a drain on resources. However, there is a gap in the literature that relates to how extensive ageism is in aged care settings, particularly in relation to residents' couple relationships. There is also a lack of research that lets Baby Boomers describe for themselves what they will want in terms of aged care services. Survey-based and interview-based data gathered from Baby Boomers is needed to fill this gap.

Also needed are key informant interview data that show what is currently happening 'on the ground' for couples in Australian residential aged care.

2.4. Australian residential aged care

In 2014-15, 30% of permanent residents in Australian residential aged care facilities reported having a spouse or de facto partner (Australian Institute of Health and Welfare [AIHW], 2015b) however there is no government data that records (1) how many of these residents cohabited within a RACF; (2) how many were accommodated separately within the same RACF; (3) how many resided in separate RACFs; and (4) how many became physically separated by only one partner entering residential care. Whether or not partners separate voluntarily or whether they feel they have no choice is also an area that is under-researched. The scant literature on married or partnered aged care residents mostly pre-dates the year 2000 and refers in the main to the situation where couples have become separated by one partner entering residential aged care alone, often due to cognitive decline.

Sexual expression as a normal healthy part of life in old age is a notably absent discourse in aged care policies at global, national and local levels. Gott (2006, p. 106) asserts that "later-life sexual health issues have typically been afforded low priority in policy, practice and research". Both internationally and in Australia, there is an acceptance of the 'asexual older person' stereotype at a policy level (Gott & Hinchliff, 2003b) and an absence of policy relating to the sexual needs and sexual health of older adults in health and aged care portfolios (Kirkman, Kenny, & Fox, 2013). Canada is an exception where, according to Marshall (2011, p. 399), "sexual health" is generally synonymous with "sexual function". She asserts that "a critical and multidimensional focus on aging and sexuality in sociology is both overdue and imperative" (Marshall 2011, p. 406).

2.4.1. The history of aged care in Australia[5]

> The Australian residential aged care facility is a post-World War Two phenomenon (Braithwaite, Makkai & Braithwaite, 2007; Crisp, 2012). Previously, institutions…took the form of large, generic asylums for society's 'refugees', predominantly funded by churches and charitable organisations (Cummins, 2003; Kendig & Duckett, 2001). They were places of "overcrowding and misery" where "incarceration almost invariably meant the separation of married couples" (Murphy 2011, p. 59). People of all ages were often fed and housed in military-like barracks (Murphy, 2011). Asylums [that] operated as totalitarian regimes (Braithwaite, 2001) or 'total institutions' (Goffman, 1962), exercise[ed] social control through "rules, routines, and the fabric of the institutions" (Crisp 2012, p. 12) in tandem with systems of surveillance and discipline (Foucault, 2001; Foucault, 2003; Markus, 1993).
>
> By the 1930s, Australian asylums evolved into 'nursing homes', 'geriatric hospitals' and 'convalescent homes'. The discourse shifted from 'incarceration' and 'inmates' to 'care' and 'patients'. Old age became medicalised, requiring nurses in attendance 24 hours a day (Crisp, 2012) (Rahn et al. 2016, pp. 4-5).

For Australian couples, aged care began improving in the 1950s.

> A new political narrative was winning favour – that institutions be more 'homelike'. By 1952 there were "140 semi-charitable organisations providing pensioner housing" (Dargavel & Kendig 1986, p. 25). Hostel accommodation emerged as an alternative to nursing homes, offering supported housing for those not requiring nursing care. As Dargavel and Kendig (1986, p. 25) note: "[c]ouples as well as single aged persons were eligible, thus overcoming the problem of couples being separated by admission to an institution, many of which separated males and females".

Services offered included meals, cleaning, bathing, and dressing (McLeay, 1982). Demand outstripped supply (Dargavel & Kendig, 1986), resulting in the *Aged Persons' Homes Act 1954* (s3.1), which prescribed government funding to churches

[5] This sub-section is an extract taken from Rahn, A., Jones, T., Bennett, C., & Lykins, A. (2016). Conflicting agendas: The politics of sex in aged care. *Elder Law Review, 10*, 1-24. Retrieved from https://www.westernsydney.edu. au.

and not-for-profit organisations to provide homes for the aged "with proper regard to the companionship of husband and wife" (Cth, 1954).

> The earliest mention of aged care residents having sexual needs was the Whitlam Government's (1972 to 1975) Royal Commission on Human Relationships[6] (Evatt et al., 1977) which was predicated on the concept of intimate citizenship; that is "all those areas of life which appear to be personal but that are in effect connected to, structured by, or regulated through the public sphere" (Plummer, 2003) (Rahn et al. 2016, p. 8).

One finding was that:

> institutions which care for old people on a long-term basis too often ignore their sexual needs, even to the point of separating husbands and wives. Double beds may be excluded from nursing homes and hostels, there may be no privacy and overnight visits from members of the opposite sex may be forbidden (Evatt et al. 1977, p. 8).
>
> The Royal Commission provoked media controversy. A Catholic archbishop expressed "concerns about the incursion of the state into family life" (Arrow, 2014). The Fraser Government (1975 to 1983) distanced itself from the Commission's final report, timing its release to coincide with the 1977 election campaign (Arrow, 2014). Few recommendations were acted on, [though] it did help open public discussion about private sexual relationships (Australian Policy Online, n.d.). Forty years on, Australia still has no specific legislation to protect the sexual needs of aged care residents, to ensure their access to sexual health information and services, or that prevents involuntary separation of couples (Rahn et al. 2016, pp. 8-9).

The Fraser Government commissioned the McLeay Report, published in 1982, which recommended the introduction of standardised assessment procedures prior to admission to a nursing home (Le Guen, 1993). Following a change of government,

> the Hawke Government (1983 to 1991) [then] engaged in substantial public consultation on minimum national aged care standards. This garnered bi-partisan support in Parliament, ensuring the adoption of Outcome Standards for nursing

[6] One of the Royal Commission's terms of reference was to "inquire into and report upon the family, social, educational, legal and sexual aspects of male and female relationships, so far as those matters are relevant to the powers and functions of the Australian Parliament and Government". See http://apo. org. au/node/34438 for further detail.

> homes (Commonwealth, 1987), later extended in 1991 to include hostels. Objectives included maintaining residents' 'social independence', 'freedom of choice' and 'privacy and dignity'.
>
> The Hawke Government commissioned human rights lawyer, Chris Ronalds, to investigate issues affecting residents in nursing homes and hostels. Submissions and interviews with 667 residents provided a unique insight into their experiences. Accounts included couples' difficulty in entering care together, forced separation of couples, interference in residents' sexual relationships, lack of privacy and private space, and pressure to conform to the religious practices of providers (Ronalds, Fiebig, Godwin, & Green, 1989). A Charter of Residents' Rights and Responsibilities was proposed, along with a Draft Model Contract between residents and providers (Rahn et al. 2016, p. 9).

The Contract proposed that residents become tenants with clearly defined spatial boundaries (Ronalds, Godwin, & Fiebig, 1989). The Charter now forms part of the *Aged Care Act 1997*. However, the proposal for resident tenancies was never adopted.

2.4.2. Current legislation and policy

Australia's government funded residential aged care is legislated under the *Aged Care Act 1997* (Cth), administered by the Department of Health and AACQA. The *Quality of Care Principles 2014* (Cth) set out the minimum accreditation standards providers must comply with. Schedule 2, Part 3 of the Principles states:

> Care recipients retain their personal, civic, legal and consumer rights, and are assisted to achieve active control of their own lives within the residential care service and in the community.

Part 3 further requires that:

> Management and staff have appropriate knowledge and skills to perform their roles effectively….Care recipients are assisted to achieve maximum independence, maintain friendships and participate in the life of the community within and outside the residential care service….Each care recipient's right to privacy, dignity and confidentiality is recognised and respected.

The *User Rights' Principles 2014* (Cth, Schedule 1) outline a Charter of Care Recipients' Rights and Responsibilities, which contains the following rights:

> (d) to be treated with dignity and respect, and to live without exploitation, abuse or neglect; (e) to live without discrimination or victimisation…(f) to personal privacy;… (h) to be treated and accepted as an individual, and to have his or her individual preferences taken into account and treated with respect;…(j) to select and maintain social and personal relationships with anyone else without fear, criticism or restriction;…(l) to maintain his or her personal independence; [and] (m) to accept personal responsibility for his or her own actions and choices, even though these may involve an element of risk, because the care recipient has the right to accept the risk and not to have the risk used as a ground for preventing or restricting his or her actions and choices.

This last category is particularly relevant when considering residents' sexual practices.

In relation to sexual behaviours, the Australian Aged Care Quality Agency (AACQA)'s regulatory standards are clearly open to the interpretation of individual operators and their staff. In the *Quality of Care Principles 2014* (Cth, p. 16), there is a provision which, if abused, may be used by staff to override residents' lifestyle choices – "Behavioural management - The needs of care recipients with challenging behaviours are [to be] managed effectively". "Challenging behaviours" are not further defined.

AACQA publishes audits of individual providers which show that many organisations have, until as recently as 2014, lacked adequate policy and staff training in dealing with residents' sexual expression (Australian Aged Care Quality Agency [AACQA], 2014a; 2014b; Aged Care Standards and Accreditation Agency [ACSAA], 2012a). Staff training relating to sexual behaviours, as reported in these reports, has tended to focus on behaviours deemed to be problematic - bullying, sexual harassment and what were termed 'inappropriate' sexual behaviours (e.g. ACSAA, 2006; 2012b) rather than sexual expression as a normal part of life. These examples suggest that improvements in handling residents' sexual expression and intimacy needs have occurred at a glacial pace in the past 40 years, given that the topic of sexual ageism appeared in the Australian *Royal Commission on Human Relationships* in 1977. In that document, Dr Gillian Diamond is quoted as saying (Everett et al., 1977, p. 8):

> the messages we have received tell us that old age brings a period either of asexuality or abnormality. All the education you have received during your life will have taught you that old men are 'dirty' and older women 'don't'. The message is sex is wrong if you are old…

Double beds are still a rarity in RACFs (Bauer, Fetherstonhaugh, Tarzia, Nay, Wellman, & Beattie, 2013) however, recent initiatives provide evidence that the culture of aged care may be on the brink of change. Resulting from the Productivity Commission's report in 2011 (2011a; 2011b) the *Living Longer, Living Better* (Department of Health and Ageing [DoHA], 2012a) aged care reforms introduced a paradigm shift towards a consumer-directed or person-directed aged care system which places more emphasis on wellbeing and choice as well as more independence-focused models of care (Chomik & MacLennan, 2014). These reforms propose a 'Positive Ageing Agenda' (DoHA 2012a, p. 34) with one notable initiative being to provide "additional funding to the Age Discrimination Commissioner to address stereotyping and discrimination of older Australians" (DoHA 2012a, p. 35).

Furthermore, the *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013* (Cth) requires all aged care institutions to provide for its residents regardless of their sexuality and gender identity, marital or relationship status, or intersex status. It notably also provides no exemptions for any aged care institutions regardless of whether they are run by religious organisations or not (which contrasts for example with religious schools for which some exemptions have been allowed) – suggesting some different thinking about provision of services on the basis of older couples/sexualities compared to those of youth.

2.4.3. Residents' quality of life

As cited on page 26 of this chapter, resident privacy and dignity, although not defined, are legally protected. Dignity in particular, speaks to residents' quality of life. Quality of life is variously defined in the literature (Courtney, O'Reilly, Edwards, & Hassall, 2007; Raske, 2010). In the context of the current study it is considered to be a subjective phenomenon that reflects a person's sense of happiness and wellbeing, largely determined by one's attitudes, morale, and general satisfaction with life (McDonald, 2016; Skevington, Lotfy, & O'Connell, 2004). This subjectivity is fluid

and responds to "personal circumstances, new information, relationships, [and] emotional status, all of which vary widely over time" (McDonald 2016, p. 172).

Normal physical functioning is not required for a person to perceive they have quality of life (McDonald, 2016). Positive feelings can exist in spite of disease or disability and, in fact, many healthy people do not perceive they have a good quality of life (Albrecht and Devlieger, 1999). While poor health, disability, and frailty do not generally drive quality of life, there is evidence that acute illness or pain, bereavement and depression can influence the way life experiences are perceived (Degenholtz, Kane, Kane, Bershadsky, & Kling, 2006; Degenholtz, Rosen, Castle, Mittal, & Liu, 2008). This is especially relevant in the context of aged care services, where "personal efforts to achieve life quality can be overwhelmed by the priorities of service providers delivering what they perceive to be essential services" (McDonald, 2016, p. 168), frequently making quality of life a lower priority than safety and risk management.

Extant gerontological literature cites the following factors as essential for positive life quality in aged care settings: (1) participation in meaningful activities to build social connections, improve functional capacity and increase enjoyment in life (McDonald, 2016; Raske, 2010); (2) involvement in self-care and health-promoting activities exercised through personal choice, free of duress from others (Elavsky et al., 2005; Hellstrom & Sarvimaki, 2007); (3) supportive relationships with people who care about the resident's happiness and wellbeing (Droës et al., 2000; Krause, 2010), including positive contact with partners, family and friends (Haggstrom & Kihlgren, 2007; Latham & Skarlicki, 1995); (4) maintaining a positive outlook and expressing appreciation for one's life, acting as if one feels 'well' or 'happy' (Chou, Boldy, & Lee, 2002); and (5) feeling safe or secure in one's surroundings (Barnes, 2002; Kane, 2001). However, feeling safe and secure is connected to the notion of privacy.

2.4.4. Privacy in in residential aged care

Privacy has been described as a basic human need (Altman, 1976; Doyal 1997) that supports (1) personal autonomy; (2) emotional release; (3) self-evaluation; and (4) protected communication (Leino-Kilpi et al., 2001; Westin, 1970). Altman (1976) conceptualised privacy as a constant process of boundary regulation undertaken in an

attempt to achieve desired levels of social interaction. Research into privacy in health settings has identified seven domains of privacy: (1) physical; (2) psychological (3) bodily; (4) territorial; (5) communicational; (6) informational; and (7) social (Hughes, 2004a; Lee-Treweek, 2008; Leino-Kilpi et al., 2001; Petronio & Kovach, 1997; Woogara, 2005). According to Newell (1994), privacy needs vary according to gender.

However, like dignity, privacy is not defined in the Act. The concept of privacy has many meanings. It is variously defined as a "state in which one is not observed or disturbed by other people", "being free from public attention" (Oxford Dictionaries, 2016), "being out of the sight and hearing of other people", "freedom from unauthorized intrusion" and "a place of seclusion" (Merriam-Webster Dictionaries, 2016). The dictionary meaning of the term 'private' derives from the Latin *privatus*, meaning "withdrawn from public life"; *privare*, meaning "bereave, deprive", and *privus*, meaning "single, individual". By this definition, someone who seeks privacy literally deprives others of his/her company and withdraws to be alone (Oxford Dictionaries, 2016).

The concept of a legal right to privacy is a relatively modern phenomenon (Australian Law Reform Commission [ALRC], 2008; Gavison, 1980). Consistent with these ideals, numerous pieces of Australian legislation exist that enshrine the concept of a person's right to privacy in RACFs. However, there remains the problem that there is no universal or legislated definition of 'privacy' (ALRC, 2008; Leino-Kilpi et al., 2001), which leaves it open to subjective interpretation. This results in the absence of a universally consistent definition of privacy in aged care settings.

2.4.5. Sexual expression in residential aged care

From the limited academic research conducted into the sexual expression and intimacy needs of residents in aged care facilities, there is evidence that some residents still identify as sexual beings and feel the need to express their sexuality in a variety of ways. These include "companionship, intimacy, touching, hugging, flirting, grooming, attire, being able to share a bed with another person, masturbation and intercourse" (Bauer et al., 2013b, p. 305). Residents' abilities to display such forms of

affection are dependent on the culture within each facility (McAuliffe et al., 2007; Nay & Gorman, 1999; Salzman, 2006).

Current barriers to sexual expression that have been identified in RACFs include staff attitudes and biases (Bauer et al., 2013b; Hajjar & Kamel, 2004; Villar, Fabà, Serrat, & Celdrán, 2015; Villar, Celdrán, Serrat, Fabà, & Martínez, 2018), separation of partners (Shuttleworth, Russell, Weerakoon, & Dune, 2010), McAuliffe et al., 2007; Roach, 2004; Salzman, 2006), inadequate staff education (Bauer et al., 2013b; McAuliffe et al., 2007; Osborne, Barrett, Hetzel, Nankervis, & Smith, 2002), privacy issues (Bauer, 1999; Edwards, 2003; Hughes, 2004a; Hughes, 2004b; Heron & Taylor, 2009; Salzman, 2006; Villar, Celdrán, Fabà, & Serrat, 2014), lack of opportunity/partner (Bauer et al., 2013b; Parker, 2006; Rheaume & Mitty, 2008), intervention by family members (Bauer et al., 2014; Frankowski & Clark, 2009), non-conducive environments, such as the non-provision of double beds (Bauer et al., 2013b; Salzman, 2006), lack of communication with residents about sexuality (Villar et al., 2014) and lack of staff attention to the personal appearance of residents (Bauer et al., 2013b).

Evidence suggests that residents feel unable to discuss sexual issues (with staff) because they regard their sexuality as a private matter (Bauer et al., 2013b), feel embarrassed (Gott & Hinchliff, 2003a) or believe staff have no expertise in this area (Bauer et al., 2013b). Conversely, staff often view residents as asexual. Sexuality as an "aspect of residents' care and quality of life is still largely ignored" (Bauer et al., 2013b, p. 307). Several authors suggest that staff in RACFs receive little or no training in relation to older adults' sexuality (Osborne et al., 2002; Parker, 2006; Villar, Celdrán, Fabà, & Serrat, 2017; Ward, Vass, Aggarwal, Garfield, & Cyby, 2005) and often view residents' sexual expression as problematic (Di Napoli et al., 2013; Ehrenfeld, Tabak, Bronner, & Bergman, 1997). Where sexuality training is offered, it helps counter negative staff attitudes and provides guidance to help staff manage day-to-day sexual situations (Villar, Celdrán, Fabà, & Serrat, 2017). There is currently a dearth of published research to guide practice and policy in this area (Deacon et al., 1995; Osborne et al., 2002; Satcher, 2013).

2.4.6. Summary

This review of the literature reveals a gap between federal aged care policy and its implementation in practice. This shows a strong need for further research to guide cultural change in residential aged care facilities in line with the new consumer-directed paradigm. In particular, there is scarcity of research on partnered residents' quality of life in RACFs or industry examples of initiatives taken to protect their privacy. In terms of facilitating the sensual, sexual and intimacy needs of partnered residents, areas to be addressed include management policies, facility planning, building design, staff training, sexual health screening and education, and transparency of consumer information prior to entering care.

2.5. The future - Aged care services for Baby Boomers

There is a paucity of research on Baby Boomers' expectations of their old age and several commentators assert that Baby Boomers need to be consulted in order to develop an aged care system that meets their needs (Fallon et al., 2004; Kendig & Duckett, 2001; Simon-Rusinowitz et al., 1998; Quine, Bernard, & Kendig, 2006). The *Living Longer, Living Better* (DoHA, 2012a) aged care reform makes no specific reference to sexual expression or the sexual health needs of older Australians. A search of this document revealed the terms 'relationship', 'couple', 'intimacy', 'privacy', 'sexual health' and 'sexual expression' were entirely absent. Reference was made to the need for staff training, services and equal rights with respect to sexually or culturally 'diverse' minorities, including LGBTI elders however the sexual needs of the heterosexual majority are ignored (DoHA, 2012a). Likewise, the Australian Human Rights Commission's (2012) document, *Respect and Choice*, which is aimed at addressing stereotyping and discrimination of older Australians, also makes no mention of the words 'couple', 'intimacy', 'privacy' and 'sexual expression'. Given the existence of at least one study which indicates Baby Boomers have expressed the desire to have a voice where their sexual expression is concerned (Rowntree 2014), this topic requires further investigation.

There is evidence that aged care facilities need better policies in place to support the healthy sexual expression of all residents (not just minority groups) in a respectful and

consistent manner (Kirkman et al., 2013)[7]. There is also a call for a nation-wide minimum qualification for workers in the aged care sector (KPMG, 2012) that includes staff training in relation to the sexual and intimacy needs of aged care residents (Bouman, Arcelus, & Benbow, 2006). One such initiative, the *LGBTI Aged Care Champion Training*, developed by the AIDS Council of NSW (ACON), aims to create 'champions' in each residential aged care setting who will be the 'go to' people for staff support and organizational change in relation to LGBTI issues (Coumbe & Hannan, 2014). This type of initiative could be extended to include the needs of heterosexual residents, especially couples, however research is first needed to identify the needs of this population.

2.6. Conclusion: Research gaps in the literature

From the literature review into the sexuality of ageing, the sexual history of Baby Boomers, ageism, the current state of residential aged care in Australia, and the aged care needs of Baby Boomers, research gaps were identified, which this study seeks to address. These include:

- the sensual, sexual and intimacy needs of older couples and the degree of importance they place on their romantic/sexual relationships;
- the current sexual behaviours of Baby Boomers (particularly couples), their sexual attitudes and preferences, the importance (or not) of their couple relationship, including sensuality, sexuality, and intimacy, and how they differ from previous generations;
- the gap between federal aged care policy and its implementation in practice.
- aged care management policies, facility planning, building design, staff training, family policies, sexual health screening and education, and transparency of consumer information needed to facilitate the sensual, sexual and intimacy needs of residents, and
- what types of residential aged care services Baby Boomers desire.

The questions guiding this research, which are drawn directly from previously identified research gaps, are:

[7] The Hebrew Home in New York serves as an example (Dessel & Ramirez, 2013).

1. ***Which aspects of their intimate relationships do partnered Baby Boomers value and wish to maintain as they age?*** This question stems from gaps in research literature on the relationship and intimacy needs of Baby Boomers, the unsubstantiated speculation that Baby Boomers will continue to identify as sexual beings in old age (Carpenter et al., 2009; Das et al., 2012) and early indications that Baby Boomers wish to be consulted about their sexual expression in residential aged care settings (Rowntree, 2014).

2. ***What are partnered Baby Boomers' attitudes to residential aged care?*** This question stems from gaps in research literature relating to partnered Baby Boomers' experiences of ageism to date (Lyons, Alba et al., 2017) and their understandings of how couples negotiate the aged care system.

3. ***What are the challenges to maintaining intimate relationships in residential aged care settings?*** This question stems from gaps in research literature on the policy and practices of Australian aged care providers in relation to the intimacy needs and sexual expression of residents (Bouman et al., 2006; Kirkman et al., 2013; Osborne et al., 2002) and staff training policies to meet those needs (Bouman et al., 2006; KPMG, 2012; Osborne et al., 2002; Parker, 2006; Ward et al., 2005).

4. ***What initiatives are necessary to support partnered Baby Boomers' coupledom in residential aged care settings?*** This question directly stems from gaps in research literature on whether Australian facilities currently meet the needs of their clients (Kirkman et al., 2013) and the absence of literature relating to partnered Baby Boomers' expectations of residential aged care (Fallon et al., 2004; Kendig & Duckett, 2001; Quine et al., 2006).

The literature review also highlighted a need for qualitative sociological research to balance out the dominant heteronormative biomedical perspective seen in many positivistic studies on later life sexuality. The next chapter supplies a theoretical framework foregrounding an interpretive-constructivist perspective that draws on grounded theory and phenomenology to bring forth Baby Boomers' perspectives on ageing and aged care to counter the dominance of institutional perspectives.

Chapter 3. Philosophical Framework, Methodology and Methods

3.1. Introduction

In the previous chapter a review of the literature identified the research gaps leading to the current study. This chapter presents the research strategy adopted to investigate (1) what partnered Baby Boomers' value most about their relationships; (2) their attitudes to residential aged care facilities (RACFs); (3) the current challenges to maintaining intimate relationships in RACFs; and (4) initiatives that might support partnered Baby Boomers' coupledom in residential aged care settings. What follows is a description of the philosophical underpinnings of this study, an outline of the mixed methods research design and the methodological perspectives employed, including the benefits and limitations of this approach. Lastly, a detailed description of the data collection and analysis methods is presented.

This dissertation sits predominantly within the discipline of sociology, specifically the sociology of ageing, or social gerontology. However, due to the complexity of the phenomena of ageing, the field of gerontology crosses disciplinary boundaries (Gans, Putney, Bengston, & Silverstein, 2009) and this study is no exception, in that it includes attention to the physical as well as social environment of RACFs. Primarily, however, this thesis presents a sociological analysis of the historical, cultural, social and structural influences experienced by couples in residential aged care settings and compares and contrasts these with the worldviews of partnered Baby Boomers. Furthermore, given that social gerontology has previously been regarded as 'theory poor' (Bengston & Setterson, 2016), this study employs grounded theory methods (described later in this chapter) to develop a conceptual overview of the phenomena. Rather than beginning with a hypothesis or theory, this study was designed with the intention of letting observations engendered by the data generate theoretical/ conceptual insights.

3.2. Philosophical framework

As outlined in Chapter One, the aim of this study was to identify what measures need to be taken to support partnered Baby Boomers to maintain their intimate relationships once in receipt of residential aged care services. In order to understand the anticipated subjective needs of partnered Baby Boomers in residential aged care contexts and the challenges they may face, an interpretivist epistemological stance was adopted. The goal of interpretivist enquiry is to develop an *understanding*, as a necessary prerequisite to explaining social phenomena (Bryman, 2016). This philosophical position was deemed the most appropriate from which to understand the complex array of worldviews where partnered individuals, aged care organisations and their employees intersect.

Consistent with interpretivism, a constructivist ontological position was chosen; one that assumes that for residents, their families and staff, the day-to day reality in residential aged care contexts, as in other settings, is interpreted and constructed through their social interactions. This constructivist view suggests that people are active participants engaged in creating their phenomenal world (Burr, 2007) as a jointly shared co-operative exercise and that the meanings they give to social phenomena are socially constructed and socially shared. By their very nature, because such meanings are produced through social interaction, they are not static, but are constantly revised according to social circumstances (Bryman, 2016). This allows multiple, contradictory, and equally valid accounts of the same event to exist (Gray, 2013). In the context of individual residential aged care facilities, residents, their families and aged care staff may construct intimate relationships differently according to their personal histories. Intimate sexual relationships, when viewed from these different perspectives, are shaped by the socio-cultural meaning they hold for each group, rather than purely from a biological perspective (Burr, 2007).

The constructivist perspective adopted in this study assumes a reciprocal interplay whereby people produce society and are simultaneously produced by it (Berger & Pullberg, 1965). In residential aged care contexts, as throughout life, individuals are presented with socially accepted tasks, roles, and identities that constitute the culture's social structures (Berger, 1973). How residents, staff and family members individually

respond to the social norms expected with each RACF subtly changes the organisational culture over time.

There is an established precedence for adopting the interpretive-constructivist perspective to study Baby Boomers' (Guberman, Lavoie, Blein, & Olazabal, 2012) and couples' experiences of aged care services (Braithwaite, 2002). It has also been applied to the sexual expression of older adults in the context of residential aged care (Palacios-Ceña et al., 2016; Villar, Fabà, Serrat, & Celdrán, 2015), disability services (Bahner, 2016) and health services (Brooks, 2017). As a consequence, the interpretive-constructivist perspective adopted in this study was chosen to illuminate how people construct meaning both within their immediate psychosocial context and within a wider cultural context (Kopala & Suzuki, 1999). Social constructionism assumes that current and future residents and staff in RACFs may view the sexual expression of older adults differently from each other because of their varied historical and cultural backgrounds and relative positions within the institution. Consequently, this research investigated the meaning that intimate relationships held for partnered Baby Boomers, the meaning partnered aged care residents and their relationships held for aged care service providers, and the extent to which those meanings may affect, and be affected, by each other.

3.2.1. Guiding assumptions

The guiding assumptions informing this research are that people construct their own understandings within the social systems they are a part of, that people's perception of the world is both individually and socially constructed, that individuals derive meaning from their experiences, and that a person's actions result from the meanings they have attributed to events (Blumer, 1986; Burr, 2007; Husserl, 1990; Kopala & Suzuki, 1999; Mead, 1934). Such meanings are not fixed but may be adapted or revised according to social circumstances (Berger & Luckman, 1991; Bryman, 2016). With this in mind, this research sought to tease out and explore the socially constituted subject positions of both partnered Baby Boomers' and people working in the aged care sector. As a researcher, a key aspect of this study was allowing people to tell their stories in their own contexts and in their own words, paying attention to participants' choice of language to reveal the meaning behind it.

3.3. Research Design

This thesis adopted an emergent (or cyclical) design where the results of each phase were sequenced to inform each successive phase. The result was a three-phase mixed methods study (depicted in Figure 3.1).

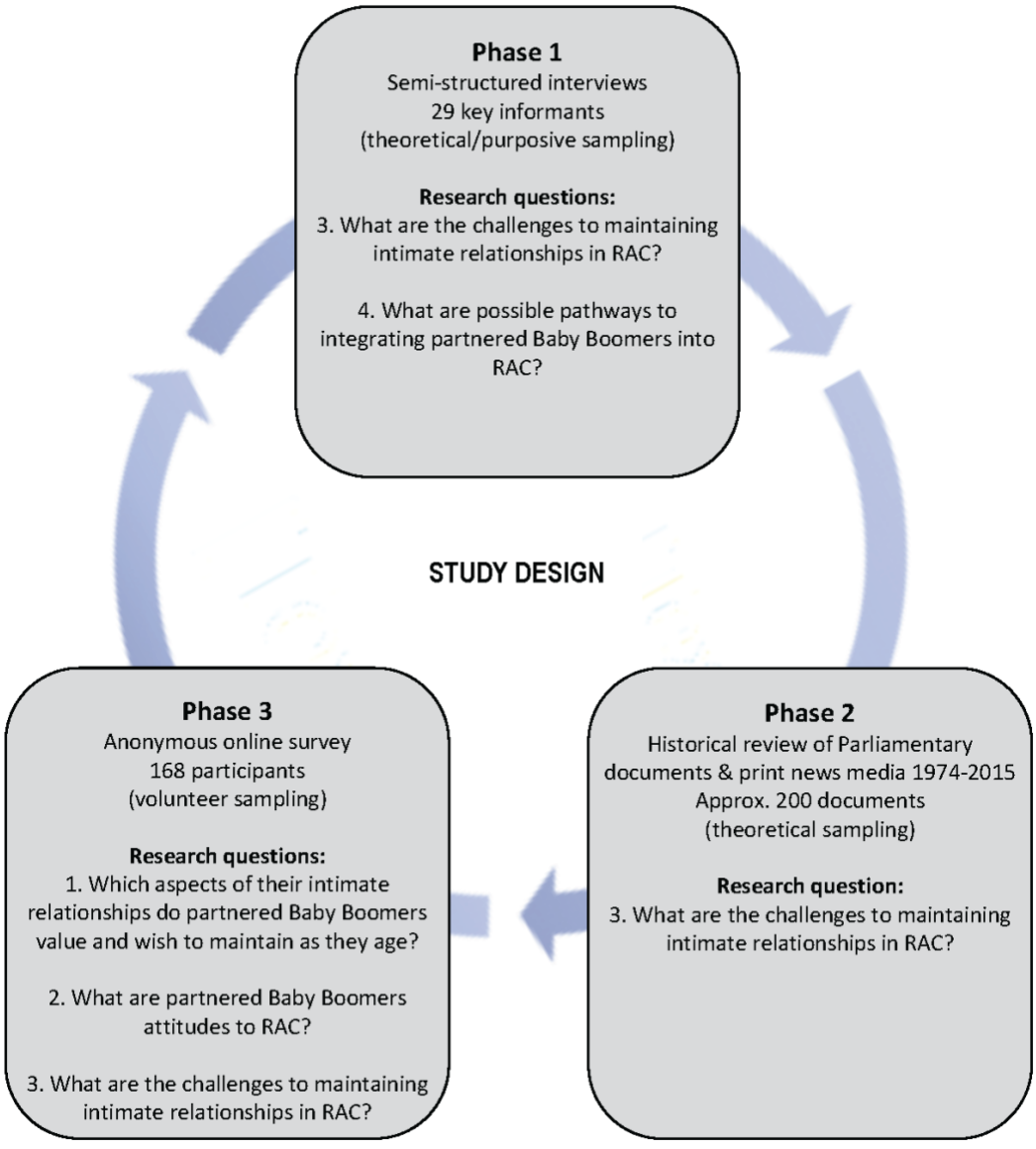

Figure 3.1. Overview of the research design

Phase One consisted of semi-structured interviews with 29 key informants in the aged care sector or allied fields. The interviews were conducted in 2015 and analysed using grounded theory methods. Phase Two, conducted in 2016, involved an inductive

thematic analysis of historical policy decisions and associated political debates recorded in Parliamentary documents and print media in the period 1974 to 2015. Themes and concepts identified in Phases One and Two were then used to inform the design of the online questionnaire in Phase Three, used to survey 168 partnered Australian Baby Boomers in 2016. Various qualitative and quantitative data analysis techniques were used during this phase. A more detailed description of each phase of the study now follows, including methodological considerations and methods of data collections and analysis.

3.3.1. Selection of a mixed methods approach

The challenge in designing this study was that the cohort being investigated (Baby Boomers) was, for the most part, not yet situated in the context being studied (residential aged care) and that, at best, their experiences of residential aged care contexts were as: (1) onlookers to the experiences of friends or family members; or (2) workers in aged care settings or ancillary fields. As future users of aged care services, it was considered important to gather both Baby Boomers' views in addition to the views of those with professional experience in aged care settings to avoid making unrealistic recommendations.

Due to there being four research questions, requiring multiple perspectives, different methods were required to answer each question. In doing so, this allowed results from each phase to be triangulated to check for consistency and strengthen arguments. In an attempt to answer the research questions from both a micro and macro perspective, a mixed methods study was devised. In keeping with an interpretivist/constructivist framework, the dominant data type was qualitative, with supporting quantitative data gathered in the final phase of the study to add weight to findings that emphasised "frequencies of occurrence, dominance of themes, and/or strength of feelings" (Cooksey & McDonald 2011, p. 201). This approach provided depth and breadth and a means of understanding and corroborating results from each phase (Johnson et al., 2007).

The research was designed as an exploratory multivariate study, which comprised three distinct sequential phases (described in Figure 3.1). Each phase warranted its

own methodology, data collection and analysis method, data source and data type, i.e. a mixed methods approach. It combined the following five dimensions recommended by Creswell, Klassen, Plano Clark, and Smith (2011, p. 4):

- focusing on research questions that call for real-life contextual understandings, multi-level perspectives, and cultural influences;
- employing rigorous quantitative research assessing magnitude and frequency of constructs and rigorous qualitative research exploring the meaning and understanding of constructs;
- utilising multiple methods (e.g., intervention trials and in-depth interviews);
- intentionally integrating or combining these methods to draw on the strengths of each; and
- framing the investigation within philosophical and theoretical positions.

A mix of primary and secondary data that could feasibly be gathered and analysed within time and budget constraints was used. The aim was to gather information that provided evidence of a range of perceptions related to: (1) older people's intimate relationships (from their own perspective and from the perspectives of others); and (2) current aged care policies and practices relating to partnered residents, in order to compare and contrast the data sets.

3.3.2. Strengths and weaknesses of using mixed methods

Whereas studies that rely solely on qualitative data, quantitative data or one method of data collection have inherent limitations, varied methods of data collection and analysis and/or a mix of qualitative and quantitative data have the potential to provide stronger results by taking advantage of the strengths of each (Creswell & Garrett, 2008; Creswell & Plano Clark, 2011; Johnson, Onwuegbuzie, & Turner 2007). In the case of this research, because social phenomena are inherently complex and multiple perspectives were sought, different methods were necessary to best draw out these perspectives (Creswell & Garrett, 2008). The intention of this mixed methods study was to provide a better understanding of the research problems than could be achieved by using either a single method (Creswell & Garrett, 2008; Creswell & Plano Clark, 2011).

An inherent risk in a mixed methods approach is that it is a much more complex strategy. Collecting data from disparate sources in differing forms using different methodologies increased complexity at the data analysis stage and there was a risk that the data gathered may not have converged to build a single coherent story and may instead have presented ambiguities or contradictory information (Cooksey & McDonald, 2011). This risk was reduced by conducting the data collection phases sequentially and incorporating learnings from each prior phase into the design of subsequent phases, similar to the concept of theoretical sampling in grounded theory research.

3.3.3. Applying the mixed methods approach

In this study, a mixed methodological approach was used in several ways – by gathering data from mixed sources (key informants, documentary archives, Baby Boomers), in mixed forms (audio recordings, documents, survey data) using different methods (semi-structured interviews, textual analysis and a survey instrument). Likewise, existing methodologies and analysis techniques were selectively applied to each phase to suit the nature of the data.

At the primary level, a combination of qualitative and quantitative data collection and analysis was used, with an emphasis on qualitative research. Quantitative data was used primarily to capture any trends in the data whereas qualitative data provided a more in-depth descriptive source of participants' experiences from which themes and concepts could be extracted. At a secondary level, several existing methodologies were used in this thesis to approach the research questions. The principle theoretical perspectives used were grounded theory and phenomenology, both of which are commonly used qualitative strategies in qualitative research (Denzin & Lincoln, 2011; Polit & Beck, 2010, 2013; Silverman, 2016).

3.4. Ethical considerations

Once a research structure had been determined and prior to commencing data collection at Phases One and Three, ethics approval was sought and granted by the University of New England's Human Research Ethics Committee (Approval Number HE15-171). Due to the sensitive nature of collecting sexuality related data from people

in varying positions of power within their organisations, much thought was given to ethical issues that may arise.

In each phase of the study, participants were notified in advance about the sensitive nature of some of the questions being asked and were asked directly if they consented to participate and to being quoted in research publications. Phase One interviewees returned signed written consent forms whereas Phase Three online survey participants gave implied consent prior to commencing the survey (see Appendix B for more detail). Participants in Phase One were offered the option of either being quoted by name, or being quoted using a pseudonym without any identifying details. The online survey was designed to maintain participants' anonymity in order to encourage them to participate and speak freely.

All participants were offered the option of declining to answer questions they found too sensitive. In the case of interviewees, this was verbally stated prior to commencement of each interview. In the case of the online survey, the survey was designed in a way that allowed participants to proceed without answering every question.

Research materials (such as audio recordings, transcripts and interview notes) used in data collection were stored in a locked cabinet in a locked office for the duration of the study. Electronic data was kept on a password-protected computer in the same location. For participants who did not consent to being quoted by name, their data was stored in a way that protected their anonymity by removing identifying information and disguising real names. Further elaboration of the data collection and analysis phases now follows.

3.5. Phase One: Key informant interviews

Consistent with an interpretive/constructivist approach, semi-structured interviews were selected to gather data for Phase One of the study since the primary focus was to understand human experience (Minichiello, Aroni, & Hays, 2008) as described by key informants. Grounded theory was the methodological perspective used in key

informant interviews. What follows is a justification for choosing this methodology, followed by a more detailed description of how it was applied.

3.5.1. Methodological perspective: Grounded theory

Classic grounded theory was selected for this study. As a data-driven inductive research approach, classic grounded theory is consistent with various philosophical perspectives, including the epistemological position taken in this study that accepts multiple, socially constructed, context-dependent realities (Walsh et al., 2015a). As a process of discovery (Glaser, 2002), it was also considered consistent with the exploratory research design adopted.

Grounded theory (GT) utilises inductive approaches to develop theoretical understanding of poorly understood phenomena (Glaser, 1992) where there is little understanding of the social processes involved (Glaser & Strauss, 1967; Glaser, 1978), as is the case with couples in the context of residential aged care. Walsh et al., (2015b, p. 21) described the GT approach as:

> …looking for patterns of behavior that explain a main concern, and then you name the patterns. Patterns are what people are doing to resolve their main concerns.

By analysing the data through a GT lens, the aim was to undertake this stage of the research free from pre-conceived theories or hypotheses, allowing patterns in the data to identify the participants' main concerns and means of resolving them (Glaser, 1978; 2002; Walsh et al., 2015b). GT was used to discover what was going on in the data and why (Glaser 1978; 2002).

Classic GT methods (Glaser & Strauss, 1967; Glaser, 1978, 1992) were selected as the best approach for this novice grounded theory researcher. A distinction needs to be made between grounded theory methodology and methods. As a methodology, Glaser (2002) described classic GT as a "perspective based" approach that considers multiple participant perspectives. It aims to raise these variable perspectives to an abstract conceptual level, rather than simply describing them (Glaser, 2002).

Classic GT provided clear methods for analysing the key informant interviews. This facilitated the discovery of meaning necessary to produce abstract theoretical understanding of the behaviours and practices in residential aged care settings that influence the experiences of partnered residents. Methods used in Straussian (Strauss & Corbin, 1998) and constructivist GT (Charmaz, 2003; 2006), which both have a more complex system of coding that risks forcing the findings (Holton, 2008), were rejected as too time-consuming to fit the constraints of this study.

In classic GT, one-to-one interviews serve an important function. Glaser (1998) described the researcher as a 'big ear' that listens to participants share their stories in order to understand their main concerns. As such, interviewer flexibility in relation to the main concerns of each participant is essential (Nathaniel, 2008). For this reason, interviews in this study were semi-structured, to allow significant points of interest to be investigated in more depth (i.e. theoretical sampling). Beyond asking questions and clarifying meanings, my role as researcher was to listen passively (Glaser, 2002). Rather than producing a complete theory, GT generates hypotheses that emerge from and are grounded in the data, which can then be verified using other research methods (Annells, 1997b; Glaser, 1992). In this study, grounded theory methods were used to develop a conceptual model (described in Chapter 8).

3.5.1.1. Grounded theory's strengths and limitations

Grounded theory's methodological flexibility and its rigorous application of research processes are its two key strengths (Holton, 2009). It allows the data to generate explanatory models (theory) to explain and understand complex social phenomena (Annells, 1997a). This is useful when investigating poorly researched subject areas (Cutcliffe, 2008; Glaser, 1978; McCann & Clark, 2003), as is the case when considering the future needs of partnered Baby Boomers in residential aged care contexts.

However, an ongoing debate among grounded theorists relates to the objectivity of the researcher. Recent authors argue that it is impossible to divorce the researcher from the research, since it is the researcher who selects, focuses, and interprets the data (Charmaz, 2009; Corbin, 2009). An important thread throughout these debates is

whether or not the researcher is transparent in revealing her/her personal bias (Clarke, 2011).

In an effort to address this methodological weakness and position myself transparently, I acknowledge a professional interest in couples gained from my training and experience as a sexual counsellor. I have an interest in intimate relationships and sexuality which means I do not shy away from discussing intimate topics that others regard as taboo. Associated with this, I have a 'sex positive' attitude, in that I view sexuality as "a *potentially* positive force in one's life" (Queen & Comella 2008, p. 278; original emphasis). This attitude colours my thinking and leads me to have greater expectations of liberal attitudes to sexuality in aged care settings. This may be partially due to being a Baby Boomer myself. Likewise, my prior experience as an architect influences my understanding of how the built environment may support or interfere with social interactions, particularly physical intimacy, in institutional settings. This combined history has influenced my choice of subject matter, research paradigm, research questions, research design and methods of analysis for this thesis. Furthermore, it is unlikely that this thesis in anything like its current form would exist had I come from a different background.

3.5.2. Interview design

The purpose of Phase One was primarily to encourage key informants with expertise in the substantive area of interest (couples or partnered individuals living in residential aged care facilities) to share their perceptions of (a) the Baby Boomer generation; (b) the experiences of couples and partnered individuals in residential aged care; and (c) cultural and structural factors that impact upon partnered residents. The interviews were designed to establish how well couples' needs were met and to provide contextual information about the social, institutional, political and financial influences in residential aged care facilities.

Key informant interviews were designed using a series of questions that explored the topics necessary to answer the research questions, rather than the questions adhering to any specific methodology. This approach was adopted due to the complex multi-disciplinary nature of the phenomena under investigation. A semi-structured interview

format was selected. This allowed participants to elaborate on details they considered important. My role as researcher was to interpret the reality of each informant through a process of listening and clarifying (Minichiello et al., 2008).

Each interview incorporated a mix of closed and open questions[8]. Closed questions sought mostly demographic information about participants early in the interview. Following this more formal initial stage, a series of open-ended questions on specific topics were designed as a guide to encourage participants to provide more detailed descriptions. Open questions allowed interviewees to answer more fully, in their own words (Roulston, 2010), rather than be constrained by the wording of the questions.

In keeping with a constructionist approach, the semi-structured nature of each interview was intended to encourage a relaxed and more conversational style of interview to develop, where the social interaction was as important as the content (Roulston, 2010). The order in which questions were asked was flexible and varied in each interview. Wherever possible, questions were inserted into the interview at times that felt natural in the conversation, rather than breaking each participant's train of thought. These were then followed up with probes to encourage interviewees to elaborate further and provide greater detail (Roulston, 2010). However, because interviewees were experts in their field and often had limited time available, unproductive topics were avoided (Minichiello et al., 2008).

3.5.3. Data collection

3.5.3.1. Recruiting participants

To begin, individuals in preferred target groups were identified based on a range of job descriptions related to professions working directly, or in close association with, residential aged care providers. Potential participants were progressively identified using online searches; gerontology conference programs; face-to-face networking at conferences; the social networking sites, LinkedIn and Facebook; or from personal recommendations and word-of-mouth by interview participants. Further advertising for participants was also attempted using ACSA's (Aged and Community Services

[8] A copy of the interview guide is included in the appendices to this thesis.

Australia) electronic newsletter, however this did not generate volunteers. Invitations to potential key informants were sent either by email or LinkedIn mail, in the format approved by the university's ethics committee. Respondents fell into four camps: (1) those who responded enthusiastically and accepted the invitation; (2) those who accepted but were not available at a mutually convenient time; (3) those who did not respond; and (4) those who declined the invitation. The most difficulty was encountered when trying to recruit public servants and Members of Parliament (both current and former ministers of health and/or aged care).

LinkedIn proved particularly useful as a recruitment medium since it had a search function which allowed me to search for potential participants according to their job title or the name of their organisation. In addition, it provided contact details that were not readily available elsewhere. Once I had developed my own online profile and built up sufficient 'contacts' on LinkedIn, it also served as a form of introduction to others in each contact's network, suggesting to them that I was non-threatening. LinkedIn allowed my targets to see which of my contacts they might know and read about both me and this study before deciding to respond to my contact request. This approach, together with the personal recommendations of interviewees and networking at conferences, proved eminently more fruitful than the other recruitment methods listed. People appeared to feel safer participating if they (1) had already met me; (2) had been recommended by someone they knew; or (3) knew someone who had already been interviewed.

The most notable challenge faced during the recruitment process was attracting people with a broad range of views to intimate relationships in residential aged care contexts. Perhaps due to the sensitive nature of the data being sought, none of the interview participants were uncomfortable discussing sexual subjects and none were opposed to sexual behaviours in nursing homes. In an effort to overcome this sample bias, word-of-mouth referrals to individuals with diverse viewpoints were obtained from participants and, in some cases, participants acted as go-betweens and made contact with such individuals on my behalf. Despite these overtures, attempts to interview people who were sex negative or less comfortable discussing sexual matters were not fruitful.

3.5.3.2. Sample

The 29 key informants recruited included senior public servants, academic researchers, gerontologists, consumer advocates, educators and trainers, aged care consultants, quality assessors, chief executive officers (CEOs), senior and mid-level managers, nurses, care workers, a recreational officer, a sexual health physician, a lawyer, a psychologist and a sex worker who has worked in residential aged care. Participants from New South Wales, Victoria, Queensland and South Australia consented to be interviewed[9]. Of these, the majority were located in regional areas. While a balance of genders was sought, 21 women and eight men agreed to participate. Of these, five self-identified as same-sex attracted. The age range of participants spanned 30 years, from ages 43 to 73 at the time of the interviews. The majority (n=20) identified themselves as Baby Boomers (born 1946 to 1965).

3.5.3.3. Interviews

Interviews commenced in July 2015 and concluded in October 2015, spanning 13 weeks in total. Sixty-nine invitations were sent over the course of the interview phase, resulting in 29 people consenting to be interviewed. Interviews were conducted in a mutually agreed upon time and setting, with participants most commonly situated at their workplaces. In order to meet the time and budgetary constraints of this study, the majority of key informants were interviewed by telephone (and one by Skype video-conferencing). For most participants, telephone interviews were more convenient than Skype. Two interviewees who lived in my geographical area agreed to be interviewed face-to-face. Interviews ranged in length from half an hour to two hours. Interviews were audio recorded and transcribed. In total, 30 hours 48 minutes of interview material was gathered.

Given the sensitive nature of the subject matter, wherever possible I attempted to create a warm, relaxed atmosphere where participants felt safe to speak freely. Adopting a relaxed light-hearted manner and a curious, non-judgemental attitude; listening without interrupting; sharing in spontaneous simultaneous laughter; and

[9] The original intention was to sample data from every state of Australia, in urban and non-urban areas, in order to compare and identify any geographical differences, however, this did not prove possible within the time constraints.

regularly acknowledging that I had understood what had just been said appeared to help create empathic engagement with each person (Bentz & Shapiro, 1998).

One approach used during the interviews was a learned counselling technique. To encourage participants to expand on their answers or to help clarify meanings I would repeat back to interviewees a paraphrased version of what I'd understood, usually prefaced with variants of "what I heard you say is…", "what you're saying is…" or "what you think is…". This gave each interviewee an opportunity to either validate or correct my understanding wherever they felt it was flawed. Alternatively, if I felt I hadn't fully understood, I would ask "when you said…, what did you mean?", "tell me more about…" or "why did you use the term…?" Often that would then prompt them to expand further.

An example of this approach has been extracted from an interview with 'Phyllis', whose parents had both died in residential aged care, as follows:

> I[10]: When you think of the current generation that's in aged care, what do you think their three key needs might be?
>
> S: Entertainment intellectually, as most of them feel their marbles are falling off the page; a peace, a sort of a space where they can just be alone in quietness; and the third one I'd say is a mediator who will actually listen to them and treat them with respect and validity.
>
> I: Ok and why do you use the term mediator?
>
> S: Because the staff are biased to the staff's ideals of running a place and they will not often take the residents', I call them 'inmates', the residents' problems seriously with the idea of formulating a good result for the resident.
>
> I: Right, ok.
>
> S. Swept under the carpet is the attitude.
>
> I: So, you think there needs to be some kind of resident liaison officer?
>
> S: Yeah that'd be a good way to put it.

[10] 'I' stands for 'interviewee', 'S' stands for 'subject'

> I: Ok sounds like a good idea.
>
> S: And that liaison officer must be primarily on the side of the resident not the institution. That's why I said a mediator, someone different and outside the concern.

Similarly, in classic grounded theory, one-to-one interviews serve the important function of allowing participants to tell their story (Nathaniel, 2008). Glaser (1998) described the researcher as a 'big ear' that listens as participants share their stories in order to understand their main concerns. As an interviewer, being flexible in relation to the main concerns of each participant was essential (Nathaniel, 2008). During most interviews, it quickly became apparent that adhering strictly to a pre-prepared script would have been inappropriate. Semi-structured interviews, as approved by the University's Human Research Ethics Committee, proved useful in this regard, allowing me to vary the phrasing and order of questions to suit each participant[11]. In fact, in many cases, participants answered my questions without me having to ask them. As interviews progressed and theoretical saturation was reached for each question, these questions were subsequently omitted from the interviews.

3.5.4. Data Analysis

Grounded theory methods were used to analyse interview data. The processes employed during data analysis were circular and reiterative, concurrent and interdependent, and did not follow a strict order, as espoused by Glaser and Strauss (1967) and Glaser (1978, 1992, 1998). To allow theoretical understandings to emerge directly from the data (Glaser & Strauss, 1967), the classic grounded theory techniques used during data analysis were theoretical sampling; constant comparative analysis; open, selective and theoretical coding; 'memoing'; developing a core category and theoretical saturation (Glaser, 1978; 1998). What follows are descriptions of these techniques.

3.5.4.1. Theoretical sampling

Initially, key informants were selected purposively based on their expertise in aged care in general or resident couples' experiences in particular, after which, theoretical

[11] See Appendix A for a copy of the interview guide approved by the Human Research Ethics Committee.

sampling was used. In grounded theory research, theoretical sampling requires that data collection, coding, and analysis be conducted concurrently. It was used to further compare and develop concepts that emerged from analyses of the interview data. Identification of useful new sources was guided by the emerging concepts, which then provided direction for further investigation and so on. This was required in order to continue to develop the theoretical concepts as they emerged (Bryman, 2016; Glaser, 1978; 1998). The application of theoretical sampling during the interview phase resulted in an increasingly focused selection of participants, with targeted expertise in areas such as aged care policy, dementia, law, sexual behaviours and psychological needs, among others.

3.5.4.2. Constant comparative analysis

Constant comparative analysis (Glaser & Strauss, 1967) was used in conjunction with theoretical sampling. On an ongoing basis, this involved promptly breaking down the data from each interview into discrete 'incidents' or 'units', coding them into categories and comparing them to the codes and categories already recorded (Glaser & Strauss, 1967; Lincoln & Guba, 1985). Initially during the interview phase this initial coding was done manually in the margins of interview transcripts. Later, it was more manageable to manually develop more selective coding using NVivo software.

Issues identified during constant comparison were further sampled for by selecting interviewees with the requisite expertise or experience. This simultaneous sampling, coding and comparing enabled me to see patterns and concepts in the data, which facilitated the development of an explanatory model that began to emerge from the data (Taylor & Bogdan, 1984). In total, four interdependent stages of constant comparison occurred, best described as: (1) open coding; (2) selective coding; (3) theoretical coding; and (4) developing a model (Glaser and Strauss, 1967).

Throughout this recursive process, ideas about categories were noted, including their properties and the links between them, in an effort to identify the core category, the central category that connected the pieces of the puzzle (Glaser, 1978; 1998). My own reflexive views were recorded[12] since the data used in the grounded theory process

[12] An example of this memo writing is provided in section 3.5.4.8.

also includes memos reflecting the researcher's thoughts, questions and ideas about the data (Glaser 2002). According to Glaser (2001, p. 145), this approach is consistent with grounded theory research since

> All is data…exactly what is going on in the research scene is the data, whatever the source, whether interview, observations, documents, in whatever combination. It is not only what is being told, how it is being told and the conditions of its being told, but also all the data surrounding what is being told.

3.5.4.3. Open coding

Initially, each incident in the data was coded into as many categories as possible while categories continued to emerge, or as data emerged that fitted a category. To avoid being simply descriptive, concepts were also developed. Each code kept track of the social group relating to each incident. Each new piece of data was compared to the other incidents in the category for that group (Glaser & Strauss, 1967). At this early stage, the aim was to fracture the data to maximise comparison of categories and their properties (Holton, 2007). Constant comparison of incidents generated theoretical properties for each category (Glaser & Strauss, 1967). During open coding, the data was interrogated by asking: (1) "what is this a study of?"; (2) "what category does this incident indicate?"; and (3) "what theoretical codes may apply to integrate the emerging theory?", as recommended by Glaser (2016, p. 109).

3.5.4.4. Selective coding

After coding had progressed substantially, the focus shifted from comparing incident with incident, to comparing each incident with the properties of the category it belonged to (Glaser & Strauss, 1967). This process clarified the properties of each category (Glaser, 2005). Working in this way, I was able to compare existing categories and gain a clearer understanding of their properties and interrelationships. By this stage, diverse categories started to become integrated and a model began to develop (Glaser & Strauss, 1967).

3.5.4.5. Theoretical coding

To prevent constant comparison from becoming an overwhelming task, delimiting features emerged. This occurred at two levels: theory modifications became less

frequent as the model solidified, and later modifications focused on clarifying the logic, removing irrelevant properties and integrating and reducing categories (Glaser & Strauss, 1967). I was then able to reduce the model to a greater level of conceptual abstraction (Glaser, 1978; Holton, 2007). This process resulted from *theoretical saturation* and helped identify the *core category*, which was 'communication'.

3.5.4.6. Developing the model

By this stage I had accumulated coded data, a series of memos, and theoretical concepts (Glaser & Strauss, 1967). Once confident that the theoretical concepts accurately represented the subject matter, I was able to develop a model. This is a conceptually complex stage requiring the synthesis of the research knowledge into a theoretical rendering that does justice to the data (Glaser, 1998; 2002).

3.5.4.7. Theoretical saturation

Constant comparison and theoretical sampling continue until *theoretical saturation* was reached, i.e. when (1) no further coding of data was necessary to develop the properties of the concepts or categories; or (2) further collection of data no longer illuminated the concepts (Glaser & Strauss, 1967).

3.5.4.8. Memo writing

While coding, memos were written to spontaneously record questions, illustrate ideas, develop hypotheses and identify connections and differences in the categories (Glaser, 1998) as an aid to conceptual analysis during the process of constant comparison. In the active search for data, recording a memo is one way of asking the next theoretically relevant question to guide further theoretical sampling (Glaser & Strauss, 1967). Memo writing also offered an opportunity for reflexivity, allowing me to record awareness of my preconceptions, observations, moments of insight etc., making it available for later scrutiny during constant comparative analysis (Glaser, 2003). This was necessary in order to develop a theoretical understanding of the data (Glaser & Strauss, 1967). An example of one such memo follows:

> Staff are in conflict with residents' needs. In residents' rooms, there is a conflict of uses - between staff duties and residents' privacy needs. Staff are in a rush and focus on performing

> work tasks to a timetable that suits them whereas partnered residents may need extended uninterrupted time alone together.
>
> Staff members behave as if they assume residents are asexual beings, without considering resident couples' privacy needs. It doesn't occur to them. Actions such as entering without knocking indicate a lack of respect or consideration for older couples. Sexual relationships are disapproved of and discouraged, especially where they involve single residents.
>
> The belief that older people are asexual guides the actions of staff and is built into their work practices and rosters. It has become a structural component of the institution to the extent that any signs of sexual interest may be actively discouraged.

Since grounded theory research is an iterative process, one technique I used during the data analysis stage was to ask myself "what is it I'm hearing here?" which I would call 'active listening'. I identified that I was being told things implicitly as well as explicitly – so I was also listening for what was not being said but which was nevertheless clearly present. Eventually the 'aha' moment came when I realised that every single interviewee was saying, in one form or another, "people are avoiding this conversation [about sex]". I then went back over previous interviews and realised many participants had actually said that explicitly, adding phrases such as "it's the elephant in the room" or "the canary in the coalmine", which confirmed it wasn't simply my interpretation.

3.5.4.9. Using QSR NVivo 11 software

Given the volume of data I was working with, rather than coding the entire data set manually by making written notations in margins, I employed NVivo 11 software to help organise and manage the data and coding, which made transcripts, codes and memos more easily accessible. Tools such as NVivo make manual handling of data less complex and tedious and facilitate the portability of data (Andrew & Peter, 2007; Dohan & Sanchez-Jankowski, 1998; Jones, 2007; Welsh, 2002).

NVivo is designed to facilitate the iterative, grounded theory processes of data collection, coding, constant comparative analysis, memo writing and model building (Bringer, Johnston, & Brackenridge, 2006). To begin the process, my interview transcripts were imported into the program. I used the software program as a highly

developed filing system which allowed me to store original data and arrange coded material and memos hierarchically, which then made it easy to retrieve data and perform constant comparative analysis.

When using NVivo to code each data set, I began by coding data line-by-line. This was still a manual process (the software did not perform this task automatically). As I became more familiar with the subject matter, theoretical sampling determined which data needed to be coded. The researcher must still "ask the questions, interpret the data, decide what to code, and use the computer program to maximize efficiency in these processes" (Bringer et al., 2006). Once patterns began to emerge, the software allowed me to group codes together to form categories, create links between codes, or further refine the coding into additional sub-codes as desired. Weaver and Atkinson (1994 cited in Bringer et al., 2006) stated that an advantage of using a program such as NVivo is that it offers a range of tools that provide multiple ways in which to view the data, making relationships between categories more visible. Once sufficient material had been coded, it was then possible to use situational analysis as a tool to visually arrange concepts to help identify patterns, assist with sorting codes into categories and see relationships between categories.

3.5.4.10. Situational analysis

Situational analysis facilitates relational mapping of data (Clarke, 2011). Its main purpose is to 'open up' the data for interrogation in fresh ways, "provoking the researcher to analyse more deeply" (Clarke 2011, p. 84). Memo writing is a grounded theory tool that was useful to use simultaneously with situational analysis so that fresh insights were not lost.

Situational analysis appealed to the former architect in me, providing a visual tool to represent a 'big picture' view of the competing demands in each situation of interest. My architectural training taught me to create relational maps of spatial, emotional, practical and bureaucratic needs as a pre-requisite to designing spaces and this type of mapping was very similar. In this study, I used self-adhesive notes arranged on a board to create situational maps that plotted elements in the situation and relations between them (Clarke, 2011).

This process was useful to identify things I suspected were present although they were not articulated in the data, what Clarke (2011, p. 87) calls "sites of silence". With each situation of interest (for instance, in residential aged care settings or couples at home) I began with a messy working version of an abstract situational map, which gradually became more ordered. In this, all human and non-human elements of concern were laid out. Non-human elements included beds, rooms or buildings, for instance. Consistent with Mead's symbolic interactionist thinking, the questions I asked when mapping these elements were: (1) who/what is in the situation; (2) who/what matters in the situation; and (3) which elements make a difference (Clarke, 2011).

3.6. Phase Two: Historical document analysis

A recurrent message I was hearing during the Phase One interviews was that older couples' relationships were inadequately protected in residential aged care, including at a legal and public policy level. Some themes that emerged in Phase One that related to historical and structural influences on residential aged care were not adequately explained by the data. This raised two questions: (1) what measures have been taken to protect couples in residential aged care? and (2) how have we arrived at the current situation? These questions prompted Phase Two, a thematic analysis of historical policy decisions and associated political debates recorded in Parliamentary documents and print media in the period 1974 to 2015. In a continuation of theoretical sampling, the purpose of this phase of the study was to further explore the third research question: what are the challenges to maintaining intimate relationships in residential aged care settings?

A search was conducted of parliamentary documents and Australian newspapers in the period 1955 to 2015 (following enactment of the *Aged Persons' Homes Act 1954* (Cth)), identifying any proposed legislation that potentially affected the lives of partnered aged care residents. Search terms included 'aged care', 'nursing homes', 'married', 'couples', 'privacy', 'sex', 'sexual', 'sexual needs', and 'sexual expression'. Given that no documents were found between 1955 and 1974, the search was revised to the period from 1974 to 2015.

Government documents were sourced from Australian Government websites and library databases. Australian newspaper stories were sourced from NewsBank, the *Sydney Morning Herald* Archives, Trove, and Google searches, using the names of proposed legislation as search terms. An inductive thematic analysis (Braun, & Clarke, 2006) of over 200 documents was then undertaken. Data sources included 40 Hansard records, 11 parliamentary bills and bills digests, 21 enacted laws and regulations, reports and submissions from six senate committees and two royal commissions, 11 government and consultant reports, eight government digests and yearbooks, and over 90 newspaper articles and press releases. Concepts and categories identified in this phase were then used to inform the next phase of data collection.

3.6.1. Data analysis

Data analysis was conducted using Braun and Clarke's (2006) six step thematic analysis method, which involves: (1) becoming familiar with the data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) reporting the themes. A description of the process will now follow.

3.6.1.1. Becoming familiar with the data

This initial stage required immersion in the data by reading and re-reading documents in an active way. Firstly, the entire dataset was read to become familiar with the content. During subsequent readings, initial ideas were noted down while searching for meanings and patterns in the data.

3.6.1.2. Generating initial codes

From those initial ideas and subsequent re-readings, codes were generated manually in a systematic fashion across the entire data set. Each code represented a basic unit of meaning that encapsulated an interesting feature of the data. Data relevant to each code was then collated. The coding attempted to answer specific questions and focused only on segments of the data relevant to that line of inquiry. Besides the research question "what are the challenges to maintaining intimate relationships in residential aged care?", two related questions being asked were: (1) what measures

have been taken to protect couples in residential aged care?; and (2) how have we arrived at the current situation?

3.6.1.3. Searching for themes

Once all the relevant data had been coded and collated, the focus of analysis shifted to establishing broader themes. This involved analysing the codes to identify how they combined to form themes. To assist with this process, thematic maps were generated using bubble diagrams. This helped to clarify the relationships between codes. From there, diagrams were drawn and re-drawn to develop a hierarchy of themes and sub-themes that accurately reflected the data.

3.6.1.4. Reviewing themes

Themes were further refined by reading collated extracts for each theme to assess whether data within themes cohered together in a meaningful way. During this stage, some themes did not adequately match the data and had to be modified. Once the themes adequately reflected the data within individual documents, this process was repeated across the data set. This involved re-reading the relevant passages in every document to verify the congruence of themes with the data.

3.6.1.5. Defining and naming themes

Further refinement involved generating clear definitions and names for each theme to distil their 'essence'. Not only did the 'story' of each theme need to be identified, these stories needed to fit the overall story told by the data in relation to the research question.

3.6.1.6. Reporting the themes

A report that told the story contained in the data was generated[13]. Each theme was illustrated using vivid, compelling extract examples embedded in an analytic narrative that made an argument in relation to the research question (the cultural and political challenges faced by aged care residents in intimate relationships) and the literature.

[13] This was published as a peer-reviewed journal article in *Elder Law Review*, as listed in the initial pages of this thesis.

3.7. Phase Three: Online survey questionnaire

The purpose of this phase was to establish the views of the next generational cohort that would require aged care services. It took the form of a self-administered, anonymous online survey questionnaire administered to Baby Boomers (born 1946 to 1965) in established intimate relationships who were resident in Australia.

There is some evidence that not everyone has difficulty discussing topics related to older adults' intimacy and sexuality (Cook, Schouten, Henrickson, & McDonald, 2017). However, since some of the data sought could be considered sensitive by some, an anonymous online questionnaire was considered the safest and most comfortable forum for participants to provide information that they might perceive could potentially be used to discredit them (Renzetti & Lee, 1993). Consistent with the interpretivist paradigm of understanding people in context (Kopala & Suzuki, 1999), one of the advantages of online surveys is that participants can complete them in safe, familiar surroundings of their choice. Participants were in control of both the location and the timing of their participation (Neville, Adams & Cook, 2016). Electronic means of data collection are less confrontational than face-to-face or telephone-based methods, which may in fact disadvantage participants (Cook, 2012). Instead, anonymous participation facilitates free disclosure without fear of retribution and may lead to less self-censorship and more honest answers (Cook, 2012; Liamputtong, 2013).

Online data collection methods have other advantages. Firstly, they overcome the barriers associated with sampling hidden and geographically remote (and therefore under-represented) populations. Being under-represented may provide added motivation for vulnerable populations to share their experiences in order to improve the lives of others (Alexander, 2010; Beck, 2005). In terms of this study, Australian Aboriginals and Torres Strait Islanders, LGBTI populations and care workers might be considered vulnerable populations. Secondly, online data collection can be cost and time efficient (Beck, 2005). Text-based data is generated instantly, which overcomes the need for time-consuming transcription of audio data associated with traditional interview techniques (Neville et al., 2016). However, one disadvantage of electronic data collection methods is the absence of non-verbal cues (Cook, 2012).

Two successful precedents for using online surveys to gather data of a sexual nature were the *Sexual Well Being Global Survey* (Wylie, 2009) and the *Survey of Midlife and Older Adults* (Fisher, 2010), which both asked extremely intimate questions. Given my clinical experience, I was of the opinion that an online survey was preferable to face-to-face interviews because it afforded respondents anonymity and choice to determine the amount of privacy and time they needed to consider their responses. This was considered important, since talking about one's sexuality is still largely a taboo subject in many segments of Australian culture (as borne out by the Phase One interview data).

Fortunately, many Baby Boomers are computer literate (Morrell, 2002) and I speculated that those already retired may have time to spend on completing a questionnaire. An online survey offered (1) the opportunity to collect data from larger numbers of people; and (2) an anonymous environment designed to encourage participants to speak more freely than they might in face-to-face interviews. Additionally, garnering basic demographic statistics provided greater meaning to the themes that arose from the qualitative data, making the current study more useful to stakeholders such as policymakers and aged care providers.

Online surveys can be a very effective and efficient means of gathering data (Brock Barry, Lawrence, Dey, & Rolffs, 2012; Evans & Mathur, 2005; Hill, Dean, & Murphy, 2014) but have also been criticised for producing biased results due to self-selection. One such bias results from the population of internet users not being representative of the overall population (i.e., skewed towards young, educated men) (Evans & Mathur, 2005; Silver, 2001). However, in older age groups there appears to be a gender balance (Gatto & Tak, 2008) and, interestingly, Gatto and Tak (2008) report that older internet users tend to be married or in de facto relationships, which was useful for this study. Furthermore, the nature of any opt-in survey, where people volunteer to participate, has the potential to produce a skewed sample. However, restricting the sample to willing respondents may be an advantage, as Hycner (1985, p. 294) argued:

> …the phenomenon dictates the method (not vice-versa) including even the selection and type of participants. In fact, part of the "control" and rigor emerges from the type of participants chosen and their ability to fully describe the experience being researched.

While a willingness to complete the survey was obviously a pre-requisite, care was taken (1) in the way the advertising material was worded; and (2) to recruit as many participants as possible in an attempt to obtain a wide range of views.

3.7.1. Methodological perspective: Phenomenology

In this study, phenomenological inquiry was employed in the framing of the survey questions. This was done in an attempt to encourage participants to describe their lived experience in specific circumstances (Pollio, Henley, & Thompson 1997) from their own subjective point of view (van Manen, 1997). In the case of this research, the survey was seeking to elicit participants' experiences of witnessing couples in residential aged care facilities. This methodology was employed to assist understanding of participants' attitudes and behaviours from their perspective (Bogdan & Taylor, 1975) taking into account the context in which events happened.

The philosophy of phenomenology holds that "any attempt to understand social reality has to be grounded in people's experiences of that social reality" (Gray 2013, p. 24). The primary concern is how individuals make sense of their world, what meaning they attach to their own acts and the actions of others, and how they subsequently behave as a consequence of those meanings (Bryman, 2016). The interpretive aspect of phenomenology seeks to tap into the unique nature of each human experience and invite us into the experience of another (van Manen, 1997). Phenomenological concepts include engaging empathically with another person and blending cognitive and non-cognitive ways of knowing (van Manen, 1997).

Heidegger's (1996) hermeneutic phenomenology was particularly relevant to this study, with the central theme being that, in order to understand a phenomenon; the researcher must also attend to the relationship between people in context (Barnacle 2001). His word for human being, *Da-sein* (Heidegger, 1996), translates as "to be there" or "being there", indicating that human beings are always situated within a context (Evens, 2005). This relates to the study this thesis reports on, in that it considers the context of residential aged care in order to understand the various study participants' perspectives. This approach facilitates multiple viewing points of

couples in aged care settings through the eyes of professionals, service providers, individuals and their families, according to where they are situated.

3.7.1.1. Phenomenology's strengths and limitations

The strength of this approach is that it provides rich data to facilitate a deeper understanding of individuals' lived experiences and the meanings they attribute to them. Much like grounded theory research, the aim is to allow findings to emerge from the data rather than them being imposed on the data by the investigator. Phenomenological inquiry was useful to understand how individuals experienced phenomena such as ageing, sexual desire, intimacy, loss and so forth (Johnson & Christensen, 2014) and helped me to move beyond surface appearances and enter the subjective world of the participant (Sharkey, 2001). While this approach assisted in creating an insider understanding, it did not, however, offer broader in-depth understanding of the multiplicity of personal, cultural and societal influences at work in aged care settings or the level of theoretical understanding warranted by this study. For this, a grounded theory approach was needed.

3.7.2. Survey design

An anonymous online questionnaire consisting of 36 questions, both quantitative and qualitative, was designed using a web-based survey tool (Qualtrics[14]). Care was taken to design the survey questions to be as inclusive of diverse populations as possible, including those with non-binary gender identities, diverse sexual orientations and relationship structures. In other words, participants were not assumed to be distinctly male or female, heterosexual, monogamous, or in dyadic or cohabiting relationships. Participants were the ones who defined whether or not they considered they were 'in a relationship' (or several). It was hoped that by approaching the survey this way, a rich diversity of data might be obtained to further extend the evidence base beyond the hetero-normative.

Qualitative questions were framed from a phenomenological perspective. The online survey was subsequently pilot tested on a small sample to test the clarity and

[14] See https://www.qualtrics.com.

intelligibility of questions and ascertain the time needed to complete the survey. The design of the questionnaire included basic demographic data in addition to neutrally worded multiple-choice and open-ended questions designed to elicit both quantitative and descriptive answers. Informed by Phases One and Two, the questionnaire covered seven topic areas: (1) participants' attitudes to their current relationships; (2) valued aspects of their relationships; (3) attitudes to physical intimacy and sexual pleasure; (4) experiences of RACFs to date; (5) anticipated relationship and privacy needs in care settings; (6) services they anticipate requiring in order to maintain their relationships in residential aged care; and (7) steps taken to communicate their future wishes to substitute decision makers. (A copy of the questionnaire in included in Appendix B).

3.7.3. Recruiting participants

Respondents were recruited using two methods of volunteer sampling: (1) Facebook advertising designed to specifically target the Baby Boomer demographic Australia-wide; and (2) advertising in electronic industry newsletters, websites and Facebook pages. Industry organisations that agreed to advertise the survey included the Australian Association of Gerontology, the South Australian and Western Australian branches of COTA (Council of the Aged) (who act as consumer advocates) and Queensland AIDS Council (an organisation that was conducting sexual diversity training for aged care employees). The online questionnaire was located on a secure, independent website (using a Qualtrics platform, where participant anonymity was protected). To participate, respondents used a hyperlink provided in the advertisement to connect to the Qualtrics website, where they gave implied consent before commencing the survey.

People aged 50 years or more are among the fastest growing group of internet users (Morrell, 2002). In Australia in particular, it is estimated that approximately 50% of Baby Boomers are Facebook users (refer to Appendix D). Facebook was selected as a recruitment medium because it provided the capacity to isolate advertising to the targeted demographic (Baby Boomers), in addition to being a low cost and time efficient means of reaching large numbers of Baby Boomers. Although the *Sexual Well Being Global Survey* (Wylie, 2009) did not specifically use Facebook, it

demonstrated that internet marketing was an efficient way of recruiting respondents in a manageable timeframe.

Participants were recruited over a two-month period in 2016. Initially, the aim was to use Facebook advertising exclusively to obtain a proportional sample of 250 respondents representative of the geographical spread of Baby Boomers in Australia. Prior to advertising, I calculated a proportional spread representative of Australian Baby Boomers by gender and postcode. Individual but identical Facebook ads were then initiated for each gender in each state in Australia with the idea being that, once each target was achieved, advertising to that segment of the population would cease. Theoretically, by using Facebook as an advertising medium, there was some ability to recruit a geographically representative sample, however this proved difficult to achieve in practice within time and budgetary constraints.

After several weeks of Facebook advertising, it became evident that the desired spread by gender and geographical location was not being achieved. To reduce gender imbalance, continuing Facebook advertising targeted men only. In an effort to balance the geographical spread, the Australian Association of Gerontology and the Victorian, South Australian and Western Australian branches of COTA were contacted, of which all but the Victorian branch agreed to promote the survey within the study timeframe. Simultaneously, in order to boost non-heterosexual participation in the survey to a more representative level, the Queensland AIDS Council was contacted and also agreed to promote the survey to their network.

3.7.4. The sample

Of the 367 surveys received, 199 were excluded (46 did not meet inclusion criteria and 153 supplied demographic data only), leaving 168 valid responses. The majority of participants were born in Australia (n=125, 74%), lived in non-metropolitan areas (n=113, 67%) and earned less than $60,000 per annum (n=102, 61%). A proportional sample of Australian Aboriginals/Torres Straight Islanders was obtained (n=7, 4%). These results indicated that the online survey had been successful at reaching non-metropolitan populations. However, despite efforts to obtain a sexually diverse sample, the majority of participants were married (n=125, 74%,) heterosexual (n=158,

94%) women (n=142, 85%). Sexually diverse participants, including those who identified as asexual, lesbian, gay, bisexual, polyamorous and/or in non-traditional relationship structures, represented approximately 10% of the sample. While the views of this subset of participants are included in this dissertation, it was not possible to draw specific conclusions due to the small sample size. Additional participant demographics are detailed in the results chapters.

Upon completion of the survey, data was downloaded from the Qualtrics website in the form of an Excel spreadsheet. Quantitative data analysis was limited to basic descriptive statistics sufficient to identify "frequencies of occurrence, dominance of themes, and/or strength of feelings" (Cooksey & McDonald 2011, p. 201) to support the qualitative data. Multiple methods were used to analyse the qualitative data. These were employed for the purpose of strengthening the "rigor and trustworthiness of the findings" (Leech & Onwuegbuzie, 2007, p. 575). Qualitative results were triangulated using four analysis tools: (1) word count; (2) keyword-in-context; (3) thematic analysis; and (4) automated content analysis performed by Leximancer software. These methods are described in more detail below.

3.7.5. Word count

Initially, qualitative survey data was analysed for word frequency to identify "distinctive vocabulary and word usage patterns" (Leech & Onwuegbuzie 2007, p. 568). This method was used in the first instance to identify patterns more easily, and to maintain analytic rigour (Leech & Onwuegbuzie, 2007). It also proved useful to enhancing understanding and reducing researcher bias by reducing the likelihood of some themes in the data being preferenced over others (Sandelowski, 2001). However, given that word frequency is not necessary to convey important concepts (Leech & Onwuegbuzie, 2007), other methods of qualitative analysis were also used, as described in the following sections. Frequently occurring terms (and their variants) were identified from multiple readings of the data. Then, using the search function in Excel, such terms were easily located and counted. To avoid decontextualising these words, they were then analysed as keywords in context.

3.7.6. Keywords in context

Keywords in context is a helpful analysis tool to utilize where the data provide less detailed information, such as in brief answers to a survey question. It can assist in the identification of underlying connections implied in participants' speech (Leech & Onwuegbuzie, 2007). Having isolated frequently used terms in the previous stage of analysis, these were then analysed in the context of narratives. Words used before and after keywords provided contextual understanding (Fielding & Lee, 1998), which helped in the development of concepts and themes.

3.7.7. Thematic analysis using QSR NVivo software

To develop themes further, qualitative survey data was separated from quantitative data. Descriptive data was then inputted into NVivo software and further analysed using Braun and Clarke's (2006) thematic analysis method, as already described.

3.7.8. Leximancer content analysis

Since unconscious researcher bias is a risk when undertaking qualitative analysis (Mays & Pope, 1995), Leximancer software was used as a back-up tool to check for this. One of the benefits of Leximancer analysis is that it can extract meaning from disparate sources of text and efficiently process large documents in a short time (Gurd, 2012). Leximancer prevents the researcher from pre-empting or manufacturing discourse, fixating on erroneous anecdotal evidence or generalising themes in one sentence to an entire data set (Jones, 2012).

Unlike NVivo, Leximancer is a scientifically validated computer program that performs automated analysis of textual data based on pre-determined statistical properties (Smith & Humphreys, 2006). Computer algorithms produce results using a Bayesian approach to prediction (Chen & Bouvain, 2009; Davies, Green, Rosemann, Indulska, & Gallo, 2006; Leximancer, 2018; Martin & Rice, 2007; Smith & Humphreys, 2006). Leximancer goes well beyond searching for keywords by examining each document for important lexical terms based on word frequency and co-occurrence to identify and extract a thesaurus of concepts (Martin & Rice, 2007; Smith & Humphreys, 2006). Concepts expressed in the data are presented visually in

the form of a bubble diagram, or 'conceptual map' (Leximancer, 2018) that depicts the main concepts expressed in the text. The colours, sizes and proximity of bubbles indicate the relative importance of each concept, its frequency, and relationships between concepts (Gurd, 2012).

Leximancer analysis was performed as described by the Leximancer Manual (2018) and Jones (2012). I began by firstly importing separate text files (survey transcripts with questions and quantitative data removed) into the software. The default Leximancer settings were then used to generate 'concept seeds'. Some editing of these was necessary to merge plural and singular versions of the same word or unmerge similar words with different meanings. Having made these adjustments, I used automatic Leximancer settings to generate concepts and conceptual maps from the data. This process was consistently repeated for each survey question in the data set. In some cases, it also proved useful to separate the dataset into two participant groups to identify differences between them (for instance, in the case of partners who preferred to sleep together and those who did not).

3.8. Summary

In summary, this chapter outlined the interpretive/constructivist philosophical framework and its relevance to this study and the field of social gerontology in which it sits. The guiding assumption was that people's individually and socially constructed perceptions of the world guide their behaviour. Also presented was my personal 'sex positive' bias as a sex therapist. What followed was a description of the emergent mixed methods study design, including the phenomenological and grounded theory tools adopted and the data collection and analysis methods used in each phase. Justification of these choices was presented, along with the strengths and weaknesses of the approaches used. In the next four chapters I will present the research findings, beginning with findings in relation to the research question "which aspects of their intimate relationships do partnered Baby Boomers value and wish to maintain as they age?" in the next chapter.

Chapter 4. Valued Aspects of Baby Boomers' Intimate Relationships

4.1. Introduction

The preceding preliminary chapters revealed a significant lack of research from the perspective of prospective aged care residents *prior* to entering residential aged care. A particularly poorly researched area related to partnered individuals, both prior to and after admission into residential aged care facilities (RACFs). Chapter Three then described the mixed methods research design adopted to investigate (1) what partnered Baby Boomers value most about their relationships; (2) their attitudes to residential aged care; (3) the current challenges to maintaining intimate relationships in residential aged care; and (4) possible pathways to integrating partnered Baby Boomers into residential aged care.

This chapter is the first of four that reports on the study findings. Both this chapter and the next are important in terms of addressing the lack of research from the perspective of potential aged care residents prior to entering care. This chapter presents findings in response to the research question "which aspects of their intimate relationships do partnered Baby Boomers value and wish to maintain as they age?" Data for this chapter were gathered from an anonymous online questionnaire administered to partnered Baby Boomers resident in Australia. What now follows is a description of the study sample, followed by findings from the thematic analysis of their survey responses. Topics covered included relationship ingredients considered 'essential'; valued aspects of living and/or sleeping together; and current levels of satisfaction with physical intimacy and sexual pleasure within participants' relationships. The findings presented in this chapter ultimately raise questions of how partnered individuals would fare if separated, especially if separated involuntarily, and what impact that might have on health and social services.

4.2. The sample

In total, 168 valid surveys were received from partnered individuals born between 1946 and 1965, from every Australian state and territory. Participants' geographic distribution within Australia is shown in Table 4.1 and Figure 4.1.

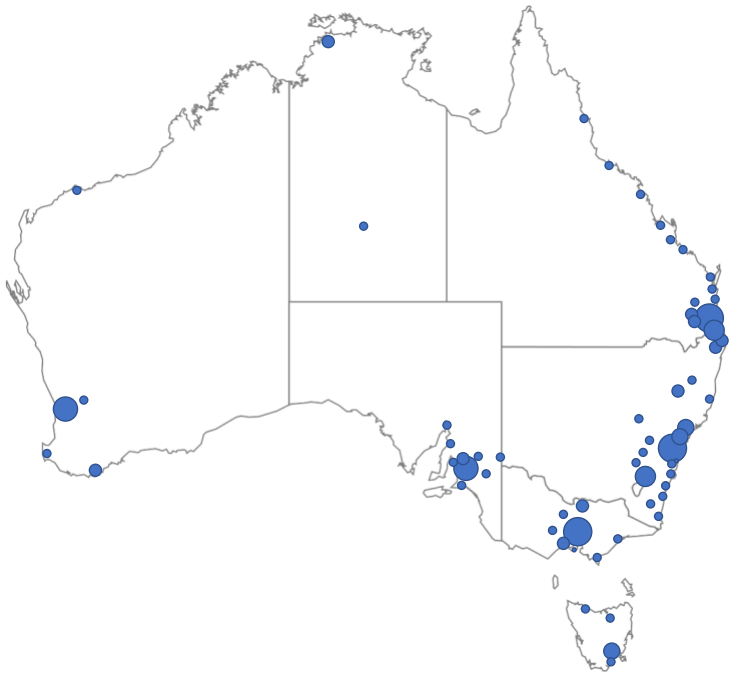

Figure 4.1. Geographic distribution of survey participants

Table 4.1

Distribution of survey participants compared to the geographic distribution of Australian Baby Boomers (as reported by the Australian Bureau of Statistics, 2014)

State or Territory	Survey participants		Australian Baby Boomers	
	N	%	N	%
New South Wales	49	29.2%	1,510,019.00	32.8%
Victoria	24	14.3%	1,123,921.00	24.4%
Queensland	39	23.2%	912,515.00	19.8%
South Australia	21	12.5%	367,221.00	8.0%
Western Australia	15	8.9%	465,334.00	10.1%
Northern Territory	4	2.4%	38,808.00	0.8%
Australian Capital Territory	6	3.6%	71,124.00	1.5%
Tasmania	8	4.8%	121,668. 00	2.6%
No permanent residence	2	1.2%		
Total	168	100. 1%	4,610,610.00	100.0%

The majority (n=112, 66.7%) were located in the eastern states, where Australia's population is concentrated. The distribution of survey participants by state was approximately representative of Australian Baby Boomers generally. Results varied by approximately three to four percent in the more populated states and less in the smaller states. One notable exception was Victoria, which was significantly underrepresented. These figures may have been influenced by the secondary methods used to promote the study (described in the previous chapter) although this does not entirely explain these results. A small proportion of respondents (n=2, 1.2%) had no permanent place of residence, describing themselves as 'grey nomads'.

Socio-demographic information about the participants is detailed in Table 4.2. The majority of participants (n=112, 67.7%) were early Baby Boomers (born 1946 to 1955), aged 60 to 70 years old, with participants' mean year of birth being 1953 (equivalent to an age of 61 to 62 years at the time of the survey). Approximately 31% of respondents indicated that they worked in aged care settings either currently or in the past. The gender balance of respondents was 15.5% male and 84.5% female.

Two factors may explain this result: (1) 31% of respondents worked in the aged care sector, which is a largely female industry that particularly embraced this study (due to its relevance to the aged care sector); and (2) women may have been more motivated to participate due to the higher probability of women ending their lives in aged care facilities (Australian Institute of Health and Welfare [AIHW], 2017d). Conversely, men may have been less interested in participating due to (a) being less concerned about their future dependence on aged care services; and (b) expectations of being cared for by their female partners (Quine & Carter, 2006).

In general, people with something positive to say about their relationships tended to self-select for this survey. Approximately 90% of participants answered every question, the remainder selectively skipped questions. Some (n=8, 5%) favoured multiple choice questions only and avoided descriptive answers entirely. Also, while sexually diverse relationships were represented in the data, in many cases answers provided were too brief to draw conclusions about this group.

Table 4.2

Socio-demographic characteristics of sample

Category		N=168	%
Sex	Female	142	84.5%
	Male	26	15.5%
Year of birth	Born 1946-55	112	67.7%
	Born 1956-65	56	33.3%
Place of Residence[15]	Major City	73	43.5%
	Inner Regional	59	35.1%
	Outer Regional	30	17.9%
	Remote Area	1	0.6%
	Very Remote Area	1	0.6%
	No fixed address	2	1.2%
	No data provided	2	1.2%
Country of Birth	Australia	125	74.4%
	United Kingdom	24	14.3%
	New Zealand	5	3.0%
	Western Europe	4	2.4%
	South Africa	3	1.8%
	South East Asia	3	1.8%
	North America	2	1.2%
	Caribbean	1	0.6%
	South America	1	0.6%
Aboriginal /Torres Strait Islander	No	161	95.8%
	Yes	7	4.2%
Sexual Orientation	Opposite sex attracted	158	94.0%
	Same sex attracted	7	4.2%
	Attracted to both sexes	2	1.2%
	Attracted to neither sex	1	0.6%
Relationship status	Married	125	74.4%
	De facto	27	16.1%
	Single, in a relationship	9	5.4%
	Other (LAT[16],polyamorous)	7	4.2%
Income (per annum)	Less than $20,000	42	25.0%
	$21,000 – 40,000	39	23.2%
	$41,000 – 60,000	35	20.8%
	$61,000 – 80,000	14	8.3%
	$81,000 – 100,000	10	6.0%
	$101,000 – 150,000	11	6.5%
	$151,000 – $200,000	4	2.4%
	More than $200,000	4	2.4%
	No data provided	9	5.4%

[15] Based on the Australian Statistical Geography Standard-Remoteness Area (ASGS-RA) geographical classifications.
[16] LAT stands for Living-Apart-Together, a relationship structure where committed partners choose not to cohabit.

4.2.1. Leximancer analysis of participants' current relationships

In response to the question "please describe your current intimate partner relationship(s), including whether you live together, any traditional or non-traditional features, and the gender of your partner(s)", participants described various relationship structures. Eight participants did not answer this question. Leximancer analysis (in Figure 4.2 and Table 4.1) identified that the most frequently mentioned themes in the text were: (1) living; (2) married; and (3) male.

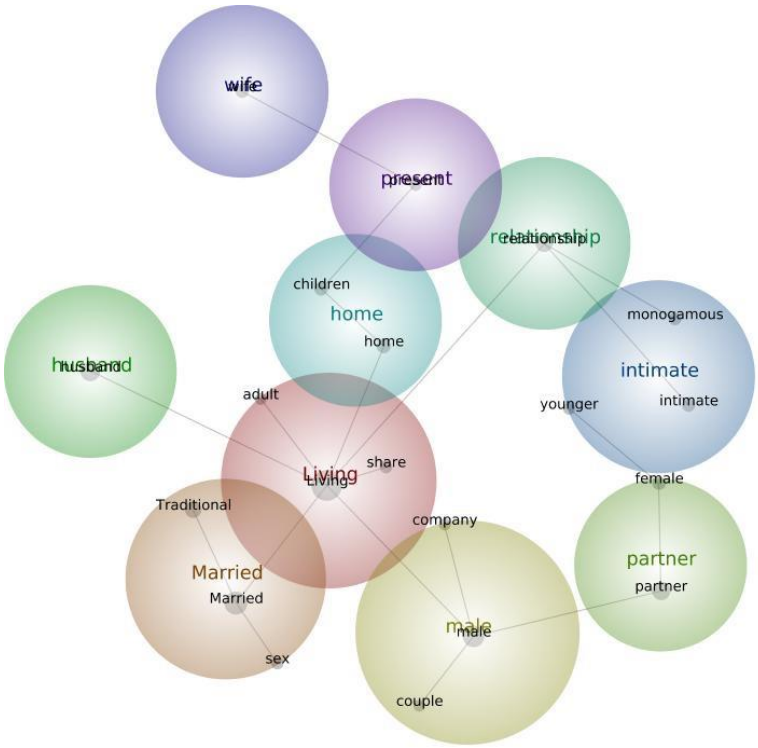

Figure 4.2. Map of lexical concepts describing participants' intimate partner relationships

In Figure 4.2, the highly interconnected concepts of "living" and "married" overlap with "male" and "home", all of which have the greatest relative importance in the data. This is an accurate reflection that the majority of (predominantly female) participants were married and living with their (male) spouse/partner in a traditional monogamous relationship in their shared home. However de facto, same-sex and non-monogamous partnerships were also represented (see Table 4.1). Some respondents had adult

children living at home and a few male participants reported having significantly younger female partners.

Table 4.3

Leximancer analysis of the question "please describe your current intimate partner relationship(s), including whether you live together, any traditional or non-traditional features, and the gender of your partner(s)"

Themes	Frequency (N)	Examples
Living	108	"Living with my only husband of 46 years. I am 67 and he is 69"
Married	67	"Our relationship would be described as a traditional marriage in every respect"
Male	47	"Married to the man I live with"
Husband	44	"married to my husband for 18 years, heterosexual""
Partner	35	"I live with my female partner of 4 years in an open relationship"
Relationship	27	"monogamous relationship"
Children	15	"[We] live together, share a queen size bed, adult children moved back home"
Wife	11	"I am married. My wife is female"
Intimate	8	"We live together in our own home and enjoy a loving and intimate relationship"
Present	4	"My partner is a male a little younger than me, we are not able to live together at present but hope to in the future"

4.3. Relationship features valued by Baby Boomers

Respondents were asked two questions to identify what they valued about their intimate partner relationships: (1) "please describe aspects of your intimate partner relationship(s) that are essential to you"; and (2) "if you live together, what is it about living with your partner(s) that you value?" The second question helped identify those people who were living with their partner and allowed participants to expand on their answers to the first question. Four themes common to both questions emerged (listed in Tables 4.4 and 4.5), regardless of whether respondents cohabited.

Table 4.4

Key themes emerging from the question "please describe aspects of your intimate partner relationship(s) that are essential to you"

Themes	Total		Women		Men	
	(N=157)	%	(N=132)	%	(N=25)	%
Joy in togetherness	109	69%	94	71%	15	60%
Emotional closeness	44	28%	37	28%	7	28%
Physical affection	33	21%	28	21%	5	20%
Sexual enjoyment	27	17%	20	15%	7	28%
Spirit of caring	21	13%	17	13%	4	16%

Table 4.5

Key themes emerging from the question "if you live together, what is it about living with your partner(s) that you value?"

Themes	Total		Women		Men	
	(N=151)	%	(N=126)	%	(N=25)	%
Joy in togetherness	116	77%	99	79%	17	68%
Spirit of caring	80	53%	67	53%	13	52%
Teamwork	29	19%	25	20%	4	16%
Intimate proximity	26	17%	20	16%	6	24%
Physical affection	12	8%	11	9%	1	4%
Sexual enjoyment	12	8%	8	6%	4	16%

In response to the first question about 'essential' aspects of their intimate relationship, 11 people chose not to answer this question. Another five could not name what was essential, instead answering "n/a". In the context of their answers to other questions, it appeared that these respondents did not consider themselves to be in 'intimate' relationships, which they interpreted to mean 'sexually active'. One woman said that "time alone" was the most essential feature. The remainder reported on their relationships in positive terms.

The next section explores in further detail the relationship features that were highly valued by this sample of partnered Baby Boomers, beginning with ingredients that were considered 'essential'. Themes that were unique to living together, i.e. 'teamwork' and 'intimate proximity', are presented separately in Sections 4.4.1 and 4.4.2.

4.3.1. Joy in togetherness

It was clear that, for the majority of respondents in this sample, being partnered was an enjoyable experience important for their sense of wellbeing as individuals. Respondents alluded to a sense of 'us-ness' that was unique to them and which both partners contributed to. The majority of responses reflecting this theme (n=109, 69%) used couple-oriented language such as "we", "us", "together", "mutual" and "each other". There was a sense that respondents saw themselves as part of a team, not merely as individuals, and that sharing life with the person they loved enriched their individual lives, as illustrated by this woman's example:

> With the exception of our respective working lives, we rarely spend time apart. It is unusual for us to be separated for more than a day or two at a time. We are both best friends and lovers, having enjoyed over 30 years of a happy and mutually satisfying relationship. The romance is alive and well in our marriage - we enjoy close intimacy (FR26)[17].

"Togetherness"[18], "being together"[19] and "doing things together"[20] were common phrases used. One woman said, "I love how we have been together so long we just know what the other is thinking" (FR149). Another valued "friendship, closeness, touching, [and] just being with him". She said, "[I] enjoy having someone close and 'just there'" (FR103). Responses suggested that being together, being familiar with each other, and sharing life moments were essential ingredients for many couple relationships. As one woman said, "time flies together" (FR12).

Respondents spoke about the personal joy they experienced as individuals within their dyadic relationship. Several referred to their partner as a valued presence in their lives. One woman summed this up as "he makes me happy just being in his presence" (FR38). Another reported feeling that "nobody knows or loves me as deeply as he does" (FR68-ACW). Sometimes the value of a partner's presence was contextualised. Being comforted by "the knowledge that the person that I have been married too [sic] for over 40 years is still sleeping beside me" was important to one woman (FR45). Whereas a male respondent placed more importance on "the companionship of another likeminded human being" (MR50).

Talking together, feelings of love, friendship, companionship, physical affection, kindness, playfulness, sharing experiences, humour and laughter were mentioned as elements that contributed to participants' enjoyment of being together. The "shared moments, laughing together - this is a must" was how one female respondent described togetherness (FR91-ACW). Some participants placed more value on the person their partner was, rather than the activities they did together. This was expressed as valuing "him" (FR51-ACW), "his company" (FR141) or "her company" (MR142-ACW). Two

[17] Codes were used to denote the gender of participants. Female respondents were denoted as 'FR' (e.g. FR1, FR2, FR3) and 'MR' was used for male respondents (e.g. MR1, MR2, MR3). People with work-related experience of aged care had the additional signifier 'ACW'.

[18] The term "togetherness" was used by participants FR67; FR82; FR90; FR148-ACW; FR149.

[19] The phrase "being together" was used by participants FR13; FR16; FR42; FR46; FR65; FR91-ACW; MR98-ACW; FR114; FR135; FR141; FR144-ACW; FR148-ACW; FR149.

[20] The phrase "doing things together" was used by participants FR35; FR40-ACW; FR59; MR60; FR150.

respondents simply said, "everything" about their relationships were essential (MR; FR12), suggesting that every aspect of their togetherness was rewarding, as in the following example:

> [I value] everything…his patience, the fact that he shares the household chores, he's a better cook than me. [He] understands my [work] pressures [be]cause he's in the same field…(FR12)

Participants' descriptions demonstrated that intimate interpersonal relationships were both important and diverse. Spontaneous humour was often reported as an opportunity to add joy to being together. Respondents described the variety of ways that they or their partners engaged light-heartedly or humorously. One woman described how her daughter "snapped a photo…and posted it to Facebook with the caption "Aw - 70 and still holding hands" which made us laugh and realise we love being together very much" (FR13). Some participants enjoyed a "slightly odd sense of humour" (FR149) and "bantering and friendly bickering" (FR128) as ritual forms of humour partners performed together. One man enjoyed "muck[ing] around [and] teasing in the kitchen" but added "my wife doesn't really like it when she's cooking" (MR99).

From the data, women appeared to place more importance on verbal interactions than did men. For both sexes, regular verbal exchanges created trust and intimacy. Women valued "closeness [and the] ability to talk to each other" (FR43) and "conversation about every aspect of our lives" (FR133). Talking, as a means of sexual and intellectual stimulation, was mentioned exclusively by men. One said he valued "privacy for racy talk" (MR96-ACW) while another said, "companionship is important. We are both politically active and like to discuss issues, philosophies etc. We enjoy the mental stimulation of discussion" (MR84-ACW). "Communication and intimacy, the spiritual communion and mental challenges implied in a relationship, the daily intimacy on all levels" was how one man expressed it (MR55).

Perhaps unsurprisingly, respondents found it difficult to separate important features of their relationship from the day-to-day business of living together, with a few (n=5) saying that what they valued about living together was the same as what they considered essential in their relationship. Many respondents explicitly stated that it was important for them to continue to remain together, expressed as variants of "[we]

want to remain living and sleeping together" (FR122). One woman said she and her husband had "always slept together & probably always will" (FR118). There was also concern expressed at the possibility of being separated. One woman expressed this, saying "I would not like to sleep apart. We have been married for 49 years and together for almost 54 years. Since our marriage we have slept together" (FR139). Another was unequivocally clear - "for better or worse, for richer or poorer I want us to live with each other until our last breath will come" (FR30).

In summary, these findings indicate that the majority of respondents who responded to this survey were happily partnered and, for most who cohabited, the companionship provided by living together was important. Relationship satisfaction appeared to be fostered by sharing day-to-day tasks. Participants illustrated the need for them, as couples, to be together and sleep together if they choose. They indicated also that regular, private, uninterrupted time together is needed for couple communication. These are important findings for providers of residential aged care.

4.3.2. Emotional closeness

Emotional intimacy, closeness and affection appeared as a sub-theme of 'joy in togetherness'. Of the respondents to the question on essential aspects of their intimate relationships (n=155), almost a third of women (n=37, 28%) and men (n=7, 29%) referenced emotional closeness. Respondents described emotional intimacy as a sense of 'closeness'. One woman referred to her "loving, close relationship" (FR111-ACW). This closeness was created through verbal expressions of love, caring actions, talking and listening to each other, and laughing together. Laughter, "compassion, respect, independence, passion, caring, sharing, sex, discussion and honesty" (FR17-ACW) and "physical intimacy, emotional support, companionship and friendship" (FR3) were cited as important features of emotional closeness. This theme was sometimes associated with expressions of emotion, such as this man's emphasis on "communication, tenderness & companionship" as well as "laughing or crying together" (MR78-ACW). There was also a sense that respondents needed to feel valued, "loved and cared [for] and appreciated" by their partners (MR134).

In summary, many participants were emotionally invested in their intimate relationships. For both sexes, relationship satisfaction and happiness in general was dependent on feeling supported, cared for, valued and appreciated by a partner. This was demonstrated through emotional, verbal, physical and sexual intimacy. These findings have important implications if expectations of consumer-directed care are to be met by aged care providers servicing couples or partnered individuals.

4.3.3. Physical affection

The theme of physical affection suggested that, for many, close body contact and loving touch were essential ingredients in the shared joy of partners being together. Sharing a bed was often mentioned concurrently with physical affection. Multiple expressions of physical contact were valued, including (but not limited to) hugs, cuddling, kissing, holding hands, touching, stroking, massage and affectionate squeezes. For instance, one man enjoyed "kissing, cuddling, snuggling, holding hands, massaging each other, dozing off on each other, swimming and playing in the water together" (MR2).

In this sample, the role of physical affection, it seems, was to communicate love and caring, described by one woman as "his consistent reminding me of his love for me...a look, a kiss, a squeeze, a compliment" (FR12). Physical proximity was considered important for creating opportunities to touch. There was the sense that such gestures made partners feel loved, appreciated, and nurtured. One woman valued "love, compan[ion]ship, cuddles, sex, [and] intimacy" (FR138). Other expressions of physical affection included "physical contact that is warm and caring, including intimate relations…while sharing the same bed" (FR136-ACW) and "closeness, hugging, touching [and] just being together" (FR91-ACW). One woman's ideal was "a hug a day and breakfast in bed" (FR134).

What these findings illustrate is that warm physical affection between partners appeared to positively influence relationship and partner satisfaction. Hugging and kissing were frequently mentioned by participants as fundamental means of communicating affection that contributed to their quality of life. These findings have important implications for aged care providers.

4.3.4. Sexual enjoyment

The theme of 'sexual enjoyment' had some overlap with the theme of 'physical affection' amongst female respondents, however, 'sexual enjoyment' was predominantly a separate theme in itself. Relative to women, male participants tended to prioritise sexual enjoyment as an essential, noteworthy feature. Interestingly, sexual enjoyment was rarely mentioned in isolation by either gender, being one of several important ingredients in the relationship experience. As an example of this mix, one man described how "regular sex, mutual support, [and] intellectual stimulation" (MR87) were essential for him. Another valued "tenderness, care, physical contact, sexual interactions" together with "humour, intellectual stimulation, companionship, support, advice and love" (MR2). One woman described her essentials as "being together, trust between us, sex, respect, fun [and a] sense of humour" (FR135).

When describing what was 'essential' in their relationship, a third of the respondents who explicitly stated that they valued sexual enjoyment (n=27), did not mention ideas of companionship or togetherness in their answers, indicating that they had a different focus. This applied to men and women in equal proportions. In fact, seven participants only reported sexual enjoyment as 'essential' to their relationship. One woman said what was essential for her was "cuddling, kissing, sexually stimulating each other, open nudity in front of each other, dressing to please him, [and] intercourse in one of our two favourite positions" (FR137-ACW). Another said that it was essential to her "to have an active sex life that we both enjoy and that enhances our lives" (FR53). A small number of participants provided more graphic detail of the sexual activities they enjoyed. One man volunteered the following as 'essential' features of his relationship:

> Full penetrative sex of all orifices, mutual oral sex and masturbation, playful breast and all over body touching and caressing, passionate kissing, mutual touching and playfulness clothed and naked, showers together, telling each other we love and care for each other. [We] use … a vibrator and phallus to enhance sex for her. [We have] great orgasms (MR24)

The findings presented in this section confirm that some people aged 50 to 70 still value and engage in partnered sexual activities. They also indicated that sex positive attitudes appear to continue across the lifespan. At much later life stages, these

attitudes may very well remain since, for many, positive sexual interactions were considered essential ingredients in a happy relationship. Again, these findings have implication for aged care providers attempting to provide consumer-directed care for residents in couple relationships.

4.3.5. Spirit of caring

The theme, 'spirit of caring', reflected a sense of "generosity of spirit" (FR151). It encompassed altruism and selflessness by one or both partners "looking out for each other" (FR136-ACW; FR137-ACW) and providing support and encouragement. *Being caring* was variously described by two men as "being there to hear about her day and provide counsel or silence and red wine" (MR10) and "care and concern for each other's feelings [and] preferences" (MR63-ACW). Another focused on the mutuality of "complete trust and care that we offer each other" (MR49-ACW). Caring for oneself as well as each other was also important. One man described this dual focus as "mutual caring and caring for our individual lives whilst creating a close relationship". He and his partner apparently did this by "compiling [an] understanding of how we can each best support the other" (MR10).

This theme also reflected *being cared for*, expressed as friendship, being loved and supported, listened to, and being treated with kindness. Women were more likely than men to reference their need for friendship and *feeling cared for*. "Friendship, caring for me, supporting me in tough times, companionship" were priorities for one woman (FR107). However, some men also explicitly valued friendship. For instance, one man described his partner as "my best friend and lover" (MR8-ACW).

Women were more likely than men to express the 'essentialness' of having a caring partner. Women valued physical and verbal communications of caring, such as a "kiss before bed and [being] told I am loved regularly" (FR72) and "physical intimacy…the intimate company, knowing the other person cares for you and vice-versa" (FR127). Where illness or disability were present, feeling cared for was especially important, which has obvious relevance to aged care settings. One woman expressed this as appreciating his "loving, caring support of me. [He] helps to look after me as I have rheumatoid arthritis" (FR44). A few men also expressed their appreciation of being

cared for, as in this example provided by a man in a Living-Together-Apart (LAT) relationship:

> She is loving, sexy, craves intimacy, loves to cook and care for me, we garden together, [she] is hard working, careful with money, keen to spend the rest of my life together and care for me if/when necessary (MR31).

He described his partner as being 26 years younger than himself, which provides evidence that some Baby Boomers are already planning who will care for them in their old age.

These findings indicate that, for this sample, selfless love/altruism/putting the other before oneself signified a commitment to maintaining the relationship. Not being able to maintain this relational strategy may have important implications in the future if partners become separated due to circumstances beyond their control.

4.3.6. Leximancer analysis of 'essential' relationship features

Leximancer analysis of participant data related to 'essential' aspects of their intimate partner relationships broadly support the manual thematic analysis of this survey question thus far. However, there are also nuanced differences. Figure 4.3 and Table 4.6 reconfigure the theme "joy in togetherness" into several smaller themes, the most central of which is "love". In this analysis, love was integral to participants enjoying life together. The term "love" encompassed a sense of caring, intimacy, verbal and sexual expressions of love. Connected with this, a partner's physical presence and physical contact was a significant contributor to love. Sharing was very important – sharing values, sharing interests, sharing time together, sharing a bed, being friends. Sharing life by living together and sleeping in the same bed created a sense of closeness.

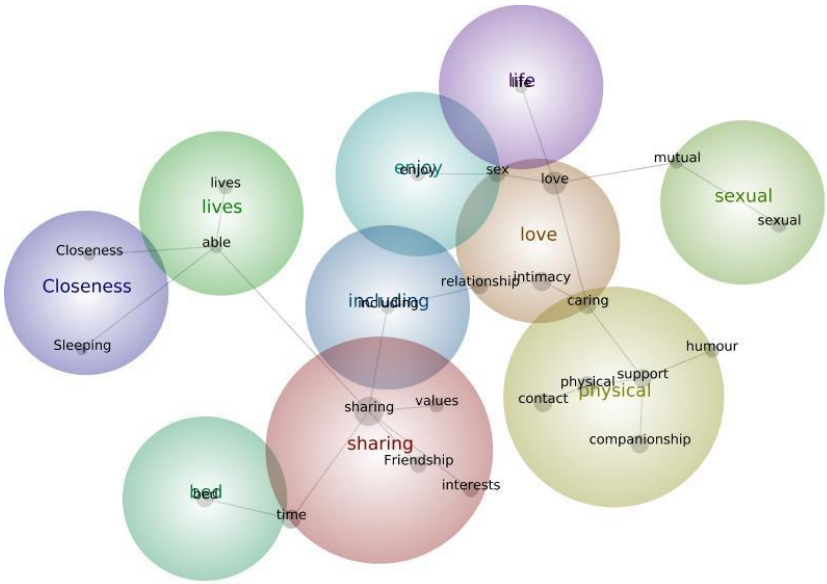

Figure 4.3. Map of lexical concepts describing relationship features considered 'essential' by participants

Table 4.6

Leximancer analysis of the question "please describe aspects of your intimate partner relationship(s) that are essential to you"

Themes	Frequency (N)	Examples
Love	55	"Telling each other we love and care for each other"
Sharing	43	"Spending time together alone and with friends, sharing a bed. Being recognised as a couple"
Physical	32	"The opportunity for close intimate contact, not necessarily lovemaking, but affectionate gestures, physical proximity, companionship and impromptu conversation"
Bed	16	"Sleeping in the same bed. Waking up together"
Sexual	13	"close sexual relationship"
Lives	10	"For better or worse, for richer or poorer I want us to live with each other until our last breath will come"
Closeness	6	"…closeness, spending [a] long time together, enjoying each other's time, keeping active"
Enjoy	6	"We are both best friends and lovers, having enjoyed over 30 years of a happy and mutually satisfying relationship. The romance is alive and well in our marriage – we enjoy close intimacy. "
Including	5	"Being able to share our lives, including sleeping together at night"
Life	4	"She is loving, sexy, craves intimacy, loves to cook and care for me…keen to spend the rest of my life together and care for me if/when necessary""

4.4. Living together

All but 18 participants indicated that they lived together. When discussing cohabitation, respondents' most frequently used word (and often their first) was "companionship" (n=32), followed by variants of "together" (together, togetherness) (n=26) and "company" (n=15). Seven respondents said they did not live together and one indicated that they lived together only part of the time. Two people answered the question "if you live together, what is it about living with your partner(s) that you value?" with "nil" or "none", possibly implying that they did not enjoy living with their partner.

Most respondents, however, reported that they enjoyed living together and associated their cohabitation with loving and being loved. For some, the partner's presence was the object of love and appreciation, as in this man's example: "I love my wife, I just love seeing her every day; being with her at night. Her company is so calm, peaceful and generous" (MR99-ACW). For others, love was expressed through a shared worldview and shared daily tasks performed together:

> I value my husband's deep love for me. He needs me and I need him. We share chores and feel safe and secure together with our dog and cat. We manage our money together, take pride in our home and in our garden and look forward to the years we have left (FR135).

The additional benefits that cohabitation provided, that perhaps were not available when living separately, were teamwork and intimate proximity. Physical affection and sexual enjoyment were less prominent themes when discussing living together, perhaps because partners do not need to live together to enjoy these forms of affection whereas teamwork and intimate proximity were best achieved by living together.

4.4.1. Teamwork

Teamwork meant a range of things, including a sense of partnership, equality and sharing responsibility, as in this man's example: "being able to create a house and lifestyle together, [and] mutual support" (MR57). One woman valued "joint decisions [and] sharing household duties, [and] having someone to discuss things with" (FR131-ACW). Another referred to "his support in all things I do. …working together to

achieve things" (FR32-ACW). Teamwork also meant being egalitarian in the division of domestic duties, as described by this man:

> We share domestic life in an understanding way. I get breakfast and she organises dinner. She cleans and I organise dishes and clothes washing. I am very fussy about coffee and always make it for us in the espresso machine (MR84-ACW).

In summary, equitable relationships involved the sharing of day-to-day routines and household duties. Such an approach helped foster feelings of love, mutuality and friendship between partners. This raises the question of how older couples might demonstrate their love and respect for each other if put in the situation where they are unable to live together and share day-to-day tasks, such as in some residential aged care settings.

4.4.2. Intimate Proximity

This theme described the intimacy and closeness created by being in close proximity to each other, described by one man as "communication and intimacy, the spiritual communion and mental challenges implied in a relationship, the daily intimacy on all levels" (MR55). The higher number of male respondents reflecting this theme perhaps suggests that men valued this aspect more highly than women. Women's descriptions included: "sharing our lives, our experiences, ideas, thoughts and the enjoyment and satisfaction of our close intimate relationship" (FR62); "our companionship, intimacy, sharing moments which we both have experienced" (FR83); and "sleeping beside each other, someone to talk to…not being lonely" (FR5). What one man valued most was the

> ongoing presence and close companionship, the intimacy of close contact, opportunities to react spontaneously to spur of the moment opportunities, [and] having someone available who can help when needed (MR50).

4.4.3. Leximancer analysis of 'living together'

The Leximancer analysis (in Figure 4.4 and Table 4.7) reinforces the importance of togetherness, a finding reported earlier in this chapter (arrived at by manual qualitative analysis). The concept map indicates that, most of all, living together offered participants companionship and the knowledge/assurance that they had someone to share time with. They loved the support, understanding and humour that their relationship offered them. Shared intimacy and open communication were highly valued and participants described themselves as best friends.

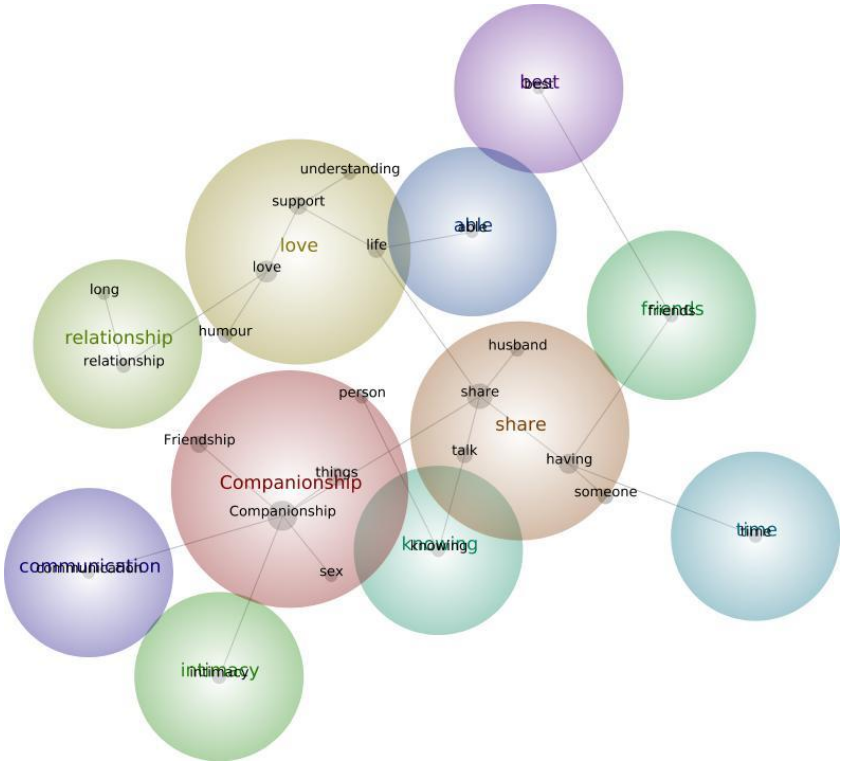

Figure 4.4. Map of lexical concepts in responses to the question "if you live together, what is it about living with your partner(s) that you value?

Table 4.7

Leximancer analysis of the question "if you live together, what is it about living with your partner(s) that you value?

Themes	Frequency (N)	Examples
Companionship	53	"Loving companionship, friendship, conversations, routines, security, contentment, playing games together, talking about little things and big, praying together, eating meals together, cooking together, shopping together and catching up with friends together"
Love	41	"I value our togetherness, our slightly odd sense of humour, the support we give each other. I love how we have been together so long we just know what the other is thinking
Share	40	"Joint decisions, sharing household duties. Having someone to discuss things with
Time	13	"…time together every day"
Intimacy	10	"Their ongoing presence and close companionship. The intimacy of close contact"
Friends	9	"We are best friends"
Relationship	8	"The comfort of our long term relationship"
Communication	5	"Companionship, same faith and cultural values, respect and open communication"
Able	5	"To be able to talk openly about everything. To be able to sit together and snuggle up while watching TV"
Knowing	5	"knowing that I always have someone there that cares for me as much as I care for him"
Best	3	"My best mate, he's got my back"

4.5. Sharing a Bed

Four themes emerged from participant data about the experience of sharing a bed, presented in Table 4.8. These themes are detailed in the following sections.

Table 4.8

Themes emerging from the question "please tell us about your experience of sleeping in the same bed"

Themes	Total		Women		Men	
	(N=158)	%	(N=133)	%	(N=25)	%
Sleeping together is comforting	95	60%	80	60%	15	60%
Bed as a relationship setting	45	28%	36	27%	9	36%
Balancing individual needs	45	28%	38	29%	7	28%
Sleeping apart	17	11%	14	11%	3	12%

4.5.1. Sleeping together is comforting

Of the respondents who answered this question, many indicated that sleeping together was comforting (n=95, 60%). Several people, predominantly women, said that it was "comforting" (n=14) to share a bed or to have their partner "beside" them (n=11).

Participants described feeling right or feeling at ease sharing a bed, making it possible to relax. One man expressed this as: "It feels right. I feel in place. If I'm in bed alone (rare) some part of my mind doesn't rest" (MR10). Participants commented that "it feels weird not to have him on the other side of the bed" (FR65) and "when we are apart we miss each other" (FR9).

Sleeping together evoked "feelings" of "warmth" (n=12), "safety" (n=5) and "security" (n=3) for some women. Touch and close physical contact with one's partner during the night appeared to be a comforting element. Several participants expressed the importance of sleeping side-by-side and being able to "reach out and touch" each other (FR25; FR91-ACW; FR117-ACW; FR133; FR145-ACW; MR24; MR50) during the night. Another referred to how "knowing by touch" her partner was close put her at ease (FR90). One woman described "hold[ing] each other's hand" until they sleep. She said, "The loud snoring sound of my husband doesn't bother me at all. It's a great comfort and security to have him beside me" (FR30). Others (n=14) simply said they enjoyed sharing a bed. One female participant described her bed as "a big bed by yourself", saying "our bed was built for two, and two it has, it is for relaxing, and enjoying each other" (FR59) (original punctuation).

In terms of sleep quality, some respondents said they slept "well" (n=1) or "better" (n=3) together or, alternatively, indicated that they "both can't sleep without the other" (FR9). However, more often, their partner's presence was prioritised ahead of sleep quality. One woman said she "could not sleep alone" (FR152). Another expanded on this sentiment by saying:

> Sleeping in the same bed is an essential aspect of our relationship, we find it so comforting and miss each other when one is away. Sometimes, one or the other of us wants to sleep alone, so that's ok too, but it happens rarely, mainly if we fight or one of us is unwell (FR5).

Despite her husband having dementia, one woman said she loved spooning and holding hands with her husband and "having a warm body to hold on to" in bed at night. She added that if "his sundowning is really bad with the alzheimers I don't go to bed until much later" (original spelling and punctuation) (FR68-ACW), indicating that her choice to continue sleeping with him sometimes came at the cost of her sleep.

4.5.2. Bed as a relationship setting

Participants described a range of bonding rituals they had in bed. Bed was a meeting place but not necessarily a sleeping place, where they enjoyed being together. Several respondents said time in bed together was an important feature of their relationship even if they didn't sleep together. Important activities in bed included talking, cuddling, keeping warm, reading, and physical gestures. One man said, "I love having [name withheld], my partner, next to me, keeping each other warm during winter, resting my hand on his chest, feeling his heart beat" (MR57). Some participants described their bed as an important setting for creating intimacy (n=12) through verbal (n=5) and non-verbal communication, such as kissing (n=4), cuddling (n=15), "snuggling" (n=3) and sexual activity (n=12), as this woman described:

> We do a lot of our talking in bed. It's the intimacy created by even just turning out the light [and] having a cuddle or a kiss [and] sometimes that can lead to even more intimate moments (FR40).

4.5.3. Balancing individual needs

The majority of participants who experienced sleep disturbances nevertheless chose to continue sleeping together. Many took proactive measures to improve their sleep. The most common challenges mentioned were snoring (n=22), followed by restlessness (n=9), sleep apnoea (n=5), illness, pain, differing bedtimes, competing for space and bedcovers, and moderating body temperature. In these situations, participants used various approaches to balance their individual needs. One way was to trade off one person's need against the other's, as in this example: "I usually sleep pretty well but it can be annoying for her as I can be restless. [I] enjoy the closeness" (MR63). Another approach was to occupy the safest position in the bed. One woman described herself moving "like a washing machine through the night". Her partner "goes on his side, on the edge of the bed and holds on!" Despite this, they "love being in the same bed" (FR12). However, the most notable response, described by several women, was adopting a positive attitude, as in this example:

> We have always slept in the same bed, my husband uses a BPap [sic] machine to regulate his breathing at night, the noise of the machine reassures me that he is ok…I sleep easier knowing he is besides [sic] me (original punctuation) (FR73).

Some respondents described sleeping together as both a positive and a negative, as this woman illustrated:

> He snores and suffers from sleep apnoea, this disturbs my ability to go to sleep and wakes me during the night. He is always warm to cuddle into on a cold night although he objects to me putting my cold feet against his warm feet. He "steals" the bed covers during the night (FR92).

One man reported "periods of sleeping in separate beds" because of his snoring, until solutions could be found. He said, "Currently this is less of an issue after [taking] some measures. I like [the] physical proximity" (MR60).

Some couples took proactive measures to find mutually beneficial solutions to address sleep disturbance. Coping mechanisms included wearing earplugs and buying a bigger bed. In response to being disturbed by her husband, one woman said: "we've just launched out and bought a King Size double bed, which is wonderful. He doesn't snore as much and it has a mattress where I cannot notice him turning over, wriggling etc. Lovely" (FR18).

What is evident about these accounts is that partners who found it comforting to sleep with each other preferred to sleep together than apart. However, while many described the importance of going to bed together, in some circumstances it was necessary to de-camp to a separate room during the night. This woman described how she and her partner "always start off in the same bed and snuggle up until whomever snores first, stays in that bed and the other one moves". They then "reconnect[ed] in the morning by snuggling up in the same bed either with a cuppa or just another hour's snoozing" (FR13). Nevertheless, for varying reasons, not all partners found it comfortable to share a bed at night.

4.6. Sleeping apart

Reasons for sleeping apart included personal preference, differing sleep patterns, partner disturbances, sharing the bed with pets, being a partner's carer, and illness. One woman said, "I prefer to sleep alone. He snores and wriggles. I don't sleep well. It works for us" (FR124-ACW). Another said sleeping together was not of her

choosing: "[I] would be happy to sleep in a seperate [sic] bed as he dislikes being touched and he snores" (FR6-ACW).

Sleeping separately did not necessarily mean that the relationship suffered. A few participants maintained an active sex life in spite of sleeping apart. As in this example:

> Whilst our sex life is a regular and highly enjoyable aspect of our relationship, and we enjoy both romance and intimacy, we sleep separately at night. (One of us snores!!!) (FR26).

Others enjoyed time together in bed as an activity in itself that was separate from sleep:

> Not sleeping in the same bed as my husband ensures we both get better quality sleep. We have separate rooms but we sometimes share a bed for comfort. We like to sit up together in the same bed on days off and spend a lot of time in bed on those days (FR29).

In some cases, sleeping apart arose from necessity rather than choice. Illness was cited by several participants as a reason for sleeping separately, indicating that some Baby Boomers already needed others to care for them. One woman indicated that her husband's cancer meant that they "can no longer share the same bed because of his pain". However, they still liked "to be alone together" (FR27-ACW).

4.7. The decision to sleep together or apart

Using Leximancer software, comparative analysis of data from respondents who slept together, compared to those who slept apart, revealed differences in partner priorities. It seemed that co-sleepers had a richer, more connected range of associations with their bed (depicted in Figure 4.5 and Table 4.9). These participants associated their bed with sleeping together and viewed this as an opportunity for touch, proximity and togetherness. As a consequence, they prioritised sleeping together over sleep disturbances caused by a partner. In fact, some female participants enjoyed their male partner's snoring – they found it comforting knowing he was beside them.

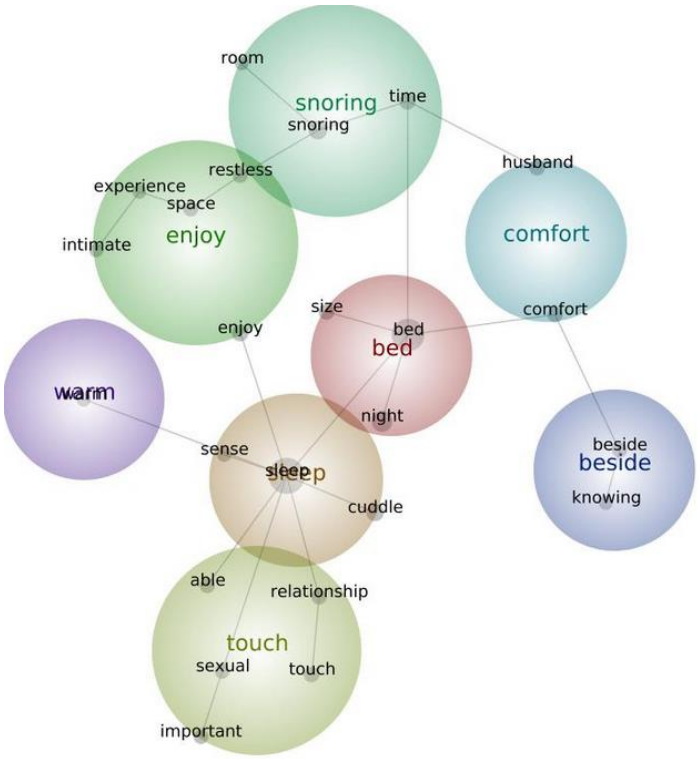

Figure 4.5. Map of lexical concepts describing 'sleeping together' by participants who slept with their partner

Table 4.9

Leximancer analysis of responses to the question "please tell us about your experience of sleeping in the same bed" from participants who slept with their partner

Themes	Frequency %	Examples
bed	100%	"Sleeping in the same bed is part of being a couple"
sleep	97%	"We always cuddle when going to sleep"
touch	49%	"Knowing he is beside me, [being] able to reach out and touch him"
enjoy	48%	"We enjoy sleeping together"
snoring	39%	"[We] feel better together than apart. I snore and some nights he or I will go to another room...but it doesn't feel as connected or supported"

While most participants indicated that they derived pleasure and comfort from sleeping together, some (n=17) chose to sleep apart (see Figure 4.6 and Table 4.10). These respondents appeared to rank individual needs for quality sleep as the highest priority. They preferred to sleep alone, in separate rooms, and there was usually an underlying reason for this (i.e. it was 'due' to something such as chronic illness, pain, snoring or restlessness). These partners appeared to derive less pleasure from togetherness, however, this did not necessarily mean that they were no longer sexual, as indicated in Table 4.10.

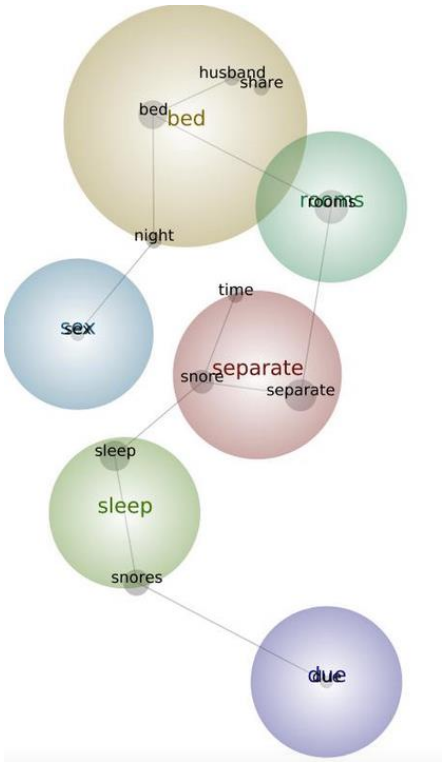

Figure 4.6. Map of lexical concepts describing 'sleeping together' by participants who slept alone

Table 4.10

Leximancer analysis of data from respondents who slept apart

Themes	Frequency %	Examples
bed	91%	"Not sleeping in the same bed ensures we both get better quality sleep"
sleep	86%	"I prefer to sleep alone. He snores and wriggles"
rooms	54%	"We sleep in separate rooms because we both snore"
sex	12%	"Whilst our sex life is a regular and highly enjoyable aspect of our relationship, and we enjoy both romance and intimacy, we sleep separately at night. (One of us snores!!!)"
snoring	39%	"Not at the moment. His snoring is disruptive. My choice. "
due	11%	"[We] sleep separately due to snoring and restlessness"

4.7.1. Summary

It appears that a couple's shared bed serves multiple functions beyond merely housing bodies for sleep. It is the setting where much of their relationship takes place. These results indicate that, for some, sleeping together is a highly valued social activity which may improves each partners' sleep quality and sense of safety and security, which are important factors in institutional settings.

4.8. Attitudes to physical intimacy

Respondents were asked to (1) consider whether they thought physical intimacy (non-sexual physical contact) was an essential part of life; and (2) describe their degree of satisfaction with current levels of physical intimacy and closeness in their relationships. The results are detailed in Tables 4.11 and 4.12. The findings in Table 4.11 suggest that men (n=22, 84%) may have regarded physical intimacy as more 'essential' than women (n=108, 76%), especially since all male respondents considered it important to answer both of these survey questions. Women (n=83, 58%) were more likely to be 'very satisfied' whereas a higher proportion of men (n=8, 31%) were 'somewhat satisfied' with their current level of physical intimacy (see Table 4.11). However, results for both sexes were generally suggestive of positive levels of relationship satisfaction.

Table 4.11

Answers to the question "do you consider physical intimacy an essential part of life?"

Themes	Total		Women		Men	
	(N=165)	%	(N=139)	%	(N=26)	%
Yes	130	79%	108	78%	22	84.6%
It varies	20	12%	18	13%	2	7.7%
No	15	9%	13	9%	2	7.7%
Total	165	100%	139	100%	26	100%

Table 4.12

Answers to the question "how satisfied are you with your current level of physical intimacy?"

Answers	Total		Women		Men	
	(N=162)	%	(N=136)	%	(N=26)	%
Very satisfied	96	59.3%	83	61.0%	13	50.0%
Somewhat satisfied	33	20.4%	25	18.4%	8	30.7%
Not satisfied	13	8.0%	10	7.4%	3	11.5%
It varies	20	12.3%	18	13.2%	2	7.7%
Total	162	100.0%	136	100.0%	26	99.9%

Respondents were asked to describe the physical intimacy and closeness they experienced with their current partners. Most participants described being in physically affectionate relationships, which included regular physical contact. Answers shown in Table 4.13 illustrate that men had a significant focus on partner touching/stroking/caressing, followed by kissing, then cuddling. Women, on the other hand, tended to discuss cuddling, holding hands, and kissing (in that order).

Table 4.13

Answers to the question "please describe the physical intimacy and closeness you experience with your current partner(s)"

Answers	Total (N=153)	Total %	Women (N=129)	Women %	Men (N=24)	Men %
Cuddling	106	69%	91	71%	15	63%
Kissing	104	68%	88	68%	16	67%
Holding hands/walking arm-in-arm	102	67%	91	71%	11	46%
Touching/caressing/stroking	73	48%	49	38%	24	100%
Hugs/pats/holding and being held	18	12%	15	12%	3	13%
Massage/back rub/foot rub	13	8%	11	9%	2	8%
Little to no physical affection	10	7%	8	6%	2	8%
Lying together/snuggling/spooning	6	4%	5	4%	1	4%
Body contact while sleeping/dozing	5	3%	3	2%	2	8%
Body contact while sitting together	5	3%	5	4%	0	0%

One woman said, "we are very affectionate with one another and spontaneously kiss and cuddle a lot throughout the day. We often hold hands when out walking…we love being together very much" (FR13). For another woman, physical intimacy meant

> [holding] hands at the movies and sometimes when…watching TV. We kiss good morning and goodnight and whenever we…part or come together…such as after the working day. Cuddles are spontaneous as well as regular! Foot massage is also a frequent part of our physical closeness (FR23-ACW).

Other forms of intimacy reported by a small minority of respondents included playing and swimming together; being naked in bed together; cross stitching together; dancing together; giving/receiving Reiki; and showering together.

Some respondents expressed disappointment that there wasn't more physical affection in their relationship however many were philosophical about it. This man said:

> my wife has never really been into overt displays of affection or romantic gestures. I on the other hand actually enjoy and seek out physical intimacy with her whenever I can. For us this means kissing every day, a bit of cuddling but not a great deal of hand holding much to my disappointment. One of the advantages of living together in the same house and sleeping in the same bed…is that I get plenty of opportunities for non sexual touching as we get on with our day to day lives. In my situation you get what you can (MR50).

Others described how they enjoyed physical intimacy some of the time but also needed their own space:

> We cuddle and hold hands a fair bit … we tend to be touching if we are in the vicinity - like on the sofa, or at tables and so on - one is usually touching the other. In bed, he likes to snuggle up, and would do so all night. I get too hot and feel trapped. So we touch for a while and then roll apart (FR104-ACW).

A small minority of respondents (n=10, 6%) said physical intimacy was non-existent in their relationships or significantly diminished, as in "[there is] no physical contact at all anymore" (FR6-ACW). In some cases, this was due to a partner's declining health. A few women regretted the absence of non-sexual touch in their relationships, indicating that their partner's touch was more likely to be sexual. For example, one said, "[there is] very little non-sexual touching, sadly, 'tho[ugh we] massage each other occasionally" (FR18-ACW). Another said she enjoyed "falling asleep in [her husband's] arms spooning" but that "there is very little non-sexual touching" She said, "[he] touches me and he is sexual" (FR59).

4.8.1. Leximancer analysis of physical intimacy

Analysis of respondents' descriptive answers, provided in Figure 4.7 and Table 4.14, indicates that physical intimacy was mostly expressed with the hands and, in fact, hands were central to the experience of physical intimacy. Intimacy included touching, physicality, and closeness and was sometimes accompanied by sexual activity although this was not central to the experience of intimacy. For many respondents, physical intimacy was expressed daily, before and after work. Sometimes, merely 'having' a partner present was an intimate experience. As indicated in section 4.3.3, physical intimacy is a primary means of communicating affection and plays a significant role in maintaining relationship satisfaction. These results raise the question of what happens to relationship satisfaction and quality of life for each partner when opportunities for physical affection are removed or limited by external factors, such as in RACFs.

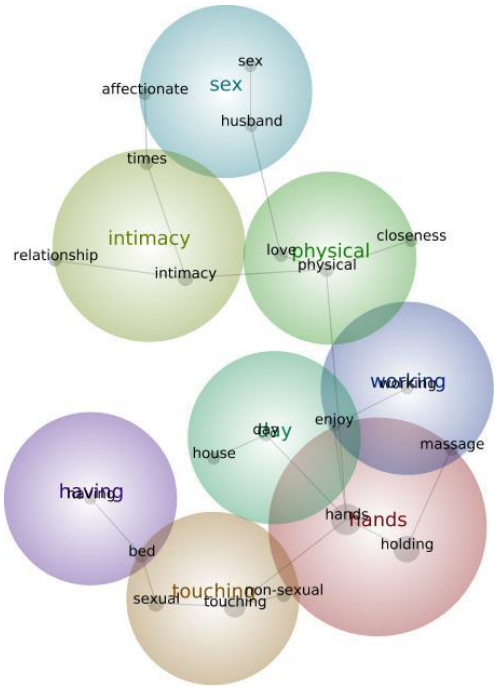

Figure 4.7. Map of lexical concepts in answers to the question "please describe the physical intimacy and closeness you experience with your current partner(s)"

Table 4.14

Leximancer analysis of answers to the question "please describe the physical intimacy and closeness you experience with your current partner(s)."

Themes	Frequency %	Examples
Hands	99%	"Kissing cuddling, holding hands, massages, rubbing my feet when we are on the lounge. We usually hold hands in the car too"
Touching	45%	"One of the advantages of living together in the same house and sleeping in the same bed […] is that I get plenty of opportunities for non sexual touching as we get on with our day to day lives"
Physical	16%	"My husband is always holding my hand, kisses [me] frequently, cuddles and caresses….I love that he shows me he loves me and still finds me desirable"
Intimacy	12%	"My gal is always up for physical intimacy and closeness, lots more than me. She would be in contact all the time and more than me"
Sex	9%	"Kissing, cuddling, holding hands as we walk, sitting together on [the] couch, sexual touching & sex"
Day	6%	"We touch a lot; hold hands sometimes when walking; we kiss hello and goodbye every day"
Having	4%	"The soft touch under the covers is assuring and just having her presence in bed is enough"
Working	4%	"We cuddle, kiss and enjoy closeness we have been missing while we were working"

4.9. Attitudes to sexual pleasure

Respondents were asked (1) about their experience of sexual pleasure in their current relationship; (2) whether they regarded sexual pleasure an essential part of life; (3)

whether they were satisfied with their current levels of sexual pleasure; and (4) if they thought they would ever stop being sexual. Just over two thirds of men and half of women considered sexual pleasure an essential part of life and did not think they would ever stop being sexual (see Tables 4.15 and 4.16). A small minority (n=27, 16%) regarded sexual pleasure as non-essential and thought they would probably cease being sexual. Approximately 18% of respondents believed that their ongoing sexual expression was dependent on circumstances beyond their control.

Table 4.15

Answers to the question "do you consider sexual pleasure an essential part of life?"

Answers	Total		Women		Men	
	(N=130)	%	(N=104)	%	(N=26)	%
Yes	80	61.5%	63	60.6%	17	65.4%
It varies	20	15.4%	13	12.5%	7	26.9%
No	30	23.1%	28	26.9%	2	7.7%
Total	130	100.0%	104	100.0%	26	100.0%

Table 4.16

Answers to the question "do you think you will ever stop being sexual?"

Answers	Total		Women		Men	
	(N=153)	%	(N=129)	%	(N=24)	%
Yes	96	62.7%	78	Yes	96	62.7%
It varies	30	19.6%	26	It varies	30	19.6%
No	27	17.6%	25	No	27	17.6%
Total	153	99.9%	129	Total	153	99.9%

4.9.1. Leximancer analysis of current sexual pleasure

Figure 4.8 and Table 4.17 summarise analysis of the question "please tell us about the sexual pleasure you experience with your current partner(s)." Many participants reported that sex with their partner as enjoyable and satisfying. Remaining sexual and continuing to try and satisfy each other was considered important. This involved spending time on pleasuring each other. There was a strong emphasis on orgasm and to a lesser extent, intercourse. For some, health issues had led to reduced sexual desire and/or sexual contact and, in other cases, sexual activity was deemed no longer possible. In the face of age and health-related changes, love and intimacy still remained important.

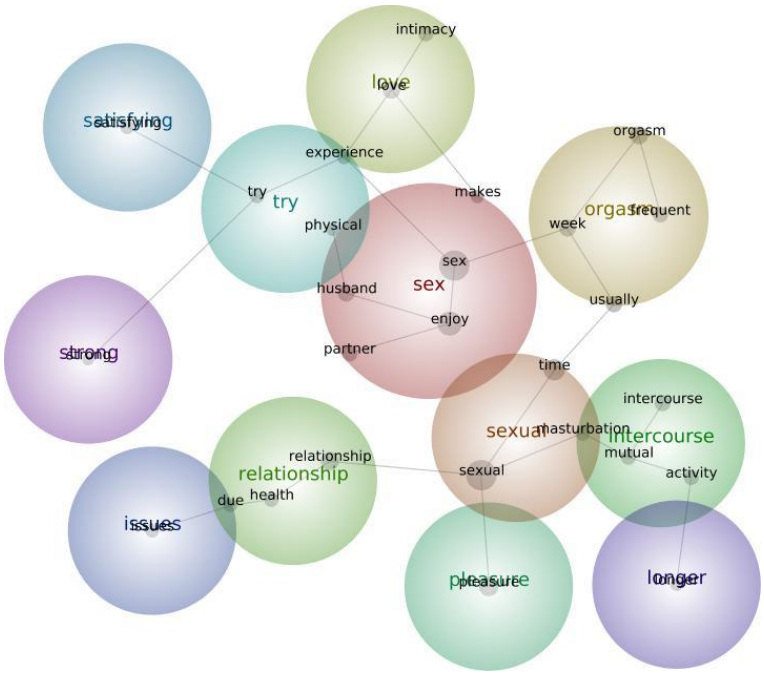

Figure 4.8. Map of lexical concepts resulting from the question "please tell us about the sexual pleasure you experience with your current partner(s)"

Table 4.17

Leximancer analysis of results from the question "please tell us about the sexual pleasure you experience with your current partner(s)"

Themes	Frequency (N)	Examples
Sex	52	"My husband is very considerate of my needs and we both find sex enjoyable"
Sexual	40	"Throughout our entire time together my wife and I have always enjoyed sexual contact and usually manage to reach sexual climax simultaneously"
Orgasm	27	"We probably have sex once every 2 or 3 weeks now but we know what pleases each other and we usually both orgasm. If not, then we just love the feeling of intimacy"
Pleasure	20	"Not comfortable to share details, but we do give each other pleasure and that is important to us"
Love	19	"Unfortunately [we] have not had full sex since my husband was 76 but the intimacy has increased in some ways. At first it bothered me as I am so much younger but just to touch and love him is enough"
Relationship	12	"We both believe it is important to maintain this aspect of the relationship and that in a lesbian relationship this can be more of a challenge (particularly for two post-menopausal women)
Intercourse	9	"Regular and varied sexual activity including intercourse, games and being together"
Satisfying	7	"Considerable [pleasure] and satisfying"
Issues	6	"Slower, [a] few issues with health but love and patience get us there"
Longer	5	"We have always had an active sex life but I no longer have the desire, I find it irritating"
Try	4	"We always try to satisfy each other"
Strong	3	"…we are very affectionate but the sexual spark is not so strong"

4.9.2. Sexual satisfaction

The results shown in Table 4.18 indicate that a significant majority of respondents experienced sexually pleasurable relationships. Almost 40% of the sample were 'very satisfied' with their current level of sexual pleasure and another 38% were 'somewhat satisfied'.

Table 4.18

Answers to the question "how satisfied are you with your current level of sexual pleasure?"

Answers	Total		Women		Men	
	(N=155)	%	(N=129)	%	(N=26)	%
Very satisfied	65	41.9%	55	42.6%	10	38.5%
Somewhat satisfied	42	27.1%	32	24.8%	10	38.5%
Not satisfied	21	13.5%	19	14.7%	2	7.7%
It varies	27	17.4%	23	17.8%	4	15.4%
Total	155	99.9%	129	999%	26	100.1%

Given that 50% or more of survey participants were also 'very satisfied' with the physical intimacy they experienced (see Table 4.19), these results may indicate that physical intimacy and sexual satisfaction are interrelated. Respondents who were 'very satisfied' with their sexual pleasure described their sexual relationships in positive terms and/or praised their lovers, such as this woman who said, "we love each other and have an active sex life that we both enjoy and that enhances our lives" (FR53). A woman who had re-married could hardly contain her enthusiasm, saying "WOW. VAVA VOOM, absolutely incredible…he should bottle it and make a fortune. My first husband…that's another story…eww yuck" (FR12). A male participant reported "very high levels of pleasure", saying he had "always enjoyed sex and physical intimacy of all sorts" (MR63-ACW).

Some respondents interpreted the question differently and instead described the sexual activities they participated in. One woman said:

> Where do I begin! My partner is the most considerate partner that anyone could wish for. We love to make up stories to take our sexual experience to the next level. [We] love to try out new sex toys and any way we can give our partner a more satisfying experience. [We have] no problems discussing if we need added lubricants (FR101-ACW).

A bi-sexual woman in a polyamorous relationship instead preferred:

> access to good lovers who can satisfy my high libido…I enjoy a tantric style with one partner. I enjoy 2 men together pleasuring me. I am both voyeuristic and an exhibitionist [and] I love being massaged by 2 lovers (FR37).

A heterosexual man in a de facto relationship said he enjoyed:

> a variety of sexual interactions with my partner, including sexual caressing and touching, licking, oral sex, vaginal intercourse, masturbation together and occasional B&D [bondage and discipline] role play spanking (MR2).

Table 4.19 compares physical intimacy with sexual satisfaction for both sexes. For participants who said they were 'very' or 'somewhat' satisfied, men (n=21, 81%) and women (n=108, 79%) were more or less equally satisfied with their current levels of physical intimacy. However, men (n=20, 78%) reported higher levels of sexual satisfaction than women (n=87, 68%).

Table 4.19

Comparison of men's and women's current satisfaction with physical intimacy and sexual pleasure

Answers	Women		Men	
	Physical N (%)	Sexual N (%)	Physical N (%)	Sexual N (%)
Very satisfied	83 (61%)	55 (43%)	13 (50%)	10 (39%)
Somewhat satisfied	25 (18%)	32 (25%)	8 (31%)	10 (39%)
Not satisfied	10 (07%)	19 (15%)	3 (12%)	2 (08%)
It varies	18 (13%)	23 (18%)	2 (8%)	4 (15%)

Female partners of men with chronic ill health or sexual problems were more likely to report sexual dissatisfaction. One woman said that "in the last 12 months", there is not much sexual pleasure due to the

> illness, extreme lethargy and medication side effects my husband is having from his chemotherapy and pain medications. Prior to that nothing [interfered]…it was good, [the] kids had left home and [it] most like[y] could have stayed like that (FR27-ACW).

Men reported being concerned about sexual changes they were experiencing, particularly erection difficulties. One such man said, "I have some impotency which is of more concern to me than her and affects my interest at times" (MR31). Despite this, participants demonstrated relationship resilience by maintaining physical

affection. One woman described how she and her husband have adapted after prostate surgery:

> My husband has undergone removal of his prostate gland and therefore we are unable to conduct traditional lovemaking. However, we frequently cuddle and body touch. [Sexual pleasure] is minimal, but that is not to say we are distant (FR157).

Although some survey participants reported a decline in sexual activity with relationship duration, couples made some effort to keep their sexual relationship alive. A married woman who identified as a practising Christian said:

> we both enjoy sex when we get round to it! We love to read 'Forum' type books which 'turn us on'; and although I need some help with KY Gel or similar [for my] dry vagina, we have fantastic orgasms and wonder why we don't do this more often! (FR18-ACW).

Another woman described her and her partner being "less often sexually intimate" than earlier in their relationship. To address this, they "aim to pleasure each other at least once a week". She said:

> …ill health has interfered with this at times but the goal remains! We both believe it is important to maintain this aspect of the relationship and that in a lesbian relationship this can be more of a challenge (particularly for two post-menopausal women) (FR23-ACW).

A man in a long-term partnership described how:

> there is less sex in the relationship…sex tends to happen more often than not these days within threesome contexts…we are very affectionate but the sexual spark is not so strong. We were quite sexual for the first 15 or so years but [this has] gradually declined. This seems a reasonably common occurrence amongst our gay friends in long term relationships (MR57).

In summary, a significant proportion of this sample of Baby Boomers value sexual pleasure with a partner. Some participants indicated that, in the face of adversity, they have taken steps to maintain the sexual aspect of their relationship. Adaptations described included lubricants, erotica and threesomes. Such adaptations will likely

continue for as long as they remain effective. These are circumstances that aged care providers will need to consider when designing services for partnered consumers.

4.10. Factors that impede sexual pleasure

Respondents were asked to describe any factors that interfered with their sexual pleasure. Their answers fell into six categories, as outlined in Table 4.20. The most significant issues were health (n=61, 41%) and lifestyle factors (n=54, 36%), often accompanied by reduced sexual desire. These results reflect an ageing generation torn between the competing commitments of work and family while navigating age-related hormonal changes. A significant proportion of respondents reported stress, fatigue, or illness being a feature of their relationships. Despite these problems, most indicated that their continuing sexual relationship was important to them and, wherever possible, they sought solutions to problems as they arose or accommodated permanent changes by adapting their sexual repertoire and/or maintaining physical intimacy where possible.

Table 4.20

Factors that interfere with sexual pleasure

Themes	N=148 (%)	Examples
Health conditions	61 (41%)	Prostate surgery, prostate cancer, diabetes, heart conditions, chronic pain, chemotherapy, Alzheimer's, urinary tract infections, side effects of medications, arthritis, joint pain, back pain, sleep apnoea, injuries, weight gain, occasional ill health, depression
Lifestyle factors	54 (36%)	Time and work pressures, stress, fatigue, TV/internet usage, financial stress, alcohol intake, different bedtimes, working away, sleeping separately
Sexual and psychosexual problems	32 (22%)	Reduced sexual desire, erectile dysfunction, vaginal pain, premature ejaculation, sexual side effects of medications, sexual aversion, past history of sexual abuse, poor body image, being performance focused
Hormonal changes	19 (13%)	Menopause - hot flushes, irritability, lubrication problems
Nothing	18 (12%)	"nothing"
Intrusions by others	16 (11%)	Children living at home, minding grandchildren, guests staying, unexpected visitors, telephone ringing, intrusive noises, societal expectations
Relationship issues	8 (5%)	Disharmony, disagreements, tension, poor communication, lack of affection, moods, emotional outbursts

Also present in the data was evidence of ageist and discriminatory attitudes by others, including privacy intrusions. Some participants felt challenged when trying to find

intimate moments with other people nearby. Two women said, "[I experience] privacy issues. [My] family seem to think that I am "past it" (FR76) and "having grown up children still living at home and having to be quiet [interferes]!" (FR131-ACW). What makes these results interesting is that they provide a glimpse into the types of challenges that Baby Boomers may face in congregate living situations, such as RACFs.

4.10.1. Sexual remedies

When asked if sexual pleasure was an essential part of life, just over half of respondents to that question (51%) answered yes. Many survey participants also indicated that they accessed products to facilitate their mutual sexual pleasure, listed in Table 4.21. As a consequence, it is reasonable to assume that because pleasure plays such an important role for these individuals, they will continue to use sexual remedies and aids in the future.

Table 4.21

Sex-related products currently used by Baby Boomers

Category	Examples
Products	Erotic literature
	Lubricants
	Massage oils
	Pornographic audio-visual media
	Sex toys - including vibrators, dildos
Medications	PDE5 inhibitors (e.g. Viagra, Cialis)
	Hormone replacement therapy
	Topical oestrogen creams

4.11. Conclusion

Being partnered enriched the lives of the majority of these Baby Boomers, improving their quality of life. The majority of respondents experienced joy, comfort and pleasure in their togetherness, with most wishing to remain together. They described the emotional, physical, mental, sexual, spiritual and social satisfaction their intimate partnership provided. Balancing individual needs, exercising tolerance, and building trust between partners was important, as was a positive attitude. There was evidence that the comfort, safety and pleasure each partner experienced contributed to their mutual wellbeing, by creating a safe, relaxed home environment. Pleasure of all sorts

was highly valued by many in this group. For most, living and sleeping together was integral to their relationship since much of their relationship took place at home and in bed.

These findings suggest that positive intimate relationships serve a protective role and that relationship satisfaction and personal wellbeing are inter-related. This study raises the questions of how these individuals would fare if separated, especially if separated involuntarily, and what impact that might have on health and social services. Assisting happy couples to remain together for as long as possible and supporting their relationship needs may be a more mutually-beneficial course of action. The next chapter explores partnered Baby Boomers' attitudes to couples being separated and with their attitudes to residential aged care more generally.

Chapter 5. Baby Boomers' Attitudes to Residential Aged Care

5.1. Introduction

The previous chapter presented the current state of Baby Boomers' intimate relationships. It described the elements that gave them meaning and value, the relationship features they considered vital (such as living and sleeping together), and the stressors and health concerns that currently impact on their relationships. In anticipation of partnered Baby Boomers remaining together in aged care settings, the research questions addressed in this chapter are: (2) what are Baby Boomers' attitudes to residential aged care? and (4) what are possible pathways to integrating partnered Baby Boomers into residential aged care?

The findings presented are drawn from data collected from semi-structured interviews with key informants in the aged care sector and an anonymous online survey of partnered Baby Boomers. The chapter begins by introducing the key informants. It then presents key informants' views on Baby Boomers' attitudes to aged care, followed by partnered Baby Boomers' attitudes to residential aged care facilities (RACFs) and the experiences that have shaped those attitudes. Lastly, discussion turns to Baby Boomers' attitudes to remaining with their partner and their anticipated privacy needs in aged care settings. The data gathered forms a resource for future discussion and policy setting in the aged care industry.

5.2. The key informants

Key informants included senior public servants[21], academic researchers, gerontologists, consumer advocates, educators and trainers, aged care consultants, quality assessors, a chief executive officer and general manager of two aged care organisations, mid-level managers, registered nurses, a care worker, a recreational officer, a sexual health physician, a lawyer, a psychologist and a sex worker.

[21] To maintain confidentiality, one senior public servant, two quality assessors registered with the Australian Aged Care Quality Agency and three research academics are listed in Table 5. 1 using their other (equally valid) job descriptions.

Interviews began in July 2015 and concluded in October 2015, spanning 13 weeks in total.

Table 5.1

Key informants by job description and location

Interviewee	Role	Location (by state/region)
Dr Anthony Brown	Executive Director, Health Consumers NSW	Sydney, NSW
Dr Rosie King	Sexual Health Physician	Sydney, NSW
'Brett'	Sex worker	Sydney, NSW
'Helen'	Lawyer	Sydney, NSW
'Nancy'	Senior public servant	Sydney, NSW
'Susan'	Family advocate	Sydney, NSW
Anne Devine	Registered Nurse	Taree, NSW
Dr Michele Chandler	Clinical Nurse Consultant/ Director, Maevis Group	Regional NSW
Dr Janice Herbert	Consultant Gerontologist	Lennox Heads, NSW
Colin McDonnell	Lifestyle Consultant, UnitingCare ACT/NSW	Central Coast, NSW
Dr Rhonda Nay	Emeritus Professor, Australian Centre for Evidence Based Aged Care, La Trobe University	Banora Point, NSW
Gabrielle Rodda	Head Teacher, Health, Aged Care and Nursing, North Coast TAFE	Ballina, NSW
Veronica Stevenson	Care Services Employee	Cessnock, NSW
Jenny Zirkler	Executive Care Manager, Nambucca Valley Care	Nambucca Heads, NSW
'Phyllis'	Family advocate	Blue Mountains, NSW
'Sally'[22]	Recreational Activities Officer	Regional NSW
Dr Ralph Hampson	Senior Lecturer, Master of Ageing program, University of Melbourne	Melbourne, VIC
'Barbara'	Registered Nurse	Melbourne, VIC
'Eric'	Psychologist	Melbourne, VIC
'Phillipa'	Registered Nurse	Melbourne, VIC
'Melissa'	Health researcher	Brisbane, QLD
Ricki Menzies	Training and Development Coordinator, Queensland AIDS Council	Gold Coast, QLD
Natasha Milner	Regional Education Co-Ordinator, True Relationships and Reproductive Health (formerly Family Planning QLD)	Gold Coast, QLD
Louise Dwyer	General Manager, Beaucare	Beaudesert, QLD
Dr Drew Dwyer	Registered Nurse/ Director, Australasian College of Care Leadership and Management	Noosaville, QLD
Janet Ryan	Registered Nurse/ teacher, TAFE QLD SW	Regional QLD
Jeff Fiebig	General Manager, Major Initiatives, ACH Group	Adelaide, SA
Jane Mussared	Chief Executive Officer, COTA[23] South Australia	Adelaide, SA
Dr David Panter	Chief Executive, ECH Incorporated	Adelaide, SA

[22] Names represented in inverted commas are pseudonyms given to maintain participants' confidentiality.

[23] COTA (which stands for Council on the Ageing) is a consumer advocacy organisation for older Australians with branches in every state and territory.

The original intention was to sample data from every state of Australia, in urban and non-urban areas, to compare and identify any geographical differences, however, only participants from New South Wales, Victoria, Queensland and South Australia consented to be interviewed. Of these, almost half were located in regional areas. Table 5.1 provides a summary of participants. Participants were sourced from conferences on ageing I personally attended, internet searches, published research, government reports, the social networking site, LinkedIn, or from word-of-mouth recommendations by other key informants.

5.3. Key informants' perspectives on Baby Boomers' attitudes

According to COTA[24] South Australia's Chief Executive Officer, Jane Mussared (BB[25]):

> [what Baby Boomers'] overwhelming demand of us is that we redefine ageing, that we turn it from a kind of chronological period where people do things to them and for them to a period where instead they are citizens who are influential, who are learning, who are working…and who are not subject to…an age stereotype.
>
> I think this next social revolution will be around age and the getting rid of this kind of ageism that pervades everything we do…and I guess I have a sense that if we ride the Baby Boomer demographic wave and use its energy, then we should create a different expectation when that group of people get to be in their 80s and 90s

The majority of key informants, most of whom were Baby Boomers themselves, thought that the Baby Boomer generation have much higher expectations than the current generation in residential aged care. This was partly because they are a generation who have lived in an era of prosperity and have learned the meaning of consumer power, and partly because of the increasing need for individuals to significantly contribute to the cost of their own aged care services, as gerontologist, Dr Jan Herbert expressed:

[24] COTA stands for Council on the Ageing
[25] BB denotes a key informant born in the Baby Boom generation.

> They're going to demand far more choice…[Those in] the residential care system now have always seen [the] doctor as god, have always accepted what they've been given. They're appreciative of anything that's done for them. I think once we start to move onto the next generation they're not going to be so accepting … aged care was something that was provided by the government and you accepted what you got…Nowadays, residential care is a very expensive option. Around here you're looking at about $300,000 to go into an aged care facility… So, if you're going to pay that you're going to say, "what am I getting for that?" You're going to be far more demanding…

With reference to Baby Boomers, Jan said that they will want:

> …privacy, the ability to make decisions about their own life - their own welfare, the quality of their care, a glass of wine with dinner. [They will say] "I've had that all my life, why shouldn't I have it now? I don't want a main meal in the middle of the day and meat pies at night with a glass of cordial. Forget it! No, I want something different and I'm paying $300,000 plus most of my pension for it, so don't imagine I'm going to sit back and quietly accept it".

Jeff Fiebig, General Manager, ACH Group (BB[26]) believed that the overwhelming view was that Baby Boomers will require assistance that "fits in with them rather than they fit in with aged care" and that "aged care ought to be built around the life of the person and be sublimated to the life of the person, not the other way around". Key informants believed that Baby Boomers will choose to continue living in the community in their own homes and, wherever possible, avoid being institutionalised. As a result of increased government funding for community care, it was thought that residents of the future will fall into one of three categories: (1) those with dementia, (2) those with chronic health conditions; and (3) those requiring palliative care. For these reasons, some interviewees anticipated that fewer RACFs will be needed in the future. According to Dr David Panter, Chief Executive, ECH Incorporated (BB):

> …a year ago, we divested ourselves of our residential care. We had a thousand nursing home beds and we sold those in order to generate significant funds to be able to invest entirely now in independent living and enabling people to live longer within their home environment and be able to die in their home environment…I think residential care is, in the longer term,

[26] BB denotes key respondents who are Baby Boomers.

> unsustainable. I think it is necessary for a much smaller group of the population than is currently the case.

With the advent of Consumer Directed Care in the Home Care[27] sector, where aged care funding is managed by the individuals receiving it, Mrs Gabrielle Rodda, Head Teacher for Health, Aged Care and Nursing, North Coast NSW TAFE[28] speculated that residential aged care as we know it could largely become a thing of the past, where "essentially, you could get a group of consumers together who will then control their own funds and distribute them rather than have a formalised residential aged care facility. " However, according to resident advocate, 'Susan'[29], grassroots models such as these may not be an improvement due to their own inherent problems:

> there are people now talking about different types of aged care, of…groups of friends getting together and buying a big house and hiring their own care and that in itself is totally fraught… we are always very optimistic about how we're going to age …just as little kids grow up in different ways - you know some people have growth spurts at different stages and they learn to speak or to walk or to run or whatever…I think we've got that same individualistic timetable of how we age and some people get dementia, some people's hearts give out, some people's legs give out…and the difficulties of coping with those sorts of things within a group of friends I reckon would be really hard.

Interviewees anticipated that, for Baby Boomers who may eventually require intensive daily care in a RACF, significant cultural change will be needed to accommodate them. This will require a shift away from rigid, task-oriented schedules to a 'person-centred' model of care, which requires flexible service delivery responsive to each individual's needs. According to Dr Drew Dwyer (BB), principal consultant, Australasian College of Care Leadership and Management:

> once they're in a residential setting, I think the key need for them will be flexibility…[of] the environment…One of the first audit questions I look at is what time they want to be woken up in the morning and most of them just want to be left alone to sleep in until they're ready to get up, but unfortunately it doesn't work that way…I think the flexibility to be

[27] Home Care is a term used for aged care services delivered to community-dwelling recipients in their homes.
[28] TAFE stands for Technical and Further Education.
[29] Names represented in inverted commas are pseudonyms given to maintain confidentiality.

> understood and to have the environment set up their way [is key].

Senior public servant, 'Nancy'[30] (BB), thought that, for Baby Boomers, quality of care will be assumed and, instead, quality of life will be emphasised:

> [If] I need it [care] then I should get it and I don't care much about it as long as the appropriate care is given. But I want more of a life and I want to have a happy life or quality in my life if I'm in residential care or somewhere besides my home. So, I think with the Baby Boomers there'll be more of a demand in that area.

A 'quality life' included residents being consulted and having the autonomy to make decisions about their daily life, including what activities they engage in, who they choose to spend time with, the degree of privacy they need, what they eat and drink. It meant being able to continue the life one had prior to entering residential aged care wherever possible. Maintaining a degree of independence and privacy, being treated like an individual with individual needs and preferences, being treated with respect, maintaining important relationships and connections with the community, and having enjoyable and meaningful activities of one's choosing were essential features. Key to many of these was the freedom to take risks.

According to participants, couples in care environments require accommodation that meets their needs and provides sufficient privacy. As Colin McDonnell (BB), Environmental and Lifestyle Coach, UnitingCare Ageing NSW/ACT put it, partnered residents require

> …double rooms when their husband or wife comes so that they can have sex and not be disturbed - a room where they can make a mess…an independent base where if "I want to do this now, I'll go and do this now".

The consensus was that improved training of managers and care staff was needed to firstly understand and, secondly, respond to couples' needs in a caring and appropriate manner. This was especially needed with young staff, fresh out of school or TAFE, since, according to Emeritus Professor Rhonda Nay, La Trobe University, "younger people just do not think older people are interested in sex and so it's never raised".

[30] Pseudonym used to preserve anonymity

Interviewees said "a change in attitude…around social taboos" was required to support older adults with all aspects of their life, including their relationships. According to Natasha Milner, Regional Education Co-ordinator, True Relationships and Reproductive Health, conversations are needed

> …about people's living arrangements, sleeping arrangements…sexuality and relationships comes [sic] into that…it's not something that's ignored. …[What is needed is] an environment where if everybody that is supporting people that are older are comfortable enough to talk about and bring up sexuality and relationships and that it's on the agenda, like anything else that you would talk about. I think [that] would be really key to change happening, and I know there's been research done into older people and that's what they want…but because of those social taboos and discomfort, it's very often not happening when it should be happening and needs to be happening, and it doesn't require really any extra resources, extra money or extra anything really. It's just that change of culture, I think.

Rhonda Nay stressed that such conversations must also include sufficient information for older adults to make informed decisions about medical treatments they consent to. She said:

> …an awful lot of the medical help they receive for other things actually stuffs their sexuality and this is never discussed with them. So really in the policy it needs to be stated in great big letters if you were going to mess with my libido you better bloody tell me otherwise you haven't got informed consent. And so many of the drugs that are given to older people do stuff with their libido but they don't know that. They are only slightly better at telling blokes when they've had a prostatectomy that it might stuff them but even here they don't necessarily always tell them.

5.4. Survey respondents' perspectives on residential aged care

Survey participants were asked "what experiences have you had with residential aged care facilities (nursing homes) and what impact did they have on you?". Just over half (n=76, 51%) had experienced visiting friends or family in RACFs, of which 64% (n=49) said one or both of their parents lived in RACFs currently or in the past. The next largest group was comprised of people who had work-related experience of aged

care facilities (n=49, 33%). Twenty-three people (15%) said they had no direct experience of nursing homes and, with the exception of one person, it was not possible to determine themes from their answers. The remainder of respondents (12%) did not indicate whether they did, or did not, have any direct experience of RACFs.

Table 5.2

Themes emerging from the question "what experiences have you had with residential aged care facilities (nursing homes) and what impact did they have on you?".

Themes	Total		Women		Men	
	(N=150)	%	(N=124)	%	(N=26)	%
Quality of life	76	51%	65	52%	11	42%
Fear of dying in an institution	76	51%	67	54%	9	35%
Autonomy and choice	60	40%	53	43%	7	27%
Staff influence	26	17%	22	18%	4	15%
Responses by family	14	9%	13	10%	1	4%
Expressing sexuality and intimacy	12	8%	10	8%	2	8%
Home-like environment	12	8%	11	9%	1	4%
Positive aged care experiences	10	7%	9	7%	1	4%
Losing a partner	10	7%	10	8%	0	0%
Respecting privacy	9	6%	9	7%	0	0%

Ten themes described the main concerns in the data, presented in Table 5.2, with the most commonly mentioned themes being 'quality of life', 'fear of dying in an institution', 'autonomy and choice' and, to a lesser extent, 'staff influence'. Each of these themes are discussed in the next section.

5.4.1. Major Themes

5.4.1.1. Quality of life

Respondents rated good quality of life as a high priority in aged care settings. The theme 'quality of life' was seen as thriving in day-to-day life rather than merely surviving. Both implicitly and explicitly, it was evident that respondents' experiences of nursing homes had caused them to reflect on what quality of life meant, not only for the older adults they knew but also for themselves as they age, as in this woman's example:

> My views about nursing homes are that they are good while you have your faculties but, if you don't, I believe in being able to end your own life. I see no quality of life laying in a bed,

> not knowing anyone, not being able to do anything, just for the sake of breathing (FR134).

"We do not see existing as living" was one woman's position (FR25), while another said, "I strongly believe that the quality of life is more important than quantity" (FR91-ACW).

Residents' quality of life, positive or negative, could in turn affect their partner's or family's quality of life and vice versa. Respondents described the positive and negative impacts of witnessing their loved one's final years. One woman had decided that, as a result of nursing three parents, "I will [be] willing [to] go into aged care" since it "frees family to live their lives without guilt and loss of quality to their lives" (FR88). Another man described the deterioration of his mother's quality of life in her final years and the effect it had on him and his family. He said she "suffered from long term dementia…it was devastating to watch her decline into a very slow lingering death. She eventually ceased to be the mother and grandmother we once loved" (MR50). Implicit in this example is the idea that a quality life includes maintaining one's identity, individuality, and meaningful connections with others. Several respondents said it is important to be "yourself". One woman described residents having "no time to be yourself, [you] always have to conform". According to her, RACFs "do not cater to the individual person", i.e. care is not person-centred (FR110). Another woman, whose mother and relatives "ended up in homes", said "[I] can't see me being in one with my outrageous personality. [They are] hotbeds of gossip [with] no privacy" (FR37).

Women were more likely than men to reflect on the emotional benefits of older couples remaining together. This example provided support for the benefits of keeping couples together, both in terms of reducing the burden on staff and improving the quality of life of individual partners:

> I have seen couples who stayed in one and their relationship is awesome. Seeing most of them look after each other. Sitting in their own couch holding hands until they fall asleep. Older ladies wanted the best clothes and care for their husbands. The sweetness...the way they looked at each other, it was full of love and commitment (FR30).

Separating couples appeared to reduce quality of life. Another woman described feeling "saddened" to see

> …the parents of a dear friend of mine, devoted to each other in a long and happy marriage, [who] were obliged to be separated in their nursing home facility, when the wife (who had MS) needed a higher level of care than the husband. As her devoted, primary carer for many years, it was devastating for him to have to live apart from her, though they were in the same facility (FR26).

Respect for people's individuality was also considered essential. One respondent said:

> It's important for me to feel that my partner and I are treated with respect, as individuals who have lived full lives, raised children and had careers. I find the infantilisation of old people in care abhorrent (MR2).

Another who hoped to be "treated with respect" said:

> I had a high level [professional] job until I had to resign to look after my husband. I'm no "little old Lady" and am probably more computer literate than many carers so I wish to be treated as an equal, maybe a friend eventually, but not just Mrs...in room 35 (FR89).

Participants spoke of the importance of older adults being able to maintain existing relationships, form new friendships, and connect socially with other people, as in this man's example:

> It seems to me that once someone enters an aged care facility they very quickly become separated from former friends and family, cut off and quickly forgotten simply because they can no longer easily engage in social activity with the significant people in their lives (MR50).

In contrast to this, one woman described her 89 year-old mother's improved social prospects after moving to a nursing home, saying:

> she has been there for two years…and is very happy there. She was VERY worried about moving into the home (it took her a year of agonising) but she feels safe, and has made a lot of new friends there. She was becoming very anxious and socially isolated in her own home, where she lived for about 5 years, after my father died (FR26).

However, for others, social connection decreased:

> My mother-in-law is in a single room nursing home, but is not encouraged to go out or mix with other residents. This is not what I would like. I would like interaction with others (FR45).

In this example, a respondent described the pressure exerted on some residents to conform socially:

> I cared for a bachelor uncle who had to go into care at 90 [years of age] due to physical frailty. He had chosen a solitary life and was very self-sufficient and content in his own company. The aged care facility tried to force him to socialise and eat at a table with 5 women. He had eaten alone for his adult life and really resented this. No allowance was made for solitary activities. He was given a garden area but had to access it at a time when others were there, taking away the pleasure for him. I felt decisions were made for the needs of others over his needs and rights [because] it looked bad, him eating alone (FR69).

One man expressed the view that one way to improve quality of life, for both residents and himself (as a visitor), was by taking the time to develop meaningful relationships with residents, in spite of its emotional toll. He said:

> I used to volunteer at a residential care home...I read to people at the home - whatever they asked me to read. I did that for a little over 1 year. The elderly women I read to suffered from various ailments, including one woman who had serious diabetes and had lost her eyesight and her legs - she loved Mills and Boon books, which I read to her twice a week (yep, Mills and Boon). They were lovely people. But two of the ladies with whom I had become friends (including the lady with diabetes) died suddenly. I was there in the last moments of one lady's life. That was the last day I ever went to a home (MR99-ACW).

As predicted by key informants, a key ingredient in quality of life was being able to continue doing the things that one had always enjoyed. As one survey respondent said: "family have to be vigilant in how their loved ones are cared for. People in care have a right to be happy" and to have their "needs taken [care]of" (FR88).

For some, having a 'homelike' and supportive atmosphere was an important aspect of the physical environment. One person (FR145-ACW) lamented:

> I have to say residential facilities have completely lost their homeliness [sic], they are so invasive now you should call them hospitals for the elderly. There are no choices left.

In residents' rooms, adequate space, suitable lighting, furniture and decorations of choice, and floor finishes all contributed to making their space feel like 'home'. Bedding arrangements were often singled out. One woman said:

> most care facilities I have been in put their residents into single beds, which I think is appalling when they have come from a double or queen bed at home. Suddenly [they are] given a bed only big enough for children (FR131-ACW).

Some respondents described nursing homes as "very depressing". One woman described people being "treated like children". She said there were "no double beds" and "couples are separated by furniture, and intimacy is not encouraged" (FR79). Unpleasant smells and excessive noise were highlighted as features that detracted from a sense of homeliness. One woman recalled "[it was] horrible, I'll never forget the smell of the place" (FR39). For another, sound transmission was more an issue, saying "if, god forbid, I finished up in a nursing home I would definitely want the walls & doors of my room sound proofed [and] not just so people can't hear me!" (FR40-ACW).

Some people valued time with animals and, as with any home, access to outdoors was considered important, as in this example: "[I want] the ability to get outside easily and garden and pat dogs" (FR9). Another factor considered important for quality of life was receiving better care than families could offer at home, as this man described:

> My mum developed alzheimers [sic] back in England and she went to a nursing home there. It was caring and more social than she actually cared for but she found her comfort. The medical supervision was more than I could have provided even if she'd have come to Australia and lived with me (MR10).

At the extreme end of the range, several respondents expressed the view that nursing homes do not represent quality of life and that, without that, life is not worth living. One man described having "volunteered in aged care facilities". He said, "I do not like them and would not want to live in one. Euthanasia is more appealing" (MR84-ACW). When it came to having dementia, one woman thought that ending one's life

was preferable, describing it as "the cruelest [sic] disease". She said, "it takes the essence and leaves a shell. It's so demeaning. I would endeavour to end my life if [I] was diagnosed with it" (FR89).

In summary, these findings include additional parameters in the concept of 'quality of life' beyond personal happiness. Importance was placed on (1) one's environment being not just safe and secure but comfortable, enjoyable and 'homelike', with adequate levels of privacy. When referring to couples, participants thought couples' wellbeing could be enhanced by providing accommodation that supports their relationship, with suitable bedding and adequate soundproofing. Lastly, maintaining people's 'personhood' (Kitwood & Bredin, 2008) was stressed, providing them with the continuing ability to make decisions, maintain their identity, do the things they enjoy and live according to their personal preferences.

5.4.1.2. Fear of dying in an institution

Fear of dying in an institution emerged as both a sub-theme in 'quality of life' and as a theme in itself. Dying, in this context, referred to the dying process, the final years of one's life. As one person expressed, "Death! That's the big one, isn't it? I think preparing ourselves for death and dying is the biggest challenge that very few of us want to confront" (MR49-ACW).

Many respondents used emotive language to evoke the theme of 'dying in an institution', revealing feelings of hate, disgust, revulsion, anger, fear, guilt, aversion, denial, dislike, and sadness in response to their experiences of residential facilities. A great many respondents expressed disgust for nursing homes, indicating that they would not choose residential aged care for themselves. The explicit statement made by a significant number of respondents was "I never want to end up there". The implied, unspoken statement being made, predominantly by women, was "that is no way to live (or die)".

After visiting relatives RACFs, one man said, "I find them completely unappealing and I would not wish anyone to be in them" (MR2). Another example of this disgust response being expressed as a rejection of the aged care experience, was:

> I hate them. I don't want to go into one. It was very depressing to visit my mother in law who was a resident and see the physical, social and emotional disability and distance in the faces and activities of other residents (MR31).

For one woman, feelings of disgust demotivated her to visit her "95 year old Mum is in a care facility". She said:

> I love my mother but I hate going to the facility. It is very expensive and they appear to look after her but I feel [that] way to[o] many drugs are given to her - in my opinion. It always smells awful to me as well (FR168).

Women were more likely than men to express their disgust in relation to smells and hygiene, as in this example:

> They smell like urine, people sit in chairs staring vacantly into space or wandering the corridors not knowing who they are. The effect [on me] is [to make] a euthanasia plan, if I don't get dementia first and forget to follow through with it (FR66).

Disgust and fear were sometimes expressed together. In the case of a woman whose mother "lived for 3 years in an Aged Care Facility", she said:

> It took me many visits to many unsavoury and unsatisfactory establishments before I found a place I felt was of sufficient standard for her according to our ability to pay. Some of the facilities I visited were, in my opinion, dreadful - in cleaning standard, staffing standard, up-keep standard, food standard, client emotional care standard, personal heigeine [sic], [and] medical attention. This had a profound effect on me in that I am fairly well afraid of having to live in one when the need arises (FR157).

Respondents also referred to examples of dehumanisation of residents by staff members and families. For instance, one woman described her experience of nursing homes as "bad", saying:

> l think they were pleased to see the end of me when Mum died. Being a reg[istered] nurse I was aware of their standards not being what they should be. Food was one of the main problems, and treating the residents like they had no brains. A lot of young people have no respect for older people (FR41).

Another woman told a tale of "loss of privacy, poor fresh air circulation, ongoing small financial abuse by staff of [one and] serious financial abuse by a family member of another" (FR147). One simply said, "they have a long, long way to go to recognize residents as human beings let alone sexual beings" (FR91-ACW).

Participants commonly expressed fear of becoming helpless, of having no alternative choices. One woman who worked "in a nursing home for 3 years" felt "very fearful of growing old and losing [her] dignity and independence" (FR32). Another expressed a fear of being separated from her partner, saying "I worked in a nursing home where married couples where [sic] separated and that [thought] frightens me - to be separated from my husband" (FR167).

Some expressed a mix of anger and contempt at the treatment of older adults and simultaneously distanced themselves from what they deemed unacceptable practices in aged care facilities. One woman, whose "mother died in aged care", said she was "cared for by people of limited imagination, intellect [and] empathy" (FR52).

For some participants, dying with dignity meant maintaining one's sense of dignity by choosing one's own time and manner of death. It is best exemplified by this example:

> I would like to have the right to die a dignified, pain free death at a time of my choosing, or at a time my guardians determine that there is no longer any hope of recovery or when the quality of my life deteriorates to the point of being an inanimate body in a bed (MR50).

While reflecting on experiences with loved ones, many people said they preferred euthanasia for themselves, as in the previous example. Dignity was associated with maintaining quality of life, especially one's sense of identity.

In summary, dying in residential aged care was an emotive topic. Most participants expressing this theme voiced a preference to die in their own home rather than receive the same treatment they had witnessed loved ones receive. A few referenced euthanasia as a preferable alternative to dying in residential aged care.

5.4.1.3. Autonomy and choice

The third theme that emerged, 'autonomy and choice' appeared as both a sub-theme within 'quality of life' and as a theme in itself. This theme referred to being given choices and having the autonomy to make decisions and was referred to more by women than men. Autonomy and choice included the question of who was making the decisions and whether residents themselves were given choices about the 'big picture' of where they chose to live. In one man's account, it suggested that his mother was not in a RACF by choice. He said:

> In the early years of my mother's incarceration (she saw herself as being in jail), whilst she was still ambulatory, she would constantly try to escape and go home. [It was] very distressing for all concerned (MR50).

Other important choices related to the details of day-to-day life, such as whether residents were able to follow their own rhythms and preferences rather than having rostered tasks imposed on them. Perhaps the most poignant description of the distress caused to residents and their families by loss of autonomy was this example:

> My Mum … didn't enjoy the regimented aspect of it and she didn't like having to mix with all the other residents as she'd lived alone for many years after my Dad died. She didn't like people walking into her room unannounced and she resented the large number of people who cared for her as she could never build a relationship with them. Dementia was an issue of course but I felt for her lack of privacy. She could never lock her door and have her own space.
>
> I fear being in this regimented environment as I spent my childhood in boarding school and I don't want to go back into that kind of environment where you have little control over what you do with your time (FR29).

For others, the loss of autonomy related not only to the small day-to-day tasks but also to the lack of help with the transition into institutionalised living. One woman thought that aged care facilities mostly "do an amazing job" however she identified that, for residents, the "biggest thing to adjust to is not being able to cook, do their own laundry, or even make a cup of tea. Everything is taken away from them so abruptly" (FR65).

This theme illustrated the role that having choices and maintaining one's autonomy plays in retaining one's identity and sense of purpose. One woman gave an account of her mother's experience, saying "a very strong, independent woman was infantilised. Her wishes were disregarded, she was kept indoors with no access to nature" (FR52). Another said her impression of aged care facilities was "that they are places where bodies go to be housed until physical death occurs". She witnessed "much learned helplessness [and] loss of sense of purpose within their communities" (FR3-ACW). There were also accounts of staff being distressed by residents' loss of autonomy. This woman said:

> both as a professional in the aged care sector, and with my late mother and an elderly friend…I have been quite dismayed about the way people in [nursing homes] have so little control and/or choice about their daily lives (FR136-ACW).

As key informants predicted, respondents preferred to envisage a future where they maintained their own autonomy. One woman summarised this sentiment:

> I want to help my husband and myself to avoid these regimented places for as long as possible. We prefer to live in our own place decorated as we choose, eat and drink what we choose and prepare, eat out once or twice a week, live to our own timetable and take advantage of [the] nearby river, bike path, public transport, shops, cafes, clubs, parks and other facilities (FR121).

5.4.1.4. Staff influence

Respondents were of the opinion that the people who exerted the most influence on residents' daily lives were the direct care workers (nurses, nursing assistants and care workers). Consequently, staffing levels and staff attitudes were a source of concern. According to one woman:

> The staff did the best they could, given staffing numbers. However, it wasn't great attention to anyone. It broke my heart to see the sad [and] lonely people living there. Then my mother finished up in one. Dad [and] I did the best we could daily to compensate for not being at home but you can't be there 24/7. I find them very depressing places (FR40-ACW).

Management policies, occupational health and safety practices, and staff attitudes appeared to determine the cultures within RACFs. According to key informants, the organisational culture in each facility influenced staff attitudes towards couples. It was clear in the data that some facilities had discriminatory policies and practices that were unsupportive of couples' relationships. In many such cases, these policies were presented as occupational health and safety rules. According to one registered nurse:

> Residents are not permitted to sleep in a double/queen bed, [this is] secondary to occupational health and safety. Beds have to be single and need to [be] adjusted up and down to reduce risk of back injury to staff when attending to resident care. We have 2 couples in our facility at present they each have their own bed in their own room. Rooms are not big enough to permit double beds anyway. [Having] couples sharing a room is not encouraged…
>
> Let's get real. An aged care facility is not going to accept a potential resident who makes it known that they are sexually active. You need to consider that management would see this as a negative when deciding if the resident was suitable. Aged care facilities are not set up for nor do they encourage any male/female relationships. It is too difficult, there are enough problems (FR6-ACW).

What is apparent in the previous example is that some aged care organisations are primarily task-oriented and are organised around staff convenience. However, divergent views were also expressed. Some aged care employees focused on the resident experience, which is consistent with the 'person-centred' model of care, as this nurse indicated:

> When working with care assistants I always remind them of the need to remember that these people were young once and lived busy active lives never giving a thought to incontinence, pain, confusion, pureed food and thickened drinks and that mostly they haven't chosen living in care as their preferred option (FR27-ACW).

The staff-resident culture within RACFs was considered important. This highlighted a need for careful selection and adequate training of staff. One aged care professional described working with "some excellent staff" as well as "some with appalling and even abusive tendencies…often from untrained backgrounds with dodgy personal values" (FR97-ACW). A former aged care worker indicated a "need for an

environment that is generous [and] inclusive of diverse ways of being - sexually or otherwise". She was particularly "concerned about people who are not vanilla in their sexual tastes", saying

> there is no catering for them at all in aged care. That's a real denial of human rights. Having things that have been part of one's intimate life denied, made shameful or treated with contempt would be a really bad outcome … It's [going to] require a much more adult relationship between staff and residents - MUCH MORE (FR104-ACW).

5.4.2. Less frequently mentioned themes

Less than a tenth of respondents raised the additional themes of 'responses by family', 'expressing sexuality and intimacy', 'home-like environments', 'dying with dignity', 'losing a partner', 'positive aged care experiences', and 'respecting privacy'. A detailed description of each of these themes now follows.

5.4.2.1. Responses by family

The theme, responses by family, indicated the ways in which families responded to a loved one living in a RACF. It particularly emerged in comments like the following:

> Dad was in a nursing home. [It had] well meaning staff but [was] totally understaffed. The six of us, dad's kids had a weekly roster to ensure he was well cared for (FR135).

This statement is indicative of the efforts some families made to compensate for inadequate staffing. However, according to a former aged care worker, other families took an 'out of sight, out of mind' approach by maintaining very little contact with their family member. She said, "I found it very sad that the inmates were left by there [sic] families" (FR148-ACW). There were also accounts of some family members financially abusing their relatives (as in the example provided on page 13). Others sought to ensure that their parents had what they needed, as in this example: "my parents were in an aged care facility in a double room. They were together and that was hugely important to me, my siblings and them" (FR149).

5.4.2.2. Expressing sexuality and intimacy

The theme of expressing sexuality and intimacy described a wide range of views. As already mentioned in section 5.4.1.4, at one end of the spectrum were occurrences of expressions of sexuality being actively repressed, as in this example:

> I've worked at [and] visited many [aged care facilities] – [it] seems suppressive in that staff are insensitive to aged sexuality [and] gender preference. In fact, [they seem] cruel in their treatment of patients who still want to be sexually active (MR78-ACW).

Conversely, there were also examples from staff members who were comfortable treating sexuality as a normal part of life. Such individuals were of the view that intervention was only required where sexual behaviours impacted negatively on others. One example was provided by a care aid with 20 years' experience:

> I have encounter[ed] lots of sexual activity. The only time I have intervened was when [a] male resident was performing cunnilingus on [a] female resident in the public lounge. I thought that was maybe too much for anyone else to encounter (FR145-ACW).

5.4.2.3. Home-like environments

In addition to comments about smells (already mentioned), the theme of homelike environments largely described atmospheres deemed un-homelike by participants. One woman referred to her grandmother's experience in a RACF, saying "they are cold and hard places, [there is] nothing of a home atmosphere" (FR59).

There was also mention of space restrictions preventing residents from being with their partner. One woman said there are "no rooms allow partners to be together, only single rooms" (FR7). Another issue was lack of space to bring mementos from home. One staff member said she "found it depressing beyond belief "that there was "lack of room for clients to bring reminders from their homes including furniture unless [the] nursing home [is] very expensive and clients [are] wealthy" (FR97-ACW).

5.4.2.4. Positive aged care experiences

Only a small number of respondents described positive aged care experiences (n=10). In these cases, given that residents themselves were not making these comments, it is difficult to discern whether family or residents were deriving the most benefit from RACFs. Comments ranged from "[they] mostly they do an amazing job" (FR65) and "[it's had a] very positive effect, [they are] great facilities!" (FR85) to one staff member saying "I nursed in Aged Care for 32 yrs. [I] loved the work" (FR34-ACW). Despite their positivity, some respondents indicated that they themselves did not wish to live in an aged care facility:

> I feel generally [there was a] positive impact in terms of caring attitudes of staff; but these facilities are overall rather depressing environments. [I] prefer to avoid [them] if possible, but [I am] realistic about this possibly becoming an option at some stage (MR113).

5.4.3. Themes expressed exclusively by women

5.4.3.1. Losing a partner

The topic of losing a partner arose in some answers (n=10). When reflecting on their experiences of witnessing couples being forced to separate, some women explicitly stated they did not want this to happen to them. One said, "the one thing we HAVE discussed and made the family aware of, is our wish to remain TOGETHER - literally until death us do part" (FR13). Others described the negative impacts of offering partners no alternative but to enter a RACF alone, which is termed involuntary separation[31]. In some cases, facilities were unable or unwilling to house couples together. A nurse in one facility said:

> I hate the way husbands and wives get separated due to lack of double rooms or one person not having a high enough level of aged care funding, so is left at home while their spouse is placed (FR137-ACW).

There were accounts of couples entering care together and being separated by the aged care provider either upon arrival or at a later date. This was a source of distress for

[31] Involuntary separation refers to couples who would otherwise choose to remain together but are offered insufficient opportunities to support this choice.

the partners involved, their family and friends. One daughter described her parents having "to live in separate rooms". She said "my father does not like being alone. I never want to be in a nursing home" (FR14). Another said:

> some family friends moved into the same facility [as my mother]. Married for even longer than my parents, they now reside in different rooms, though they are on the same floor level. I thought that this was rather sad for them. (FR26).

However, respondents also reflected that staying together was not a priority for all couples, especially when a serious illness emerges:

> My father is in [a] nursing home. My mother is not very sad they are separated - my mother does not want to leave her home. My father is dying from cancer' (FR90).

5.4.3.2. Respecting privacy

Some women (n=8) in this sample expressed their disapproval for the lack of resident privacy in RACFs, especially for couples. One aged care employee enumerated four forms of privacy infringement in RACFs:

> Either none or very little consideration is given to married couples, or any resident's sexuality. Privacy is not guaranteed....Wandering residents and staff [are] always interrupting When a couple share a room, there is very little consideration of either partners privacy / intimate moments. [There is] Little to no understanding of either partner needing time out from each other (117-ACW).

5.4.4. Leximancer analysis

In Figure 5.1 and Table 5.3, themes identified, in order of relative importance, were: (1) care; (2) nursing; (3) room; and (4) live. Care, was of central importance to respondents. It referred to both visiting a care facility and the nature of the care residents received. Nursing referred to residents becoming separated as result of being in a nursing home. These themes suggested that entering a nursing home meant partnered individuals had to leave where they lived and live apart from both their partner and their community in order to receive the care they needed. Their 'care' was thought by participants to be unsympathetic to couples. The theme, room, referred

both to room size and to the people who entered residents' rooms. Single rooms were described as the norm whereas couple-sized rooms were rare. Rooms generally lacked privacy. The theme, 'live', referenced both living and dying. It referred to the quality of life lived in a RACF (positive and negative), particularly after the death of a spouse. Many respondents experienced their mother and mothers-in-law entering care after being widowed, particularly if they had dementia. A number of respondents worked in aged care and a small number had no experience of RACFs. Staff were described as having a high impact on the quality of the 'care' residents received.

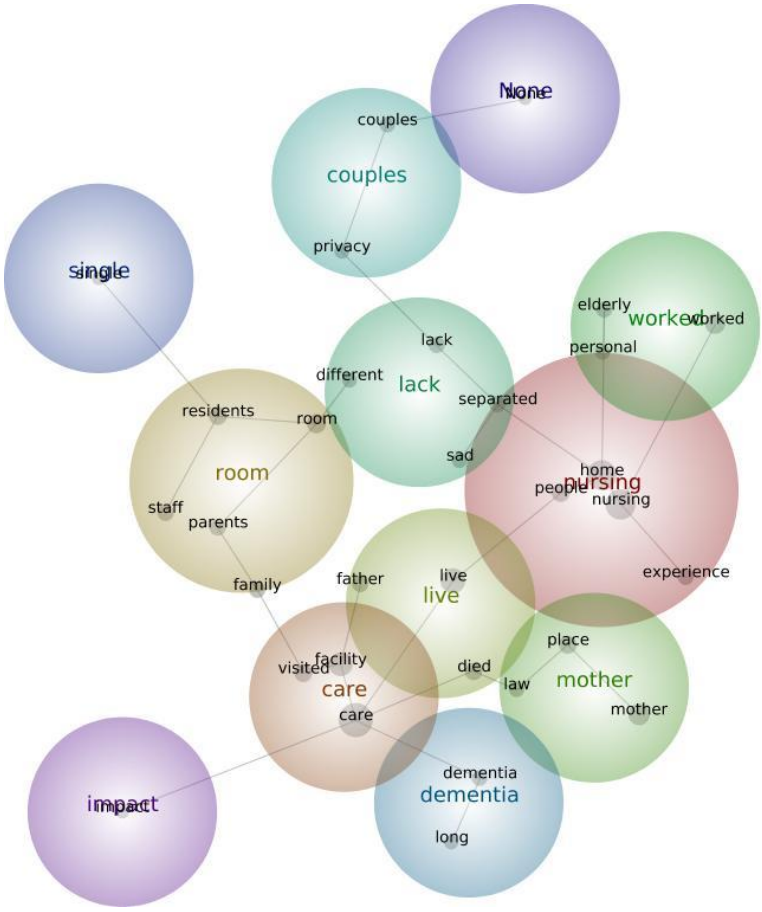

Figure 5.1. Map of lexical concepts in response to the question "what experiences have you had with residential aged care facilities (nursing homes) and what impact did they have on you?"

Table 5.3

Leximancer analysis of answers to the question "what experiences have you had with residential aged care facilities (nursing homes) and what impact did they have on you?"

Themes	Frequency (N)	Examples
Care	87	"I've worked at & visited many. [It] seems suppressive in that staff are insensitive to aged sexuality & gender preference. In fact,[they are] cruel in their treatment of patients who still want to be sexually active. "
Nursing	67	"I worked as a registered nurse most of my life. In the 70s I witnessed an elderly couple (no English) separated in different nursing homes. No one knew. "
Room	52	"…wandering residents and staff always interrupting. When a couple share a room, there is very little consideration of either partner's privacy"
Live	49	"She was becoming very anxious and socially isolated in her own home…after my father died. Her home is a very expensive facility (I won't be able to afford such a Rolls Royce style of nursing home) and is providing her with quality care. "
Mother	43	"My mother in law was placed in a home as she had dementia. She seemed to decline at an alarming rate. [She] spent her days… in chairs around a tv".
Worked	32	"I work in one"
None	13	"None"
Dementia	11	"My mother has dementia and is in a special nursing home. She does not go out."
Couples	11	"[I] worked in 3 different homes. One was good. Others didn't allow couples together"
Lack	8	"…limited share rooms are available and [there is a] lack privacy for couples"
Single	6	"...beds have to be single and need to be adjusted up and down"
Impact	5	"…individual carers have the greatest impact on residents' daily lives"

5.5. Survey respondents' attitudes to remaining together

Survey participants were asked "if you and/or your partner(s) ever need to move to a residential aged care facility for health reasons, how important is it to maintain your intimate partner relationship(s)?" Their responses are summarised in Table 5.4. Almost two thirds of participants (n=92, 60%) answered that they considered maintaining their relationship in a RACF was 'vital' and another 27% (n=42) considered it 'somewhat important'. Men appeared to have stronger feelings than women on this topic. A small number of people remained neutral (n=11, 7%) however very few answered that their relationships were at all unimportant or contingent on other factors (n=9, 6%).

Table 5.4

Responses to the question "if you and/or your partner(s) ever need to move to a residential aged care facility for health reasons, how important is it to maintain your intimate partner relationship(s)?"

Answers	Total		Women		Men	
	(N=154)	%	(N=130)	%	(N=24)	%
Vital	92	59.7%	76	58.5%	16	66.7%
Somewhat important	42	27.3%	38	29.2%	4	16.7%
Neither important nor unimportant	11	7.1%	9	6.9%	2	8.3%
Somewhat unimportant	1	0.7%	1	0.8%	0	0.0%
Not at all important	3	1.9%	2	1.5%	1	4.2%
It depends	5	3.2%	4	3.1%	1	4.2%
Total	154	99.9%	130	100.0%	24	100.1%

Participants were also asked how important it was to share a room or a bed in an aged care facility. Their answers are recorded in Tables 5.5 and 5.6. For the majority (n=98, 64%), it was 'vital' to be able to share a room, however more so for women than men. This may be due to safety and security reasons. The majority (75%) also thought it was 'vital' (n=65, 43%) or 'somewhat important' (n=49, 32%) to continue sharing a bed, although this appeared to be slightly less important than sharing a room. Less than 4% of respondents (n=6) thought it was 'not at all important' to share a room or a bed. These findings demonstrate that maintaining their relationships and being in close proximity on a day-to-day basis, either by sharing a room or a bed, was very important for the majority in this sample of Baby Boomers.

Table 5.5

Responses to the question "if you and/or your partner(s) ever need to move to a residential aged care facility for health reasons, how important is it to sleep in the same room with your partner(s)?"

Answers	Total		Women		Men	
	(N=154)	%	(N=130)	%	(N=24)	%
Vital	98	63.6%	85	65.4%	13	54.2%
Somewhat important	26	16.9%	20	15.4%	6	25.0%
Neither important nor unimportant	5	3.2%	4	3.1%	1	4.2%
Somewhat unimportant	3	2.0%	2	15%	1	4.2%
Not at all important	6	3.9%	5	3.8%	1	4.2%
It depends	16	10.4%	14	10.8%	2	8.3%
Total	154	100.0%	130	100.0%	24	100.1%

Table 5.6

Responses to the question "if you and/or your partner(s) ever need to move to a residential aged care facility for health reasons, how important is it to sleep in the same bed with your partner(s)?"

Answers	Total		Women		Men	
	(N=153)	%	(N=129)	%	(N=24)	%
Vital	65	42.5%	55	42.6%	10	41.7%
Somewhat important	49	32.0%	41	31.8%	8	33.3%
Neither important nor unimportant	8	5.2%	6	4.7%	2	8.3%
Somewhat unimportant	3	2.0%	3	2.3%	0	0%
Not at all important	13	8.5%	12	9.3%	1	4.2%
It depends	15	10.0%	12	9.3%	3	12.5%
Total	153	100.2%	129	100.0%	24	100.0%

5.6. Survey respondents' attitudes to privacy

Both Chapter Four and preceding sections of this chapter enumerated various ways that privacy can be eroded in Australian RACFs, which illustrated where inadequate consideration was given to couples' privacy needs. It was evident from responses to the survey that privacy infringements were still commonplace in Australian RACFs. To find out how important privacy is to potential future consumers, participants were asked two questions about their anticipated privacy needs in residential aged care settings. Answers to these questions are presented in Tables 5.7 and 5.8.

Table 5.7

Baby Boomers' answers to the question "if you and/or your partner(s) ever need to move to a residential aged care facility for health reasons, how much privacy would enable you to feel comfortable relating intimately or sexually with your partner(s)?"

Answers	Total		Women		Men	
	(N=155)	%	(N=131)	%	(N=24)	%
As much as possible	133	85.8%	114	87.0%	19	79.2%
A little	10	6.5%	6	4.6%	4	16.7%
It's not important	9	5.8%	8	6.1%	1	4.2%
It depends	3	1.9%	3	2.3%	0	0.0%
Total	155	100.0%	131	100.0%	24	100.1%

A significant majority of participants indicated that they needed as much privacy as possible to conduct their relationships in residential aged care settings. In order to obtain more meaningful data, by teasing out what privacy meant for participants, definitions of privacy were provided for the next question. These definitions were:

Visual privacy:	I choose if I can be seen.
Private space:	I have my own bed, room and storage space – where I can lock the door and my consent is required before others can access me, or my belongings.
Bodily privacy:	My consent is required to undress me or perform bodily procedures.
Acoustic privacy:	I choose if I can be heard.
Communication privacy:	e.g. talking, writing, using a computer in private.
Social privacy:	I choose who I am seated with and who I do/do not spend time with.
Personal information:	My personal and medical details may only be shared with my consent.

Baby Boomers were asked what kinds of privacy were important to them when relating intimately with their partner, if one or both of them were to live in a residential aged care facility. The results, presented in Table 5.8, show that a significant majority of respondents anticipated that privacy of all kinds would be very important to their relationship if they were living in a residential aged care facility.

Table 5.8

Baby Boomers' answers to the question "what kinds of privacy are important to you?"

Answers	Total		Women		Men	
	(N=154)	%	(N=130)	%	(N=24)	%
Visual privacy	138	89%	117	90%	21	81%
Private space	137	89%	116	89%	21	81%
Bodily privacy	127	82%	111	85%	16	62%
Acoustic privacy	123	80%	104	80%	19	73%
Communication privacy	118	77%	95	73%	23	88%
Social privacy	117	76%	98	75%	19	73%
Personal information	110	71%	95	73%	15	58%
Other – private time alone	2	1%	1	<1%	1	<1%

Important types of privacy, for both men and women, were visual privacy and private space. However, men indicated that their most important privacy need related to protected communication. Women distinguished themselves from men by placing considerably more importance on bodily privacy. Respondents' attitudes to each of form of privacy provide a basis for further discussion to develop clearer privacy policies for residential aged care.

5.7. Leximancer analysis of combined qualitative survey data

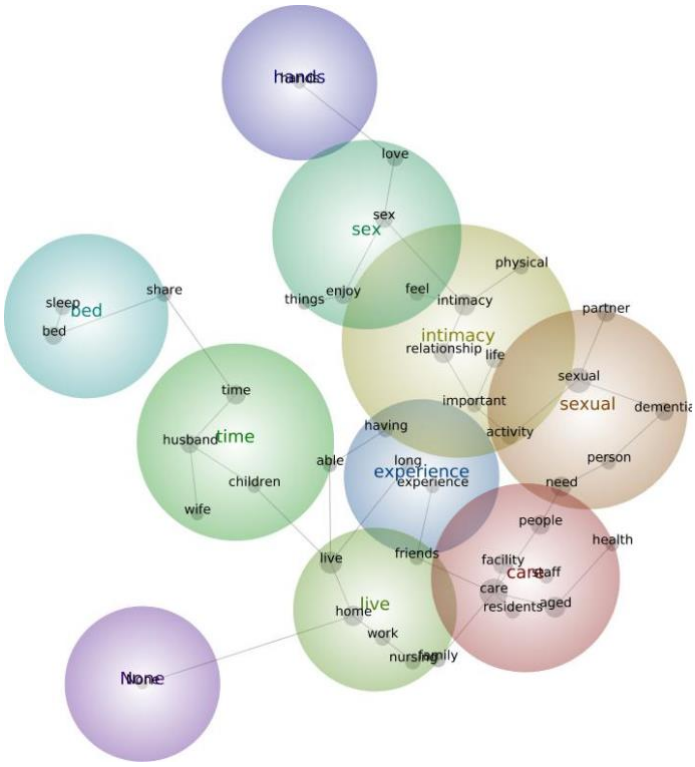

Figure 5.2. Map of dominant lexical concepts in answers to all qualitative survey questions combined

The most prevalent themes identified in the combined qualitative survey data (from all questions) were: (1) sexual; (2) intimacy; (3) care; (4) live; (5) sex; and (6) time. The theme, sexual, referred to sexual relationships. Intimacy referred to sexual and physical intimacy and care represented residential aged care. Life in a RACF was termed 'live'. The relative placement of these themes indicated that life in a RACF was not generally conducive to sexual relationships.

Expressions of physical and sexual intimacy between partners were important to participants and, in the context of a RACF, they thought that services should be in place to support partnered residents who experienced physical difficulties that impeded their ability to be intimate. The theme, 'none', referred to participants who had no experience of residential aged care. The Baby Boomers sampled were at a life stage where they had more time and freedom for physical pleasure with their partners. They enjoyed the shared experience of sex and other forms of physical intimacy, such as holding hands. Shared time together in bed was a fundamental part of their relationship.

Table 5.9

Leximancer analysis of all qualitative survey answers combined

Themes	Frequency (N)	Examples
Sexual	466	"…[if] you have a sexual relationship with your partner, why should you be denied your enjoyment of a relationship? It is not as if…you are going to have sex for hours on end and endanger your partner's life. You adjust accordingly to the situation. It is what we have done all our lives. You keep adjusting to your life."
Intimacy	285	"I believe that if elderly people are still able to enjoy sexual intimacy whilst living in nursing facilities, then this should be acknowledged by having such [sexual health] services in place. This would support "choice" in residential aged care."
Care	278	"I have studied Cert[ificate] III in Aged Care and also experienced people with dementia in the aged care facility, so I understand some of the effects of dementia in terms of sexual behaviour and the losing of some inhibitions."
Live	264	"I currently work as a registered nurse at a hospital with residential care attached. I do know that most people wouldn't choose to ever live in one…"
Sex	245	"With an empty nest, we have more opportunities to enjoy daytime sex than we did when the kids were here."
Time	227	"It's comforting, safe and feels like home to be near my husband through the night. If we are separated for a short time, I do miss him."
Bed	136	"We share the same bed"
None	89	"None" (a frequently used one-word answer)
Hands	73	"[we enjoy] cuddling, holding hands, kissing"
Experience	40	"[I have] no experience with such matters"

5.8. Conclusion

This study provides evidence that, for this sample, partnered older adults were invested in maintaining their relationships. As key informants predicted, this generation wish to maintain their autonomy by having the continuing ability to make choices. Quality of life was what made life meaningful, of which one's intimate relationship was a key contributor. Participants wished to remain together for as long as they choose, even in institutional settings, with most preferring to share a bed in the same room. Privacy was highly valued, however, men and women varied somewhat in the types of privacy they prioritised. This chapter provides much needed information on Baby Boomers' attitudes to institutionalised living. It indicates that this cohort prefer to avoid this fate themselves where possible, with some entertaining alternative models of aged care service delivery (and in some cases euthanasia). This information fills a research gap and provides a basis for further discussion and policy setting in the aged care industry, if it is to adapt to consumer expectations. The next chapter will explore the current challenges to maintaining intimate relationships in Australian RACFs and issues that will need to be overcome to support partnered Baby Boomers' coupledom.

Chapter 6. Challenges to Maintaining Intimate Relationships in Residential Care

6.1. Introduction

The previous chapter described the anticipated aged care needs of partnered Baby Boomers and their attitudes to residential age care, based on experience. The majority surveyed expressed their desire to maintain their relationship and continue living and sleeping together if they are institutionalised and detailed their anticipated privacy needs as a couple in such a setting. Chapter 5 described how essential physical and sexual intimacy was to Baby Boomers' relationships and in Chapter 6, survey respondents provided some initial insights into their perceived relationship needs in residential aged care. The research question guiding this chapter is: what are the challenges to maintaining intimate relationships in residential aged care settings? The chapter begins with findings gathered from key informant[32] interviews reflecting their perceptions of (1) the underlying issues; and (2) current policies and practices adopted by aged care providers to manage couple relationships, including residents' sexual expression. What then follows is analysis of the political challenges posed by intimate relationships in residential aged care settings based on findings from the review of historical political debates of aged care legislation (undertaken in Phase Two of the study).

6.2. The main concerns

The main concerns of key informants were that Australian society does not value ageing or old age and, as a consequence, older adults *per se* are not respected, nor are their relationships. Ageist attitudes and assumptions were perceived to be widespread in the aged care sector. This was thought to influence the wellbeing of the aged care workforce as well as residents themselves. Key informants perceived that older couples' needs were neglected in public policy and that, partly as a result, consulting partnered aged care residents about their specific relational needs was uncommon.

[32] Key informants included senior public servants, health researchers, gerontologists, consumer advocates, educators and trainers, aged care consultants, quality assessors, a chief executive officer and general manager of two aged care organisations, mid-level managers, registered nurses, a care worker, a recreational officer, a sexual health physician, a lawyer, a psychologist and a sex worker.

According to informants, 'person-centred' care was notably absent in some establishments. Instead, decisions were frequently made in an authoritarian fashion on residents' behalf, based on (1) organisational priorities; (2) staff convenience; and/or (3) ageist assumptions and prejudicial attitudes by staff or management. From interviewees' perspectives, task-oriented establishments denied residents their autonomy and significantly limited consumer choice. Authoritarian and ageist attitudes manifested themselves in organisational policies and practices that implicitly and/or explicitly discriminated against partnered residents. Perceptions were that poor staff selection, inadequate staff training and the physical environments within residential aged care facilities (RACFs) further reinforced discrimination against couples.

6.2.1. Societal ageism reflected in the aged care sector

A central concept in the interview data was respect together with a related concept, ageism. According to key informants, old age was not valued and respected in Australian society generally, which in turn influenced the attitudes of aged care organisations and their employees. In other words, the culture in residential aged care reflected the national cultural context, one that devalues old age. Dr Rosie King (BB)[33], a well-known Australian sexual health physician, used racism and sexism as a basis for understanding ageism:

> ageism is rife in our society and like all bigotry it's totally offensive. It's like racism or sexism, we stereotype older people. We see them as useless, toothless, hairless and sexless and we live in a society that worships at the altar of youth and growth and disposability and we marginalise the aged…I think one of the biggest challenges is tackling ageist attitudes in the staff, in the families and even in the residents themselves.

For Rosie, ageism meant "a bias directed towards older people by the (temporarily) young"[34]. Registered nurse, 'Barbara'[35] (BB), also felt strongly that older people living in RACFs deserved more respect. However, for her, this was contingent on Australians collectively placing more value on their own ageing:

[33] BB is used to denote someone born in the Baby Boom generation.
[34] This quote provided by Dr Rosie King is attributed to Louise Anike (http://www.olderdykes.org/words/articles/ageing.html).
[35] A pseudonym was given to maintain the interviewee's confidentiality.

> I think what's happening in residential aged care is a reflection, in some ways, of what's happening in the broader community. We don't value our own ageing and we don't value older people.

The concept of ageism was also present in an interview with La Trobe University's Emeritus Professor, Rhonda Nay (BB), who said, "we don't value, as a society, aged care. We don't really value older people and old age. We're very much a youth-worshipping society".

Ageism was perceived by key informants as widespread, socially-sanctioned and went largely unquestioned. There was a perceived tendency for Australians to distance themselves, physically and metaphorically, from older adults. Rosie King's view of Australian society was one where older adults are grouped together on the margins of society and given non-essential activities to occupy their time. Once people are no longer seen as useful contributors to society, she said, "we put them out of sight…and we relegate them to the only activities they're suited to…the three B's - bus trips, lawn bowls and bingo".

Key informants from the Baby Boomer generation (and earlier) were willing to confront the realities of aging. Dr Ralph Hampson (BB), Senior Lecturer in the Master of Ageing program at the University of Melbourne, believed there was a growing movement to mythologise and deny the process of ageing by promoting images of perpetual youthfulness in the media. In his view, this was another form of social distancing:

> that is the real challenge…the realities of living longer and living with disabilities and…[the] mythology that we're all going to be jumping out of planes when we're 90…I think it's a really contested area…All the sayings around 70 is the new 50 - well no, it's not, 70 is still 70…this distancing ourselves from old age and the stigma associated with old age is quite difficult.

Principal Consultant at the Australasian College of Care Leadership and Management, Dr Drew Dwyer[36] (BB), stressed that a denial of ageing ignored the very real needs of

[36] Dr Drew Dwyer is also Adjunct Associate Professor at the University of Queensland's School of Nursing and Midwifery.

older people. He feared that planning for essential services to meet the needs of ageing Baby Boomers may be neglected as a result. He said:

> We're dumbing down the reality. We're ignoring it…and the real part of what happens with most human beings is the decline towards death….At the moment we're busy telling everyone they can live forever, they can have it all and it's all active, healthy, positive, sexy and so forth. I know the science insists that we will eventually be in those spaces, but the science doesn't exist for the cohort of millions of Baby Boomers now that are about to suffer…They will suffer that change that has not been thought about in a real way....The reality of it is being clouded.

Participants' perceptions were that ageist thinking pervaded decision-making at every level of society, from politicians to company directors, facility managers, doctors, care staff, families and even the residents themselves. Such devaluing of old age had a cascading effect. It was thought to influence government funding and aged care providers' fiscal policies, which in turn influenced employees' working conditions and pay rates. This ultimately affected each resident's quality of life. According to Barbara[37] (BB), a registered nurse with more than 20 years' experience in the aged care sector, "residential aged care is very underfunded and so we've got a fairly poorly skilled workforce, in the main, and high turnover and that all affects the lives of older people in residential aged care".

Quality of care was perceived as directly linked to levels of funding. In Barbara's opinion, the federal government and employers need to invest more in the education, training, and retention of aged care staff:

> because we don't value older people, we don't currently adequately fund residential aged care, which means that we're not attracting a highly skilled workforce and we're not investing a lot of money in their education once they're there …and that has a direct impact on quality of care.

6.2.2. The aged care workforce

The perception amongst key informants was that society's systemic de-valuing of old age resulted in staff enduring poor working conditions and low wages. As a

[37] A pseudonym given to maintain confidentiality.

consequence, working in aged care was seen as a demanding and unrewarding. Compared to other jobs, care work was characterised as poorly paid, undervalued, and held in poor repute. According to Drew Dwyer, the wider community views such work as a menial, dead-end job. He said such attitudes reflected a society that does not value older people:

> …at the end of the day, we ask the most underpaid, overworked and never thanked person to do one of the hardest jobs that most members of our community are not capable of doing themselves…and we're asking, as a society, to have a standard and an approach that is not remunerated or has any pay parity…it's hard work….Then you pay that person 20 dollars an hour to do that job. My 16-year-old daughter works in Coles and gets 25 dollars an hour….I think we've got it all backwards in Australia.

Staff were considered too stressed, busy or preoccupied to attend to anything more than the most basic needs of residents. Drew Dwyer described working in aged care as a complex interplay of competing forces he called "onion layers", composed of:

> crap pay, crap conditions, crap policy, crap procedures, governance, law, legislation, emotion, you know, OH&S [Occupational Health and Safety guidelines]. These are the things we compound and its onion layer on top of onion layer on top of onion layer….You need to peel back each layer, work with it or bite into that onion and chew. Either way you are going to cry because it's an onion and we need to do this as leaders because…currently in Australia, we keep lumbering the care workers with the onions and they're not smelling the roses.

There were reports of few opportunities for staff to upgrade their skills or make career advancements. However, concurrently, staff increasingly needed good clinical skills. According to Rhonda Nay:

> …with the increase in the complex care needs and comorbidities, and so on, it's going to become even more important that the people who are working with older people, especially the old, old, the frail old…here's going to be a much higher need for clinical skills and…I think they need to be licensed, quite frankly, but skills in personal care…that don't require a university education but are currently not in the work force

Consequently, working in aged care was not seen as a popular career move. This state of affairs affected providers' ability to recruit a high quality workforce, leading to under-qualified staff being hired. Rhonda said

> a large proportion of the staff working in aged care [are] very much under-qualified. A lot have trouble even speaking English. A lot of GPs do not want to go there and, by and large, RNs [registered nurses] don't want to go there. So, it's an area that desperately needs skills and knowledge, but they don't have it.

There were perceptions that government-funded job placement agencies have tended to fill skills shortages by directing those on unemployment benefits to undertake certificate-level training and take up positions as aged care workers. Similarly, in an effort to enter Australia, many immigrants ere purported to have taken up positions as personal care workers in the last decade. According to participants, what this has meant is that not all staff who sought positions in aged care were motivated by a desire to care for others. For some, it was simply a means of finding employment. Dr Jan Herbert[38], a consultant gerontologist with approximately 50 years' experience in the aged care sector, referred to this phenomenon. She said that because working in aged care was often seen a job of last resort, the sector attracted a poorly skilled workforce and consequently:

> we're not dealing with a very educated staff. The majority of staff are Cert IIIs[39]. A lot of those Cert IIIs have come to aged care because…they're on unemployment benefits, so they have to do a course and do something to get a job. They…often [have] low education, limited life experience, and…a very large number…are from other cultures

Key informants felt that in order to improve resident wellbeing it was first necessary to improve staff wellbeing. Resident advocate, Susan[40], believed that one consequence of staff being undervalued, underpaid and inadequately trained was that they sometimes took out their frustrations on residents:

[38] Over the course of her career, Dr Herbert has taken up roles as a policy writer for the Australian Government, a company director of aged care organisations, an external assessor for the Australian Aged Care Quality Agency and as a private consultant.

[39] A Certificate III in Aged Care is the minimum aged care qualification awarded by TAFE (Tertiary and Further Education) colleges.

[40] Names represented in inverted commas are pseudonyms given to maintain confidentiality.

> I think that we would be really pissed off at being treated the way many aged care workers treat older people. Gee I think that one of the really big needs in aged care and I don't ever know how this is going to happen because the pay rates are bloody abysmal and a lot of the work is absolutely awful, but one of the real problems in aged care I think is the lack of education of aged care staff…

She felt that, I order to improve staff attitudes, an industry-wide cultural shift was needed to improve the lot of staff:

> I think that an awful lot of aged care workers they do terribly shitty jobs. They are full of good intentions [but] they are… often inappropriately over-friendly and/or inappropriately dismissive and almost aggressive sometimes…[there's] an uncaringness. You know 'I've got a shitty job and I don't have to be polite…and I've had a shitty day and…stiff!"…then there are some who are overly solicitous and say, "what do you want to do today love" and "it's time to have a shower".

The end result of society's under valuing of aged care work, in her opinion, was that residents were less likely to trust or respect the people employed to care for them:

> being brutally honest,…the truth of so many older people's situations [is] that they are surrounded by people, they depend on people, they are cared for by people who they don't have perhaps an intrinsically high regard for.

6.2.3. Organisational responses to accommodating couples

Key informants' perceptions were that the most common scenario was for couples to become separated by the aged care system, i.e. one partner would enter care and the other would remain in the couples' home. The distress caused by the separation of long-term partners has ripple effects beyond the couple concerned – it effects entire families. Care services employee, Veronica Stevenson, used her own circumstances as an example. She moved to be near her parents and now works in the same RACF where her father is housed. She said:

> in my own situation I'm now a single mother, [a] single parent with two kids and trying to basically…[provide] primary care [to] my parents - one who's in a nursing home and one who's at home…I'm not working full time but I can't really afford to not be working full time so it's a really vicious kind of cycle that comes into play.

> I would like her [my mother] to move closer to him [my father]…[into] an independent living situation, but there's not one on the premises where he is yet but there is some down the road…but that doesn't seem like it's possibility to do that at this point.
>
> …splitting this 50 year relationship where one goes off first is really full on. If we had a system that was more supportive it would be much easier.

To further compound couples' difficulties, there were reports that the built environment of most residential aged care facilities (RACFs) did not easily accommodate couples living together. Recreational activities officer, Sally[41], had worked in RACFs across three Australian states. She said:

> usually it's one person goes in…I've never seen someone sort of be allowed to stay with their partner, husband, wife, partner whatever. That should be an option. If someone's in high care …they should have it built so that when the husband or wife or partner wants to stay there they should be able to…it's very regimented…they keep doing the same things…building how they do, nothing's sort of set up for [partners]. And nobody really talks about it.

Where partners were housed together, perceptions of how couples' relationships were handled varied from one aged care organisation to the next. Some facilities supported couples wishing to sleep together in a double or queen sized bed[42], while others did not[43]. Sometimes, accommodating couples together required that families be determined to stand their ground, according to Louise Dwyer (BB), General Manager of Beaucare:

> certainly my experience has been that as people need supported care, it's not always available in a framework that suits couples…[such as] when they only can have a single room. I've had personal experience with an aunt and an uncle who'd been married for over sixty years and their family stood very firm. It was a small country town and they didn't have a lot of options. But they stood very firm around them needing to still share a bed. So much to the nursing home's great

[41] A pseudonym used to protect confidentiality.

[42] According to interviews with Annie Devine RN (BB); Louise Dwyer, General Manager, BeauCare (BB); and Jenny Zirkler, Executive Care Manager, Nambucca Valley Care (BB).

[43] According to interviews with Janet Ryan RN, teacher in aged care, TAFE Queensland South West; Dr Michele Chandler, Clinical Nurse Consultant, Maevis Group.

> frustration, in the end they handed one of the rooms over to be used as a bedroom with a double bed in it and the other room they could then use as a lounge area but it certainly created huge drama which to me seemed entirely unnecessary.

Likewise, with partners who had been assessed at different funding levels, with differing care needs, some facilities housed both partners together in a room or suite, while others accommodated them separately. Registered nurse, Annie Devine (BB), provided this example of a couple housed in separate wings of the same facility:

> she was in low care he was in high care…every morning… [she'd] walk around to the high care area to her husband's room and she'd say good morning and give him a kiss…As his legs got worse she would then push him in the wheelchair…at the end of the day…she would push him back to his room give him a kiss and she'd go back to her room.…they would hold hands and she would fuss over him….It was lovely.

For couples who were able to remain together, privacy was perceived as an issue. Executive Director of Health Consumers NSW, Dr Anthony Brown, said:

> apart from holding hands, and maybe a kiss on the cheek, where in a nursing home environment, if you're in a four bed room, and a person's not very mobile, where in a nursing home can you actually express anything? Where can you even lie down on the bed next to each other… and just cuddle? Let alone any form of sexual activity.…I think that the range of physical expressions of intimacy that you can do in a nursing home is limited because…someone's always around…not all the rooms have doors in some of the older places.

6.2.4. Staff discomfort with residents' sexual expression

According to Dr Rosie King, ageist attitudes reflected in culturally ingrained stereotypes were most apparent in interactions between staff and residents, especially in response to residents' expressing their sexuality. She said:

> My experience when…visiting nursing homes, was that sex is very much an unwelcome visitor in most aged care facilities …I would say the biggest, biggest issue is [the] attitude…that just because you're old that you're no longer interested in sex or that you no longer want sex or that there's some kind of use by date on sexual functioning.

One category in the data that connected to several others was that of staff being confronted by feeling uncomfortable when residents expressing themselves sexually. The phenomenon of staff reacting negatively to residents' sexual expression was perceived as an indicator of ageist attitudes. Such ageism was seen to be so widespread that no-one was immune. According to registered nurse, Barbara (BB):

> older people expressing their sexuality is like exerting their right to exist. To admit to the canary down the mineshaft, I think that if we are in a world that is respecting older peoples' sexual being then we are in a world that values and respects older people.…I don't think you'd be doing your PhD in this area, if we lived in a world that valued and respected older people.

Some key informants were spontaneously self-reflexive, acknowledging instances when they had been confronted by their own culturally indoctrinated beliefs about older age sexuality. In Barbara's case, she described how:

> sexual expression…in residential aged care takes every form you could imagine…they tell you stories that sometimes make my hair curl…there's every sexual scenario that we would expect in the broader community…we don't expect it with older people and we don't expect it to continue in residential aged care. And I recognise a couple of times people have shared stories with me and I've been shocked and then I've thought "well why am I shocked, why do I think an older person wouldn't do that?" And then I recognise that even though I think older people are the most extraordinary people in the world and sexuality is incredibly important, I still have got that entrenched ageism.

Likewise, consumer advocate, Dr Anthony Brown, reflected on the hidden, unspoken nature of ageism and how it shapes individual and collective views of older age sexuality:

> I think one of the things we haven't talked about…and I'm as guilty of this as anyone is that we still do tend to think of older people as genderless and sexless and that once you get to a certain age you're not an older man, you're not an older woman, you're just an old person and that you're 'past it' now …which I think leads to some of the moral outrage that some nursing home staff feel.

In his view, cultural stereotypes were so ingrained as a form of social control that it was unnecessary to speak them out loud for them to have power. In fact, perhaps the unspoken nature of such assumptions is what made them so powerful (because they went unchallenged). He said:

> Some of the stereotypes around 'dirty old men'…we didn't really touch on the stereotypes but I think they're huge, the biggest thing that holds, not just older people back, because we do internalise negative stereotypes around the groups we belong to, but also those stereotypes become another sort of unspoken form of control…that nursing home staff rely on to …police what they feel's appropriate behaviour.

The word that was most often used to describe staff's responses to expressions of resident sexuality was "shock". Anthony Brown attributed this shock to an absence of policies and procedures that leave staff unprepared. He said, "my sense is staff are quite shocked…[they] don't really know how to react and tend to over-react…I think there's a general lack of good policies around this".

Many interviewees perceived that residents' sexuality was demonised by staff, who often labelled it as 'inappropriate behaviour'. Colin McDonnell, Environmental and Lifestyle Coach for UnitingCare Ageing NSW/ACT, gave this example:

> [staff] go into someone's room in their own privacy and then if the person [is masturbating and] they see them doing that they write it up as…inappropriate sexual behaviour. Yeah, it happens stacks of times.

6.2.4.1. Inadequate staff training

Key informants attributed such responses to inadequate sexuality training, policies, and resources, resulting in staff being unable to distinguish between their personal and professional values, which left them to respond as best they can. According to registered nurse, Barbara:

> I think at the moment one of the real problems is that there are a lot of negative comments made that age care providers are not addressing sexuality but it's not part of undergraduate training, it's not part of any Certificate III or IV training, so service providers are going into their job and encountering

> situations they're completely unprepared for…the first step is that we prepare service providers by giving them education and resources so they feel confident and comfortable managing the situations they encounter.

6.2.4.2. Male sexuality is perceived as a threat

When discussing staff comfort levels, a sub-category that emerged from key informant interviews was that it was regarded as a common occurrence for female staff to perceive male sexuality as a threat. At one end of the scale, there were accounts of male residents who were regarded as opportunistic or too friendly with female staff and somewhat of a nuisance. Former Care Service Employee, Veronica Stevenson, gave her account of this phenomenon, indicating her sense of vulnerability around certain men and her avoidance of unwanted touch in particular:

> there [were] a couple of older guys, that I was very careful with …one in particular…if I knew he was going to be in his room and I had to go in there then [strategies included] leaving the door open [and] speaking loudly so that anybody outside could hear…. He was a bit amorous but, you know, it's a little bit borderline. It's just their personality, and it's not really meaning anything but I certainly was careful around a couple of the older gentlemen…yeah nobody likes a grope from an old guy [laughs].

At the extreme, male residents were sometimes perceived as sexual predators that needed to be segregated and controlled in order to protect female residents. Clinical nurse consultant, Dr Michele Chandler (BB), said:

> if they've got a man, particularly, and he's quite interested in women, they'll put them at the furthest end of the building, with other men. Quite often they'll use a physical barrier, in terms of where they locate them in the facility….The men are definitely seen as predators, and the women not so much.

Accounts of staff discourses around male residents' sexuality suggested that female staff tended to view such sexuality as a threat, irrespective of circumstances, rather than as a normal part of a man's life. This appeared to be due to staff framing (1) RACFs as 'public' spaces; (2) female residents as frail and vulnerable; and (3) all residents as childlike (making demonstrations of sexual interest 'taboo' according to societal standards).

6.2.5. Older age sexuality is largely a taboo topic

In most key informant interviews, the core category, communication, arose. According to participants, older age sexual expression was a taboo topic in the aged care sector. Once again, Dr Rosie King (BB) perceived this as a symptom of societal attitudes:

> there's one subject that remains taboo and that's septuagenarian sex…the media tell us that sex is only for young fit fertile bodies and older people need not apply… there's no mention of dentures or stiff hips…or dry vaginas or flagging erections and you know we mock and we deny and we ignore the sexuality of older people.

Perceptions were that staff demonstrated their discomfort by ignoring or avoiding discussion with residents their sexual needs. Nevertheless, residents' needs did not disappear simply because they were not discussed. Health researcher, Melissa[44], described residents' sexuality as "the elephant in the room", meaning that it was an obvious issue that few people were willing to talk about. She said:

> People see it and it seems to be a problem. Sometimes it's not a big problem, it's the people that respond to it that make it a problem. And it's because it's about older people having sex it just seems to have that barrier like, older people shouldn't be having sex. If they do it's "ooh, I don't want to talk about it, I don't want to think about it!" Every generation thinks they invented sex….Just because we don't talk about it, doesn't mean the need is not there.

Key informants highlighted the need for more mature conversations about older age sexuality in order to better service the needs of aged care residents. According to them,

> people involved with older people, and indeed older people themselves, tend[ed] to avoid conversations that made them feel uncomfortable. Secondly, when older people did ask for something they need[ed], they were not always listened to (Rahn, Lykins, Bennett & Jones 2015, pp. 57-58).

Open, respectful conversations about their sexual and companionship needs were perceived to be uncommon between residents and those representing them and caring

[44] Pseudonym given to maintain her confidentiality.

for them (i.e. family, lawyers, doctors, and aged care providers). Perceptions were that this lack of discussion generally led to staff making assumptions consistent with their cultural stereotyping. As Ralph Hampson said, "if we don't talk about it and say what we want, because we avoid it, then we'll get more of the same".

6.2.6. A culture of fear exists in residential aged care

Several key informants attributed staff responses to a widespread culture of fear in RACFs. This fear took many forms. At an institutional level, a fear of media attention, litigation, and being reported to 'the Department' led to an excessive focus on risk avoidance. Because of the mandatory requirement for providers to report cases of sexual assault, staff were apparently especially vigilant in their surveillance and management of residents' sexual expression in order to prevent any possibility of sexual assault. According to registered nurse, Barbara (BB), this fear stemmed from multiple influences:

> fear amongst service providers of there being an allegation of sexual assault. Another part of it I think is service providers, professionally and personally as individuals, do not want to see somebody who is in their care being sexually assaulted… [and] there is this sort of fear of adverse publicity or adverse attention from either the government or from the media and so there is a kind of a…conservative backlash which is around repressing sexual expression…sometimes sexual expression is suppressed because of peoples' fear of litigation of complaints.

She and others perceived that mandatory reporting had created a culture of fear, whereas what service providers really needed was more support in understanding how to prevent sexual assault. According to Barbara:

> If a service identifies unlawful sexual contact, or if there is an allegation, then they are required to report to the department and then the department investigates…some service providers say that has created kind of a fear of reporting….I think there needs to be more support around it…on one hand we've got compulsory reporting, which puts the fear of god in some people, [however] we need to be able to draw service providers to want to engage with understanding how to prevent sexual assault.

In one informant's account, it was clear that staff at one RACF did not understand the mandatory reporting legislation, believing that *any* sexual contact between residents was unlawful, irrespective of whether residents had the capacity to consent[45]. In one instance, this had led to the police being called and the residents in question being interrogated and subjected to medical examination, resulting in unnecessary distress.

According to senior public servant, Nancy[46] (BB), preventing non-consensual sexual activity was "something that's at the forefront of people's minds…they don't really want to report things to the Department so therefore you'd be more ultra-careful about non-consensual things happening". Interviewees described measures currently employed by providers to avoid non-consensual sexual contact. The most commonly reported response involved physically separating residents and maintaining high levels of staff surveillance at all times. In one example, clinical nurse consultant, Dr Michele Chandler (BB), described measures she had directly observed:

> Seclusion [is used]…putting people in certain areas of the home. They'll have an 'open door' policy [laughs] for the residents, not for the managers - so people can't close their doors. People don't have any keys to their doors, they can't lock the door…because 'that's a fire hazard'…doors are left open all the times…it's…over surveillance.

Michelle believed that some staff were obsessed with perceived sexual misdemeanours by residents, often spending time monitoring these rather than attending to more important matters:

> they call it 'the incident' if they find people sexually active… It's not an incident…they were just holding hands. God forbid!.…then they'll be over zealous in documenting the details of sexual activity where they won't document the important things.

This culture of fear had consequences for managers and staff as well as residents. Some informants believed that blame was often directed to the easiest target when mistakes were made. According to Michelle, in such cases, facility managers often had their employment terminated, which resulted in a high turnover of managers

[45] For reasons of confidentiality, the interviewee wished to remain anonymous to protect the identity of the RACF and the residents in question.
[46] Pseudonym used to protect confidentiality.

throughout the industry. She referred to institutionalised "immaturity" in the aged care industry, saying

> the manager turnover is so high. If someone makes a mistake they get the sack because…if something goes wrong they always look to blame the first person …[they think] "we'll get rid of them and it will never happen again". Well guess what, it does [laughs]…and people less mature learn…and they become quite risk averse themselves.

6.2.7. Inexpert handling of residents' sexual expression

According to key informants, inexpert staff handling of residents' sexuality was considered more common than skilled handling. They described tactics used by staff members when confronted by residents expressing themselves sexually that violated residents' dignity (Jacobson, 2009). Responses included: (1) rudeness; (2) condescension; (3) avoidance; (4) intrusion; (5) objectification; (6) restriction; (7) labelling; (8) discrimination; (9) deprivation; and (10) abuse and assault. Further description and examples will now be provided.

6.2.7.1. Rudeness

Rudeness was a common theme in key informant interviews. Examples of accidental and deliberate rudeness most commonly included speaking rudely to older people or entering residents' rooms uninvited and unannounced. Resident advocate, Susan[47] (BB), described nursing staff giggling about

> having walked in on my parents once in the middle of the night …apparently something was going on under the covers and they were quite shocked. Dad was furious…it's so unkind and cruel that their intimacy was interrupted during the night…it's an appalling thing…I was thinking … god what would I do if I had people coming in during the night unannounced into my bedroom, and it's not just me, it's me and someone else).

In this example, Susan displayed empathy for her parents. She was angered by the lack of respect shown to them by unthinking staff, albeit accidentally. Rudeness, demonstrated here as a privacy intrusion, represented hers and her parents' general inability to control their lives in the institution. This was accompanied by a sense of

[47] A pseudonym used to protect confidentiality.

injustice, verbalised as "it's an appalling thing". This sense of injustice was common in informants' accounts of rudeness, highlighting residents' relative lack of control and the perceived power imbalance between residents, family and staff. A consistent theme throughout Susan's interview was her sense of powerlessness to protect her parents. This created an added a sense of anxiety when imagining her own future self in the same situation.

6.2.7.2. Condescension

Key informants described residents being spoken 'down to' and infantilised. When asked to consider the key needs of aged care residents, clinical nurse consultant, Dr Michele Chandler (BB), answered "not to be treated like children…because that's what happens". It appeared that staff behaviours towards residents may have been unconscious to a certain extent, being largely reinforced by external triggers. The hierarchical nursery-style structures of RACFs, strict timetabling, associations linked to objects such as nappies and the need to provide the type of care reminiscent of raising children (such as feeding, washing and wiping bottoms) may have all played a part in shaping staff perspectives. Consequently, as with children, staff may have felt obliged to repress or correct residents' sexual behaviours, which resulted in disempowerment of residents and their loss of dignity. According to Michelle:

> you know 'they've got dementia so they're just like children', or they're incontinent so they have to put nappies on them…. Because they're like children then they need to mothered and they can't make decisions for themselves, particularly around sexual behaviours.

6.2.7.3. Avoidance

A preference by staff and families to avoid discussing sexual matters was raised by key informants. For the individuals concerned, residents' sexual needs and behaviours were uncomfortable topics that were best avoided. Such behaviours by staff were thought to reflect the lack of open discussion of late life sexuality in Australian culture generally. However, by remaining silent, residents' needs were effectively disregarded. Educator and aged care consultant, Dr Ralph Hampson (BB), said he was not aware of "much discussion of sexuality in nursing homes". Even in cases where

older adults raised the topic of their sexual needs, whether with staff or family, it was often met with embarrassment and silence. Ralph said:

> I do remember one time when a son went to visit his father and he said to him "I'd just like to have sex one more time" and his son just left the room and never raised the topic again, [he] couldn't bear it.…How do we give people permission that it's all right to talk about it? But I think we're not good at sex generally in our community so I'm not surprised that it's in aged care.

Staff discomfort was further compounded in cases where their religious or cultural beliefs were challenged. Consultant gerontologist, Jan Herbert, described cultural differences between staff and residents as "the elephant in the room" that was not being discussed. Ralph Hampson said:

> I think one of the tensions that certainly did arise was that many of the staff who work in residential aged care come from cultural backgrounds where sex might not even be talked about, or could have lots of stigmas and taboos around it.

As an educator, Ralph was grappling with the larger social context – the cultural differences in constructions of sexuality, their impact on individuals, and the enormity of the change that may be required in society at large, not just within aged care settings.

6.2.7.4. Intrusion

In key informants' accounts, intrusion took many forms. Central to these accounts was the concept that residents were powerless, vulnerable human beings with the same needs for autonomy, respect and privacy as everyone else. There were descriptions of paternalistic task-oriented regimes within RACFs which resulted in intrusive practices by staff. Intrusiveness was often associated with a lack of empathy for residents and was most evident in the contested space of residents' rooms, which are both workplace (for staff) and home (for residents). This was further complicated by multiple laws operating simultaneously within residents' rooms, as described by lawyer, Helen (BB): "you've got security of tenure provisions and you've got mandatory reporting provisions and you've got the rights of all the other residents…and the rights of your staff too".

The absence of a clear demarcation of residents' territorial boundaries, and the power imbalance created by staff duties taking precedence over resident privacy, resulted in residents regularly experiencing intrusion into what they considered their private space. A common practice was to enter residents' rooms without first knocking on the door and gaining permission to enter or, alternatively, to knock but not wait for a response. This problem was compounded by residents' doors not being "routinely closed", according to registered nurse, Annie Devine (BB). In some cases, "not all the rooms have doors in some of the older places", according to consumer advocate, Dr Anthony Brown.

Intrusive behaviours were best exemplified in the interview with Emeritus Professor Rhonda Nay (BB). She said:

> the culture is pretty much "it's the staff home and you're here so we might knock but we'll still walk straight in"….I think there is pretty much a sense of "we know what is best for you".

Rhonda expressed dismay at staff intruding into residents' private lives, their private space, and their belongings, indicating that she felt compassion towards residents and was able to empathise with them:

> it's about those little nuances that say I respect that this is what you've got left of the world and I'm not going to invade it without checking in first…if somebody walked up to you and took your handbag and started going through it, you would be terribly affronted and yet staff see no problem with that…it's no longer personal.

For Rhonda, dehumanisation of residents by staff was evident in their interactions with residents' personal space and personal property. In her view, this was indicative of a lack of respect and empathy for residents, highlighting a need for improved staff training:

> The area that now needs so much attention is more around attitude and how we go about showering, how we go about walking into a person's room, how we go about going through their cupboards…we've seen a lot of improvements around the privacy of the individual body and how it's treated but I guarantee you in a lot of places if you happen to be lurking on the wards at two o'clock in the morning you'd still see nurses going in and ripping the sheets off unceremoniously to change

> the bed while they talk to each other and ignore the person in the bed.

Although rare, staff sharing degrading photos of residents, including on social media sites, was a serious issue raised. UnitingCare's lifestyle consultant, Colin McDonnell, referred to hearing about "people in a place not far from us who were having photos of vaginas…and genitals and then they'd have to guess who owns these genitals at a staff afternoon tea every Friday". Such a breach of aged care standards highlighted a toxic organisational culture and a serious lack of staff supervision. As a result, this establishment was reported to the authorities (Australian Human Rights Commission, 2015).

Privacy intrusions also took the form of staff gossiping about residents amongst themselves. According to Rhonda Nay:

> there's also a lack of privacy in terms of chatter. I think people ridicule, talk about…because of their attitudes. If there is any sexual behaviour on the part of residents…it doesn't seem to take very long for that to get about the place and people snickering about it.

Informants also expressed dismay at staff unnecessarily sharing private details about residents' sexual relationships with family members, Clinical nurse consultant, Dr Michelle Chandler (BB), said "if there's handholding or any sort of sexual stuff, my God! They'll document it in fine detail, they'll run and tell the family". She said:

> [staff] over-share with the families around sexual behaviour and a lot of kids don't want to know what their parents are doing sexually. If it's not relevant to their care plan why on earth are you telling them? But they can't help themselves. … The lack of privacy is huge.

Rhonda Nay added:

> if two residents are acting sexually toward each other the natural thing [for staff] to do is to discuss it with the family. The question is, should you? You know, if they [family members] don't have medical power of attorney or financial power of attorney or guardianship…?

6.2.7.5. Objectification

Interviewees referred to cases of staff displaying a basic lack of regard for human dignity. Reminiscent of Foucault's (2003) clinical 'gaze', there were accounts of staff treating residents as tasks to be performed. This resulted in residents being objectified, dehumanised and/or shamed. Michele Chandler (BB) was shocked and disgusted by staff's "obsession" in one facility, where they took:

> photographs of wounds…Oh my god, you should've seen these photographs. There was no draping, there was no nothing! They've got these people just legs apart, taking full photographs to look at a bit of a red rash on their inner thigh. You can't do this!…They forget there's a person.

According to registered nurse, Annie Devine (BB), staff denied residents' "humanity" when they treated them as "just a 'bod' that they have to shower and dress". She was concerned that staff had were suitably screened as she recalled "really nasty nurses that shouldn't be in aged care".

6.2.7.6. Restriction

Restriction meant limiting individuals' ability to exercise autonomy and make choices about how they lived their lives. Key informants described residents being restricted in a variety of ways – as a direct result of management policies, the design of the built environment, strict scheduling of tasks, and interference by staff and families. As referred to in Section 6.2.6, the aged care industry was perceived as extremely risk-averse, fearing sexual assaults and the resulting accusations of negligence, media attention, and withdrawal of public funds that may ensue. In many RACFs, this had bred a culture of over-vigilance which focused on preventing residents' sexual behaviours. The most popular method adopted was to segregate the sexes[48].

In some accounts, staff were directed by family members acting as substitute decision-makers to intervene in residents' relationships. Enduring Guardianship and Power of Attorney documentation was seen as problematic if residents hadn't been specific in their instructions, particularly if there was an inheritance involved. Educator, Dr Ralph

[48] From interviews with consultant gerontologist, Dr Jan Herbert; clinical nurse consultant, Dr Michele Chandler (BB); and nurse educator, Dr Drew Dwyer (BB).

Hampson, was incredulous that because one woman's relatives had Power of Attorney they could interfere in her intimate relationship:

> the staff were really open about her relationship with him and used to let her lover come and visit…but then the family found out…. They didn't know their mother had been having a relationship with someone else for a number of years so they then stopped that from happening.

Another form of restriction that featured in key informant interviews involved physical forms of restraint. According to Emeritus Professor Rhonda Nay:

> if I was lying there masturbating when they [staff] arrived they'd probably get a terrible shock and then they'd put the draw sheet over me so tight that I wouldn't be able to get my hands down into that terrible place and do horrible things.

6.2.7.7. Labelling

Interviewees were disapproving of staff who applied derogatory labels to sexually active residents, which they perceived to be a common occurrence. One female resident was reportedly described as a "black widow"[49] and others were "promiscuous"[50]. Men were commonly labelled "dirty old man"[51], "dirty old bugger"[52], or "you dirty old thing"[53]. Informants were dismayed by staff characterising sexual expression by residents as "inappropriate behaviours", or simply "behaviours", when residents believed they were acting in the private in their rooms. Once again, many of these responses by staff were attributed to inadequate training. According to clinical nurse consultant, Dr Michelle Chandler:

> there's no privacy…he's a 'dirty old bugger' because he's jerking off into his pillow and all this sort of stuff. The language is classic…[staff] might walk into someone's room and find them masturbating and they call that inappropriate… that's really appropriate, it's not inappropriate…just close the door, walk away, it's not difficult.

[49] From an Interview with Melissa (pseudonym), a health researcher at an Australian university.
[50] From interviews with registered nurse, Annie Devine (BB) and health researcher, Melissa.
[51] From interviews with Dr Ralph Hampson; Dr Michele Chandler; Dr Jan Herbert; and Louise Dwyer.
[52] From an interview with Dr Michele Chandler.
[53] From an Interview with registered nurse, Janet Ryan.

6.2.7.8. Discrimination

Consistent with stereotypes held at a societal level, ageist attitudes were rife in residential aged care, according to participants' reports. Particularly prevalent amongst younger care staff with minimal training, residents were stereotyped as "[not] interested in sex", according to Rhonda Nay (BB). Lawyer, Helen[54] (BB), was appalled by the outcomes of such stereotyping, saying, "I know some facilities…have separated husbands and wives because "at that age, wives don't want to be bothered with that type of stuff" and I think did you ask them?" Registered nurse, Annie Devine (BB), believed that "that mindset that there was no possibility that they could be doing anything sexually 'at their age'" contributed to staff assuming that "don't need to worry about knocking".

Ageist attitudes led many RACFs to exclude sexual health assessments during the admission process, according to Michele Chandler (BB). As a result, sexual needs were often omitted of from residents' care plans:

> even when you look at admission data…God forbid there's a question in there about sexual needs or sexual preferences or anything like that…and in the rare event that you get them, staff don't ask anyway, they just don't ask.

Again, due to inadequate vocational and public education, people with dementia appeared to be particularly discriminated against in aged care settings, largely because they were perceived as childlike or incompetent. Educator and registered nurse, Dr Drew Dwyer (BB)[55] countered this myth:

> the family may be telling me 'but mum has dementia, she doesn't have the capacity to make those decisions'. They're actually incorrect….For example, Margaret might clearly tell me exactly what her personal parts are, how they work, how she works them, who's allowed to touch them…but she can't remember she's married or has children….I very much find that even people with heavy disability know all about sexuality and their sexual parts. It really is about the people who care for them…and whether or not they understand that as well….They might lose their memory but they haven't lost their humanity.

[54] A pseudonym given to protect confidentiality.
[55] Dr Drew Dwyer is Principal Consultant at the Australasian College of Care Leadership and Management.

6.2.7.9. Deprivation

Deprivation referred to the denial of the necessities of life, including one's human rights. Although it was not a common topic raised by key informants, it did unfortunately occur on occasion. In one example, Michele Chandler (BB) expressed her horror when a man was deprived of access to and autonomy over his own body:

> I saw a man in the bush once and he used to wear a continence pad and then at night he'd masturbate and so he'd pull the continence pad off. And they [staff] ended up putting him in a suit with a zipper up the back so he couldn't touch himself… horrendous stuff!

She was also concerned about the tendency to demonise men who became sexually aroused, which sometimes led to them being chemically restrained. She said, "they'll use medication sometimes in bad cases…give them a bit of oestrogen just to calm them down a bit…The men are definitely seen as predators".

6.2.7.10. Abuse and assault

Jacobson (2009, p. 1542) defined assault as the violation of dignity that occurs "when physical force is used to damage or demean an individual's body and spirit". Two interviewees provided accounts of staff violating male residents' bodies to control or demean their sexuality. Registered nurse, Barbara (BB), alluded to the discrimination, objectification and labelling that must necessarily precede physical assault by staff:

> there are no shortage of stories [of] sexuality being constrained and restrained…one of the things that's concerned me for a long time has been the use of Androcur testosterone suppressants for men who behave in a sexual manner…It's seen as a sexual 'behaviour' rather than an expression of something that's really quite fundamental…But my colleagues tell me they're not using Androcur as much now as they're using antipsychotics and other medications.

She saw sexual expression as a fundamental human right and was particularly concerned when this was forcibly prevented, especially as a first line of defence. Aged care providers appeared to find it difficult to find a healthy balance between preventing sexual assault of female residents and respecting the human rights of male residents. Barbara said that, due to inadequate staffing:

> service providers will often say to me that they just don't have the capacity to provide the level of supervision or redirecting of someone's behaviour that they need to and so rather than run the risk of…[sexual assault], the behaviour gets stopped. And so that's a very fundamental violation of the rights of older people to be sexual beings.

She described her shock at the seemingly unremarkable everydayness of seeing a nurse abusing male residents earlier in her career:

> I remember when I first started working in residential aged care that if a male had an erection it was considered inappropriate and there was a nurse who had…dessert spoons in the freezer…and so if a male got an erection she would just go to the freezer, pull out a spoon, and put it on his penis.

6.2.8. Inadequate attention paid to physical environments

Key informants perceived that aged care facilities were rarely designed with couples in mind. According to ACH's General Manager, Jeff Fiebig (BB), much of the industry is stuck in the past when it comes to housing couples. He drew parallels with the sexually repressed era of Victorian England. His account suggested that many providers lacked the motivation to provide 'person-centred' or 'consumer-directed' care for residents, preferring instead to focus on the needs of the organisation and the workplace. In his view, their position on housing couples highlighted the sector's priorities:

> unfortunately, not a lot of aged care facilities cater for married couples. Why, I don't know…aged care is very much built around a demand-driven economy not a supply side economy …. It's good around the needs of the organisation and the needs of staff, not around the needs of people…it's based on a system which is outmoded, outdated and very much out of what it is consumers actually want. And yet we continue to put up with it and we continue to live with one bedroom rooms that people live in, which will in effect next century make us the Bedlam of the 1880s.

Recreational activities officer, Sally, stressed that, from her experience of working in aged care facilities in three Australian states, it was unusual for RACFs to be designed for couples. She said, "the way aged care facilities are built it doesn't allow for that

[couples sharing a room]….Even new ones - they've got bigger rooms but they're not really enough [for couples]".

6.2.9. Lack of organisational policies addressing sexual relationships

Key informants referred to a widespread absence of formal organisational policies addressing couples generally or their sexual expression specifically. Lawyer, Helen (BB), said that where sexual consent was concerned:

> I think most places just avoid the issue altogether….I'm not aware that facilities have really, really addressed this…. I mean I'm happy to be proved wrong, but I'm not aware of any [organisations] that have got specific policies about this.

6.3. Political challenges

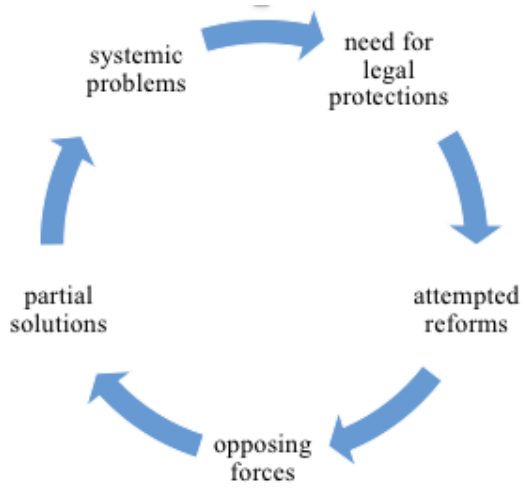

Figure 6.1. Cycle of parliamentary debates on sexual rights in aged care (Rahn, Jones, Bennett, & Lykins 2016, p.18)

The findings reported up to this this point in the chapter derived from key informant interviews, however, this section now explores findings from a review of parliamentary debates from 1974 to 2015 conducted in parallel with this thesis (Rahn, Jones, Bennett, & Lykins, 2016). They revealed a "cycle of conflicting agendas and partial solutions to systemic problems experienced by couples in residential aged care facilities". Historical debates concerning residents' sexual and relationship needs

"have been heated and often sensationalist, with opposing groups arguing in their own interests to limit reforms. Consequently, the needs of ordinary married and de facto couples have been overlooked in aged care legislation" (Rahn et al. 2016, p. 17).

The "recurrent pattern has been that problems are identified and brought to the notice of the Government. Consultant reports are subsequently commissioned, bills drafted, and new reforms introduced into Parliament, often followed by protracted periods of political debate". Parties with vested interests[56] have "fuelled debates by privately lobbying politicians and using news media to garner public support". This often resulted in "tinkering with the wording of the legislation until a consensus was reached. However, some of these compromises failed to protect the people originally intended, i.e. aged care residents" (Rahn et al. 2016, p. 18).

There were examples of "religious institutions aggressively lobbying to override residents' needs (e.g., by dictating the moral standards of residents). In the case of residents' rights, church groups succeeded in exercising social control of residents both within their own facilities" and in some regards

> more widely across the entire aged care sector. Likewise, politicians who opposed residents' sexual rights often expressed [Australian] society's ageist and religious beliefs. Conversely, there have also been occasions where politicians supported reforms for what they perceived to be the common good in spite of vocal opposition, such as with the *Human Rights (Sexual Conduct) Act 1994* (Rahn et al. 2016, p. 18).

which applies as much to aged care residents as it does to the entire population.

> An inherent problem identified in the political debates was poor communication. Effective two-way communication was lacking. This denied all parties an opportunity to speak and be heard, or to have each speaker's point of view understood. Not all parties affected by the proposed legislative changes were consulted. This applied especially residents themselves. Instead what was demonstrated was an adversarial system where people with conflicting agendas competed to be heard *1994* (Rahn et al. 2016, p. 18).

[56] Such parties included Aged and Community Services Australia (ACSA), Leading Age Services Australia (LASA), COTA (Council on the Ageing), National Seniors Australia, the Australian Catholic Bishops Conference and other church and charitable organisations, to name a few.

> Successive governments insisted that aged care funding be linked to standards of service. This was apparent in the development of the Outcome Standards, the *Quality of Care Principles 2014* (Cth) and the removal of religious exemptions from the *Aged Care Act 1997* (Cth). In the latter, the Government dismissed calls for religious freedom, citing its responsibility to all Australians to ensure equal access to government funded aged care services (Rahn et al. 2016, p. 19).
>
> Historically, however, the majority of residential aged care providers have been religious and charitable institutions. They currently provide 57.1% of residential care places, down from 66% in 2005. This majority position has been used as political leverage (Rahn et al. 2016, p. 20).

One example was:

> threatened closure of Catholic residential aged care facilities in response to the Charter of Residents' Rights and Responsibilities proposed in 1989 (Rahn et al. 2016, p.11). This misuse of power not only made politicians listen, but also cast residents as political pawns. In this case, residents were the losers - they either risked losing their 'home' or their rights, while having no direct voice in the legislative process (Rahn et al. 2016, p. 20).

In the past,

> the human rights of religious freedom and privacy have been used to argue, in an adversarial manner, for or against aged care reforms. Such rights extend to individuals, not organisations, however the Australian Catholic Bishops Conference (2012) cited religious rights when arguing against anti-discrimination amendments when, in fact, such rights are limited (Rahn et al. 2016, p. 20).

The "freedom to manifest one's religion or beliefs may be subject…to…limitations…to protect…the fundamental rights and freedoms of others" (United Nations General Assembly, 1966).

> Some religious organisations incited followers to support their cause by decrying 'moral deviance' when it was proposed that aged care residents have sexual and emotional rights. However, this drew attention away from the plight of ordinary

> married couples, whose sexual relationships are sanctioned by both church and state. By forcing removal of the right for 'sexual and emotional needs and choices' from the Charter of Residents' Rights and Responsibilities and failing to insist on protections for couples, the amendments pushed through by churches created an opportunity for institutions, faith-based or not, to override the civil rights of couples, including the practice of forcibly separating them (Rahn et al. 2016, p. 20).
>
> An argument used by Catholic supporters was that residents choose to abide by an organisation's moral standards when choosing a faith-based facility. This argument is flawed for two reasons. Firstly, rarely do aged care facilities provide documentation of their moral standards; as such, would-be residents often cannot make informed choices. Secondly, with residential aged care dominated by religious and charitable organisations, and waiting lists for vacancies in many locations, there may be no other choices available (Rahn et al. 2016, p. 20).

6.4. Conclusion

A number of structural factors have been identified in this chapter that limit couples' abilities to remain together and maintain their relationships in residential aged care settings. These impediments are underpinned by cultural, religious and ageist beliefs at societal, political, organisational and personal levels. Many of the attitudes, policies and practices directed towards partnered aged care residents are relics of the past that have not kept pace with social change in Australia. The effort required to make the structural changes that are needed (if consumer-directed care is to become a reality) will be enormous. At present, there are no specific legislative or public policy protections for established couples using residential aged care services. This absence of political support results in some aged care organisations either ignoring or discriminating against this group of service users. To compound this, the culture of fear in some organisations that has been generated by mandatory legal requirements to report sexual assault has led to over-vigilance and over-surveillance of residents by staff. This, in itself, limits consensual couples' privacy.

Associated problems lie with the aged care workforce – workers' low status in society, low rates of pay, poor advancement opportunities, understaffing and inadequate education and training. Given that staff exert the most influence over residents' daily

lives, these are structural issues that must be addressed. In the case of couples, it is especially important that staff be trained to meet the specific needs of this subgroup. Likewise, building designs that lack couple suites were identified as a physical impediment to couples remaining together. These issues will be explored further in the next chapter, which will focus on presenting solutions to some of these problems

Chapter 7. Initiatives Needed to Support Couple-Centred Care

7.1. Introduction

The previous chapter presented an overview of the challenges faced by partnered aged care residents wishing to maintain their coupledom in residential aged care settings. In many cases, a lack of respect within the aged care industry for older couples' relationships reflected ageist attitudes at a societal level. Associated issues included organisational policies, staffing levels, building design and the physical attributes of residential aged care facilities (RACFs), staff education and training and the personal and cultural attributes of staff. This chapter addresses the research question "what initiatives are necessary to support partnered Baby Boomers' coupledom in residential aged care settings?" and responds to issues raised in the previous chapter with some possible solutions identified in the key informant data. Such initiatives might prove useful on an industry-wide basis to support partnered residents' sense of coupledom.

The chapter begins with examples of couple-centred care in practice, together with a description of the underlying conditions necessary to support a couple-centred approach. Initiatives to create healthy workplace cultures are then presented, followed by measures needed to normalise partnered residents' relationships in residential aged care settings. Discussion then turns to the necessary education and training required for staff to support residents' intimate relationships, while simultaneously preventing sexual assault. Lastly, the need for changes to aged care legislation and accreditation standards is explored.

7.2. 'Good news' stories – Industry examples of couple-centred care

In key informants' stories, examples that positioned couples at the centre of their care stood out as exceptions in the data. As a consequence, they may serve as a valuable resource for use in peer-based learning in the aged care industry. From interviewees' perspectives, in essence, couple-centred care relies on holding partnered residents in positive regard. Positive attitudes towards older adults' intimate relationships and

acceptance of them as sexual beings were key features of the 'good news' stories reported by interviewees. In these accounts, positive regard, together with empathy, served as precursors to (1) open communication between staff and residents; (2) the development of positive resident-staff relationships; (3) staff becoming residents' allies/advocates; and (4) organisational initiatives to support couples' relationships.

7.2.1. Positive resident-staff relationships

The concept of unconditional positive regard, which formed the basis of Rogers' (1951) client-centred therapy, means accepting and respecting others as they are, irrespective of what they say or do. This concept was conveyed in language used by key informants to describe older adults. UnitingCare's Lifestyle Consultant, Colin McDonnell (BB), described his affection for "people in general…but particularly those in aged care". However, interviewees acknowledged that practising unconditional positive regard was not always easy, since it required ongoing self-awareness. Registered nurse, Barbara (BB) said, "I recognise that even though I think older people are the most extraordinary people in the world and sexuality is incredibly important, I still have got that entrenched ageism".

According to Colin McDonnell, holding residents in positive regard allowed him to develop relationships with them over time, to "get to know them all personally" and "know their histories". He described this as recognising each resident's 'personhood' (Kitwood, 1997):

> it's all about relationships. Personhood is bestowed by another person. You can't be a person without it being bestowed on you by someone else, right. So, unless you've got a relationship you can't have personhood because it's the way a person treats you that makes you a person…you can either be treated like a shit and you don't feel like a person or you can be treated with respect and then you will feel like a person.

Key informants perceived that developing meaningful relationships with residents required taking one's time (being unhurried), being genuinely interested in them, maintaining an open channel of communication and listening in a non-judgemental way. These are features described in person-centred models of care. According to TAFE teacher and registered nurse, Janet Ryan (BB), the industry as a whole has not

yet adopted person-centred care. She said, "we're still thinking that we're doing person-centred and person-directed care but we're not because we still…must do everything in a certain time frame". However, according to Colin, where staff take the time to develop meaningful staff-resident relationships, the benefits are reciprocal. He said, "the more you do that [get to know them], then the closer you get to someone and you can learn so much from them. It's about sharing. So, I learn from them and they learn from me".

Educator and registered nurse, Dr Drew Dwyer (BB), stressed that person-centred care requires that residents' needs become the priority. He said, "always in a nurse's perspective, our values come second because the value of the client comes first". According to him:

> the core focus of nursing is person-centeredness. It is really understanding that holistic view, the ins and outs, the inside and out of the person, their needs, their wants, their demands, their desires, what drives them and what creates them as human beings, their history, their learning….We need to make sure that everything we do for their care is individualised and flexible and changing to [suit] them

Shifting from a person-centred to a couple-centred approach had an added layer of complexity because there were two persons involved and no two relationships were the same. According to Jenny Zirkler (BB), Executive Care Manager of Nambucca Valley Care, "sometimes you have to be a little bit careful, especially if one's been caring for another and if there's a little bit of dementia". Like Colin, she stressed that "you really have to get to know them and the family".

7.2.2. Staff becoming residents' allies

According to key informants, staff who held partnered residents in positive regard and maintained open channels of communication with them became their allies. As a result, they were best able to take action to respond to and/or advocate for their needs. One example of this was provided by consultant gerontologist, Dr Jan Herbert. Having visited many different RACFs, she perceived one facility as "unusual" because "the most gorgeous nun" assisted a couple to remain sexual. She said:

> because the woman had multiple sclerosis they're actually using a lifting machine to assist her onto the bed and to assist her husband to do what was needed to make her comfortable, so that they could have sexual intercourse in whatever way was most comfortable to her.

Colin McDonnell said that by learning about residents he could then "teach the relatives as well so they can understand [their relative] better". This allowed them to "become relatives again, rather than carers". Clinical nurse consultant, Dr Michele Chandler, provided an example this in practice. She said that, in cases where a resident with dementia started a relationship with another resident "on the inside", families would normally "put the khyber [sic] on it". However, she recalled "negotiat[ing] with a couple of families" when, on one occasion, staff took measures to support a newly-formed relationship between residents. This included successfully communicating each resident's needs to their families to educate them and enlist their co-operation:

> we had a guy and a woman, they were just lovely and we sat them at a single table, just themselves, for breakfast….And how we set that up - they had separate rooms but they were adjoining rooms…and she was really quite frail but we gave them like bigger beds and things like that…But the families were fully supportive…that will rarely happen unless you get family permission.

This and the earlier example illustrated that, in addition to positive regard, empathy and communication, adjustments to the physical environment were sometimes necessary to facilitate relationships (i.e. using a hoist or providing larger beds in adjoining rooms). However, adjustments to the social environment were also necessary, which in this case took the form of seating residents together and possibly altering other residents' seating arrangements.

7.3. Creating healthy workplace cultures

In order for staff to develop meaningful relationships with residents and align their practices with residents' needs, key informants identified that staff required supportive working environments. This began with aged care organisations nurturing their staff.

7.3.1. Nurturing aged care employees

In the previous chapter, key informants described the thankless task that working in aged care can be for some. This risks staff discontent spilling over into interactions with residents. To help counter this and lift staff morale, educator and registered nurse, Dr Drew Dwyer (BB), described an initiative instituted to acknowledge and appreciate staff. He said it began with his children asking: "dad, why do you do the job you do? Why do these people work so hard? You get really shit pay and you don't get any thankyous". In response, he explained:

> …that's the flame in the light of a carer. It's what keeps our oil burning in our lantern…we don't join care work for money. That's one of the key things about a person in care nursing or in care. They do it because they want to. So that key attribute is something that needs to be nurtured.

In response, his children devised an initiative called "passing on appreciation", which Drew said "drives a better culture":

> …my children came up with a 'passing on appreciation' badge that we give out….People nominate other people to get it and they hold it for a month and they have to think about somebody else that they work with that they want to pass the appreciation badge to…. It's passed amongst all different people within the care service with no rules from head office, no rules from management. They choose the person that they want to walk up to and say, "I appreciate the work you do every day here". They take the badge off themselves and they pass it to the next person and they teach them the rule around the badge.

7.3.2. Fostering a culture of openness

Key informants believed that residential aged care, as it is currently offered, must fundamentally change. According to COTA South Australia's Chief Executive Officer, Jane Mussared (BB):

> I don't think the present model of aged care will work for couples…this *extreme* kind of no capacity to set your own level of risk for different types of risk will be unacceptable. I think the lack of ongoing normal relationships will be a big barrier for people. I think the fact that people don't interact with the outside world on a regular basis will be a problem.

> So, I think there's a faulty assumption that people who've got free choice will continue to choose [residential aged care].

In the case of partnered residents, for residential aged care to become consumer-directed in practice, interviewees identified that each RACF must foster a culture of openness. In such a culture, ideas and suggestions would be welcomed by upper level managers. According to consultant gerontologist, Jan Herbert, residents' needs were:

> only going to be met by proactive and forward thinking and open managers, and above. There has to be a culture of responsiveness and a culture where people are open to their [partnered residents'] needs. I fear at the moment we're not there yet. There's a long way to go…you've got to have that culture of openness - of acceptance - of looking at these people saying, okay what do you want - how can we meet it?

Furthermore, to successfully foster a culture of openness, one interviewee identified the importance of creating a sense of community within each RACF.

7.3.3. Creating a sense of community

According to key informants, residents' needed continuity of care from staff with whom they had built relationships of trust. UnitingCare's Lifestyle Consultant, Colin McDonnell (BB), said this is because permanent staff "get to know people [residents] better and the relatives better". To achieve this continuity in his facility, Starrett Lodge, the concept of person-centred care was extended to care for the needs of staff and families as well as residents. As a consequence, the organisational structure was changed "from the manager down". Rather than it being hierarchical, residents, families and staff were involved in decision-making. For instance, staff had input into their work rosters. Instead of "being dictatorial…and having it so rigid", he said, "you've got people out there making decisions and being creative and just the whole world flows".

The system at Starrett Lodge was based on the principle of reciprocity. According to Colin, in cases where staff "just give, give, give and…don't get anything back, they revert back to [being] task orientated robots…rather than being human…and having the relationship". Reciprocity consisted of "letting the residents have a say", with the idea being that "then they'll give back" to staff. He said if residents are "having fun

and enjoying life", staff see that "what they're doing [is working] and then they get more back themselves". At Starrett Lodge, residents also reciprocated by providing after school child minding for staff. The benefits to female staff were that they "didn't have any problems with babysitters until their husbands came home". Instead, they "brought them in after school" and "had 60 grandmothers looking after them". This provided residents with multi-generational social contact, which, according to Colin, "they loved". He said, "the mothers [female staff] were happier and then fathers would turn up and take their kids home". He added, "that sort of stuff works; it's called community". As a result of this sense of community, staff and resident morale was high, resulting in no staff turnover. Colin said:

> if you have flexible staff and flexible programs like we have then you don't have any staff turnover…every single person was permanent. No one left unless they wanted to…go on to something higher or their husband left town. So [we had] less sick leave, less Workers Compensation. If it is done right, you save money and you make money.

However, despite Starrett Lodge winning "lots of awards" and creating a documentary film[57] about their approach, Colin said "other people in our own organisation didn't even know we were doing it". He used the analogy, "islands rather than continents", to describe the relationship of individual RACFs within the larger organisation. This example highlights a need for more structured peer-to-peer learning in the industry, both within and between organisations.

7.4. Normalising partnered residents' relationships

7.4.1. Organisational policies

Formal written policies addressing couples' needs were considered rare by key informants. However, there were references to positive regard for partnered residents being written into formal policy documents. These served two functions: (1) to communicate couples' needs to staff; and (2) to communicate to potential residents the organisation's attitude to their relationships. According to Queensland AIDS Council's Training and Development Coordinator, Ricki Menzies (BB), when it comes

[57] This documentary, *Finding the why: Enabling active participation in aged care*, is available to view online at https://www.youtube.com/watch?v=hZN1CyEiFNM.

to policies related to residents' sexuality, organisations need to consider how such policies "fit within the context of all their other policies…how do they all work together?" She said, otherwise the policy is tokenistic and "nobody actually really thinks about it".

Jenny Zirkler (BB), Executive Care Manager of Nambucca Valley Care provided a copy of her organisation's Sexual Expression Policy, which she said was motivated by seeing "more husbands and wives or partners coming in together". She acknowledged that "as males are living longer we're seeing the need now…to cater for couples". This resulted in her organisation modifying both the physical and social environment to accommodate couples. She stressed that accommodating couples involved more than simply providing the physical space and furniture. Their social needs also differed from singles which, for instance, required a different approach to planning activities:

> [in] one of our facilities we actually have two bedded rooms and we've had six couples at a time….We've pushed the beds together so that they have a bed. They might not necessarily want to sleep with each other but they have a bed in one part of the room and we've sort of cordoned it off a little bit to make it like a lounge in the other part so that they can be together as much as possible.

To create privacy for couples, she said they had "put up notices on the door, [saying] 'do not disturb' or sometimes 'care in progress'". According to her, "we know that they…want to spend a lot of time together" so in order to create a couple-friendly social environment in the facility she said, "[we're] trying to look at activities that individuals like but also that the couples like together".

7.4.2. Designing services that support partners to remain together

Key informants described how distressing it could be for long-term couples who became separated when each partner's differing health needs did not fit providers' models of service provision. Ricki Menzies (BB), imagined it must be possible for services that:

> enabled someone that was needing care to have their partner who wasn't requiring care to be living in the same space. I

> think that would be ideal because if you've been together 40 or 50 years and one's needing care and the other one's left at home alone I think it would be ideal if they could actually be there in that space together.

A European model was proffered as a solution to this dilemma. According to consultant gerontologist, Dr Jan Herbert, in Europe there is a "division between accommodation and care". She said:

> What happens is that…when the person goes into aged care, effectively they're provided with their accommodation. The care aspect and services aspect…they're controlled separately [by residents] with…their own budget. So, if they don't want the meals that the home provides, then they can ring McDonalds if they want…there are a number of services who will provide meals. [Nor do they] have to have meals at the home.

She likened this to Australia's recently instituted 'consumer-directed' model of community care, saying:

> like CDC[58] in the community; they don't have to use the physiotherapist provided by the home. They can direct that service elsewhere. So, care is a separate budget from accommodation, and it works.

This model would allow couples to choose a supported living arrangement that foregrounded the style of accommodation most suited to their needs. If they subsequently deemed that the care services offered by that accommodation provider were not suitable, the couple could then purchase those services separately from external providers. It follows that accommodation service providers would then be motivated to provide the style of service desired by consumers. In the case of couples, this would require organisations to ask their clients what their needs are. Family advocate, Phyllis (BB), suggested that this process could be facilitated by an independent liaison officer, someone who "will actually listen to them and treat them with respect and validity", who is "primarily on the side of the resident not the institution".

[58] Jan was referring here to Australia's community-based consumer-directed care (CDC) system, where residents remain in their own homes and are allocated a budget for aged care services delivered at home.

7.4.3. Starting the conversation about residents' relationship needs during the admission process

In Colin McDonnell's (BB) account of Starrett Lodge, partners were consulted from the beginning about "how much they want[ed] to be involved in the care of [their partner]". He said this meant they did not have to "second guess what they can do and what they can't do". Several key informants identified the admission process as an important point in time to discuss how the organisation might support partnered residents' sexual relationships. Health researcher, Melissa, said:

> I think it's about having an open conversation with older people as soon as they are admitted into a care environment… having a discussion about…their sexual needs as such. It's understandable that some may not feel comfortable talking about it from the outset but if you have that conversation at the beginning to let them know that, "this is something we're willing to have a discussion about, we're open to it. If this is a real need of yours that might surface in the future, know that we're willing to talk to you about it"…[then you can] work towards addressing the needs that they have.

She was of the opinion that the absence of up-front conversations with residents about their relationship needs made it unsafe or uncomfortable for residents to raise the subject themselves:

> I often find that in not having that conversation up-front, older people get put on the back bench and they feel like it's not something they feel comfortable in saying or they feel like they're not allowed to express it.

Ricki Menzies (BB) reiterated this point, saying:

> I've come across…the occasional form that asks around sexual expression….What it comes down to quite often is that people [staff] feel that this is something personal and they don't want to offend by asking. They're embarrassed to ask but what I generally explain to people is if you don't put it out there, the client probably won't ask because you're not saying this is an option.

Ricki thought "a really cool" assessment form was an "awesome" example of how to ask sensitive questions, including "stuff around your gender presentation". She said that the organisation had structured the assessment questions to look "at a day in the

life of" each resident. For instance, one question was "when you get up in the morning if a care worker comes in, what are the things step by step for when you get out of bed, how do we support you, and then cater to them". For instance, "will that person want to be dressed, do they want to have a little shower before that, their breakfast…everything". She said it included:

> opportunities for questions [such as] do you require some days a week some private time for your sexual expression? Because, oh God, we can't use the word masturbation!" Yeah, [it would] try and work out that sort of stuff…it's still an area that everyone's really scared to talk about.

However, having well written forms was not sufficient. Staff needed to be adequately trained to initiate sensitive conversations with residents. According to Ricki, this included making sure they understood the concepts and terminology written into policies and procedures and had developed sufficient comfort with discussing sexual subject matter. She said:

> I looked at one form…and it actually asked about sexual expression. I said, "Hey, this is awesome. Do you use it?" [They said,] "Oh, we don't use that. We don't know how to ask that question"…I said to them, "what do you mean by sexual expression?" They went, "we really don't know. So, if a client asks us what that is, we don't know what to say. So, we just don't use that form."

7.4.4. Counselling services to manage the transition into care

Key informants perceived entry into residential aged care as a stressful and/or traumatic transition for residents. Separated partners struggled with the grief of losing both their former life and their long-term partner. Psychologist, Eric[59], regarded entering care as "traumatic for families". He said, "there's very little emotional assistance given. It tends to be very procedural. In his view, rarely was this "emotional toll…recognised or addressed". According to him, providers did not offer access to counselling services because they did not understand their value. He described:

> prejudicial attitudes amongst some of the gatekeepers [staff]…about the usefulness of talk therapy…If aged care

[59] A pseudonym given to maintain his confidentiality.

> staff have poor knowledge about the benefits of psychology services, they are less likely to make those services available to the resident.

It was suggested that Australia could learn from the Dutch model. COTA South Australia's Chief Executive Officer, Jane Mussared (BB), said:

> I was in the Netherlands about ten years ago and their use of access to psychologists was much more commonplace that it is in Australia.…attention to people's social mental health was…[a] much more proactive part of their system.

Key informants felt it was in providers' interests to provide counselling and psychology services since some separated partners expressed their inability to cope with their changed circumstances by acting out, complaining, or being rude to staff. Nancy[60], a senior public servant with the Australian Government, viewed such behaviour as a cry for help in her father's case. In response to her mother moving to "a nursing home", she said her father:

> is at the nursing home every day….He's still able to drive so he hasn't been totally separated from mum but still…he's gone through ups and downs at the nursing home in dealing with how mum is declining and so how he shows that is either [by] complaining a lot or being rude to staff…he struggles through all of this.

She felt that more support could be offered to struggling partners rather than labelling them as difficult, demanding, or a nuisance:

> they could manage dad better…it is about looking more at his emotional needs because of the different experiences he's having with mum in her decline….I bet you anything if we did ask them they'd just see him as a 'cranky old shit' and he always complains.

When asked if she was aware of any grief counselling offered to partnered aged care residents, family advocate, Susan (BB), identified that grief counselling was also relevant when couples entered care together. She said:

> That almost moved me to tears when you just asked me that question because…it was totally devastating for dad when he

[60] Pseudonym given to maintain her confidentiality.

> moved into care so that he could be with mum….They would not be separated and I have never heard of grief counselling for that situation.

Such grief was not a singular event, it was ongoing. In Susan's father's case, he had the added grief of his wife dying after he had given up his autonomy to be with her. However, staff seemingly had little comprehension of his distress. Susan described her dad as:

> so grief stricken after mum's death and there was nothing [offered]. They do the DSM-4[61] or the DSM-5 and they say no he's alright, he doesn't need to see anyone….We asked if there was someone he could see to talk about his grief…but it didn't seem to get through.

Susan perceived that staff, especially "RNs in charge of a couple of floors on a nursing home" who "have got an awful lot of things to think about" were simply too overstretched. She added that because they tend to be "fairly practical or medication based", they had limited capacity to listen, comprehend, and respond to requests for psychological services.

Educator and registered nurse, Dr Drew Dwyer (BB), added that counselling is "a skillset not taught to nurses" in their undergraduate degrees. He regarded this as an oversight, given that "nurses in aged care environments constantly are counselling staff, family and residents on…massive issues: grief, loss, pain, quality, culture, religion, lateness and absenteeism, sickness, abuse, bullying, harassment, neglect". In his opinion, "counselling is a service that is hugely under-noticed and terribly underused and should be a skillset embedded into clinicians so that they have the ability to apply more service to the client as needed".

7.4.5. Measures to facilitate couples' privacy

While couple spontaneity was absent from key informants' accounts of organisational support, there were examples of organisations supporting partnered residents' relationship needs. One such example from General Manager of ACH Group, Jeff

[61] DSM stands for the *Diagnostic and Statistical Manual of Mental Disorders*, published by the American Psychiatric Association. See reference list.

Fiebig (BB), described staff being tasked with managing couples' privacy as part of their duties:

> [there were] a number of arrangements where partners were brought in and doors were locked and people were given time to be intimate together, whether that was sex or if it was just talking or whatever it was. So, there were a number of those sorts of arrangements.

The weekly scheduling of residents' social activities was also used by some managers as a mechanism to create privacy for couples. Emeritus Professor Rhonda Nay (BB) referred to another RACF "with limited environmental privacy" where "the 'boss' arranges BBQs weekly to enable a couple to enjoy their sexuality without fear of intrusion.

7.4.6. Couple-sized rooms

Interviewees perceived that aged care facilities were generally not designed with couples in mind. Recreational activities officer, Sally, said that "only in Sydney have I seen couples [together] in an aged care facility and there was only two of them…even new ones [RACFs] - they've got bigger rooms but they're not really enough" for couples. Some couples' accommodation came about by accident rather than by design. However, there were cases of managers being motivated to compensate for this oversight in situations where rooms were of adequate size. Sally described a facility where partnered residents' coupledom was supported by making the best use of the room configurations they had:

> this wasn't necessarily on purpose but it worked. They had rooms that shared a bathroom so one side was the bedroom and then there was a middle bit that was a bathroom and you could access it from both sides and it really worked well for couples, because they would have say room 17 and 18 and they'd use room 17 as a lounge room and they'd use room 18 as a bedroom and then they'd have the bathroom as their own.

However, she stressed that, in her experience, this case was unusual and most facilities were not easily adapted for use by couples:

> This was just someone using what they had really well. But that's not what it was built for. It was built…for less privacy, you had to share a bathroom with someone you didn't know.

7.4.7. Couple-sized beds

Although rare, in some key informants' accounts, partnered residents were able to share a bed. Interviewees provided a few examples of RACFs where double or queen sized beds were either provided or condoned in couples' rooms, most often for married couples. According to registered nurse, Annie Devine, married couples in her former place of work "had a double room and basically that allows them to have a double or a queen bed in the room so they will sleep together."

7.4.8. Conjugal visits

Several key informants' accounts highlighted the plight of couples who became separated by the aged care system[62]. Educator and registered nurse, Drew Dwyer (BB), described an initiative in one RACF that could be used by organisations to support separated partners wishing to maintain intimacy in their relationships. He said:

> I consulted to a home for a number of years where they always kept one spare room away from the nursing home, like an area, and the residents (only through the care manager) were allowed to book the room. The care manager would then set it up with chocolates, champagne, fruit, a bar, run a bath, rose petals, selections of their favourite movies and music, things they wanted in there…. [Partners] would meet in that room and have their own intimate Friday night out. I loved it and the list was full constantly. There was always two residents wanting to have some private time in that room and it was great….There's a double bed in it, there's everything they would want as a hotel, a love hotel room. They were just beautiful to see.

The booking process was managed privately by one person in the organisation. Drew said that in order to make a booking, "both [partners] met with the manager…[who] privately ran that, booked them in and…set the room up". The need for such a facility

[62] These findings were presented in the previous chapter.

to be handled discreetly and treated respectfully by both staff and residents was stressed:

> I often say to staff, you know, the heart has no wrinkles, so don't look at their age as a barrier and we don't know what they're doing in that room and we shouldn't be interested…. Everyone [residents] knew what it was and everybody used it appropriately and privately.

Some Australian RACFs actively supported conjugal visits, according to Queensland AIDS Council's Training and Development Coordinator, Ricki Menzies (BB). She said:

> in some of those older residential settings where it was very much dormitory style stuff and it was just mostly single people, they had a conjugal suite. So, if someone's partner was visiting, they had a room with a double bed where they can go and have sex, and they would get the person ready when their partner would come and visit and a couple would go [to the conjugal suite].

A European example was provided by health researcher, Melissa., who said she had visited nursing homes in Amsterdam where they had "what they call stimulation rooms". She said such rooms were set up with "pornography videos, magazines [and] toys" for use by residents. "If they [residents] want to use it, they go to the room [and] watch a video there". Key to the success of this facility was that residents "feel safe" and "there's no judgement" by others. She added, "if there's a need, why not? Who are we to judge whether they use the toys?"

7.5. Staff Education and Training

A number of key informants were actively involved in providing sexuality training to the aged care sector, which demonstrated there was a growing interest within the aged care sector. According to registered nurse, Barbara (BB), some managers and staff were voluntarily learning about residents' sexual wellbeing, which indicated positive signs of change in the industry:

> I can remember the first conference I went to…[where there 6was] a paper on sexuality and older people…it was 20 years ago…and three people turned up….No-one was interested, no-one, no-one, no-one. And now…service providers are coming

> from a very different space….There is much more of a focus on sexual wellbeing than sexual behaviour. I'm not saying the focus on sexual behaviour doesn't exist, it does, but there's much more recognition of the rights of older people to be sexual…there are many more conversations about sexuality as it is expressed by older people in residential aged care facilities than there were in the past. I think there's been a massive shift.

7.5.1. Supporting staff comfort levels with sexual matters

Where residents' sexual relationships were concerned, key informants emphasised the important role that resident-staff interactions played in supporting, or stigmatising, sexually active residents. A necessary precursor to staff being supportive was their personal comfort level with sexual subjects. According to key informants, workplace training had a role to play in staff members feeling supported or traumatised when encountering sexual situations.

According to True Relationships and Reproductive Health's[63] Regional Education Co-ordinator, Natasha Milner, "acknowledgement that older people are sexual beings" was needed sector-wide. To support residents' social connections, she believed that "breaking down taboos [about] discussing sexuality" and "supporting sexuality for older people" were necessary in RACFs. According to her, this required "a change in attitude", adding "there's nothing really major or difficult that needs to be implemented…it doesn't really require any extra resources, extra money or extra anything really". She said some staff are "going to require more training because they're not comfortable and confident and perhaps not competent…but it's something that's not difficult to learn".

Interviewees offered two approaches to assist staff who felt personally uncomfortable with supporting residents to remain sexually active. Where staff had cultural, religious or other reasons that prevented them from practising positive regard for sexually active residents, it was suggested that they instead be assigned to care for residents where this was not a concern for them. Lawyer, Helen (BB) said "you'd have to be very careful with your staff" when it comes to them assisting sexually active residents in order to ensure that they "are totally supportive". She said, "otherwise you'll have

[63] Formerly named Family Planning Queensland.

staff going off on stress leave". She did not feel it was fair to "put it onto *all* staff because some staff may not be comfortable with it [being sexual] themselves, let alone with someone else [being sexual]".

However, it was felt that most staff discomfort was due to inadequate life experience and/or education, in which case it could be largely overcome by providing adequate modelling by experienced staff, in-house training and one-on-one supervision. In the case of sexuality training courses, key informants believed that sexuality-related education (and aged care training generally) was best delivered face-to-face by skilled educators able to model their personal comfort levels and positive regard for sexually active residents. Helen stressed that educators must be "people who are really qualified", not "someone who comes in and says, 'oh look, we've got to do this module first of all on a OH&S[64] issues and then we've got this other module about assisted sex practices". According to educator and registered nurse, Dr Drew Dwyer (BB), sexuality education programs for aged care staff must draw on an "evidence base" of identified "best practice".

An added benefit of the face-to-face training offered by specialist external training providers, according to Natasha Milner, was that it provided an opportunity to flush out whether or not staff were familiar with their organisation's policies. She said, often "the staff aren't aware of what the policy is and so that training provides an opportunity to have that discussion". She continued by saying, "normally what we've found in those cases is when the policy's discussed, it's usually quite a good policy. It's very reasonable and it's workable and it's not encroaching on anyone's human rights or anything like that, but it's just that nobody really knew". This speaks to a lack of internal communication and training within some aged care organisations.

However, key informants agreed that the take-up of specialist sexuality training courses offered by specialist training providers is not high within the industry. This was "partly reflective of attitudes", according to Natasha, suggesting that aged are residents were still viewed as post-sexual by many aged care organisations. She said:

> It's not something we get asked to do often…that's not a high volume of work for us compared to how often we've been

[64] OH&S stands for Occupational Health and Safety.

> asked to go into disability organisations or schools or organisations that support people with mental illness….Our aged care work would be very small scale compared to other organisations that we support.

External training provider, Dr Drew Dwyer, reiterated the taboo nature of older adults' sexual expression. He said he and his team offered training packages "on sex, sexual health, sexuality" for aged care providers, including "how you implement it [and] train your staff…we offer them the whole service". According to him it "rarely gets taken up. It's a taboo subject" but added:

> then again, we offer public service courses to clinicians and carers to come and learn from us. We have a whole course in sexual health and sexuality of the elderly and it is one of our hardest courses to fill or get anyone to come to. They won't come. We hold counselling courses for registered nurses in aged care, people won't come. We have another course we run which is understanding and managing difficult and complex conversations in advanced care planning and end of life care. People won't come to the course.

He attributes much of this resistance to dual factors: (1) once staff learn a new skill they are obliged to use it; and (2) they receive no extra pay and therefore little personal benefit from adding to their workload. He said:

> once they come and they learn the skill, it then becomes a competency which they have to and must put into practice. If they don't have the competency, they have the right in practice to say, that's out of my scope, I don't understand, I can't do that.

In other words, staff need to be provided with incentives and be subsequently rewarded for improving their skills.

7.5.2. Training staff to distinguish between consensual and non-consensual sexual activity

Key informants referred to residents' sexual behaviours as an expression of a fundamental human need. However, for reasons aforementioned, not all staff understood this. Ignorance, combined with the culture of over-vigilance that had developed throughout the industry in response to mandatory reporting rules, meant

that consensual sexual relationships between residents were being infringed upon. According to consultant gerontologist, Dr Jan Herbert:

> Every staff member undertakes education…on the compulsory reporting of abuse. Then it's repeated annually. That's the kind of mandatory education that goes on in every home, which puts a very negative connotation on sexual expression…my god, this is awful - because it's tied up with legislation to stop abuse.

In the absence of clear direction within aged care organisations, key informants perceived that many staff were unable to recognise consensual relationships and, instead, automatically responded as they would in cases of sexual abuse[65]. As a result, staff training tended to be retroactive, delivered in response to 'problems'. Proactive staff training, developed from the perspective of residents with the capacity to consent, was perceived as much less common. Registered nurse, Barbara (BB), said:

> the problem with just responding when there's a problem is who says it's a problem? I think that sometimes there are problems that are not articulated as problems because people don't know where the benchmark is. So just to rely on delivering education when there's a problem runs the risk of …be[ing] quite explosive…service providers have often been affected in traumatic ways and residents too…there might have been a sexual assault that has taken place, for example.

She considered that, in the case of sexual assault prevention, it was:

> really important…to give service providers the education that …[identifies] some of the things you look out for rather than thinking that they'll be able to pick [them] up…or assuming that they'll pick up on everything they need to pick up on.

Part of this training involved modelling how to (1) remain calm; and (2) assess each situation according to the facts presented. Barbara gave an example of how she modelled her response to residents' sexual behaviours. She said that, with inexperienced staff, she would: "okay let's talk about what's happening for this resident". She would then "unpack" the sexual behaviour that was causing the staff member concern, while emphasising that, for the resident, "it's an expression of their sexuality". In some cases, she might have to explain that "they may have lost capacity

[65] This was discussed in the previous chapter.

to express their sexuality in appropriate ways". She said, "often the conversation's then about how do we redirect that sexual expression so that it is appropriate and it's not violating the staff members and not infringing on the rights of any other residents".

According to key informants, in most cases, once staff were able to reframe residents' 'behaviours' as needs, this diffused the situation and allowed mutually beneficial solutions to be found. Many key informants spoke of diversional tactics that were compassionately employed by experienced staff to redirect unwanted behaviours. For example, registered nurse and TAFE teacher, Janet Ryan (BB), said it was not uncommon to receive invitations to come to bed. When asked "are you coming to bed with me?" she said she would respond:

> yes, but I have to go and do my rounds first. So, you get in there and warm up the bed. You [then] pop your head in the next morning. You can sit there and go, "you fell asleep". …So, it shows them that they're accepted as a person, not just a patient.

Sex worker, Brett (BB), provided an example of staff facilitating his regular visits to a resident previously labelled with problem behaviours. He said he was:

> called specifically to work with a resident of a semi-secure facility for people with acquired HIV-related dementia….The staff were at their wits end because he would keep escaping in his pyjamas and going down to the local pub and just asking …every single man whether they would have sex with him on the principle that someone will say yes eventually…much to the horror of customers.

The solution staff devised was "to get someone in who could meet his needs within the facility". Brett said, "not only did it happen, but [it] worked". The benefits to both the resident and staff were that:

> once [that] was an option for him…maybe only once a month or every six weeks…he was able to modify his behaviour to wait because [he knew] the outlet was coming, [that] it was foreseeable and so that enabled him to take back some measure of control in how he dealt with those urges.

While this example may represent the extreme end of the range of possible situations, it provides evidence of the mutual benefit to both staff and residents of: (1) specialist

staff training; (2) acknowledgement of residents' sexual needs; and (3) incorporation of residents' sexual needs into their care plans.

7.6. Couple-centred initiatives needed in aged care legislation and accreditation standards

Due to resident sexuality being treated as a taboo topic by some providers, one key informant thought that the legislation needed to be amended to explicitly acknowledge sexual relationships. According to clinical nurse consultant, Dr Michele Chandler (BB):

> At the moment…[in the accreditation standards] there is no actual measure of sexuality in there at all. If it's not there, it's not going happen. If they've got it in the Act, it needs to go into the standards.

She added that the accreditation standards themselves needed to be more prescriptive and less open to interpretation, since they formed the basis audits undertaken by the Australian Aged Care Quality Agency (AACQA). According to Michele, there are currently templates used for smaller-scale "support contacts" undertaken by AACQA. She said,

> when they do those they actually have templates that they follow and they must follow the templates. You know "are consumers consulted in their decisions", tick yes/no. They're very restricted templates that they use. That'd be a perfect place to put something like that in there around sexuality but there's nothing in there at the moment.

As a result of the lack of assessment of residents' sexual relationship needs, providers say "no, we don't have any residents who have those needs". Her response to that was:

> Well how do you know? Is it assessed? So, again, if it's not in what the assessors are using, the tools, then it won't happen". …that was my point, you really need to get it into the standards. Because we got it into The Act but we didn't get the next hurrah, which is something that assessors have to measure when they go out there…because if it's not, they won't.

7.7. Conclusion

In response to the research question "what initiatives are necessary to support partnered Baby Boomers' coupledom in residential aged care settings?", this chapter presented a range of initiatives identified in key informants' data that could be implemented in a couple-centred model of aged care. The building blocks identified as essential to couple-centred care were: (1) positive regard for residents and their intimate relationships; (2) empathy; and (3) open, non-judgemental communication. These attributes applied at the level of staff-resident interactions, management policies, staff training and the arrangement of the physical environment. Staff member's positive regard for partnered residents could be facilitated by responsive organisational cultures that (1) placed partnered residents' needs ahead of the needs of the organisation; (2) nurtured the wellbeing of staff; (3) developed a sense of community between residents, staff and families; and (4) encouraged reciprocity between staff, residents and non-resident partners.

It was considered essential that staff receive specialist education and training to enable them to distinguish between consensual and non-consensual sexual activity. This was necessary to both (a) identify and proactively support residents' consensual sexual relationships; and (b) identify and act upon warning signs to protect residents from sexual assault. Furthermore, the need for such training needed to be reinforced by explicit mention of residents' sexual expression in aged care legislation and accreditation standards. The next chapter will provide a discussion of these findings together with the findings presented in the preceding chapters. Included in that discussion is a conceptual model developed from the data.

Chapter 8. Discussion

8.1. Introduction

The previous four chapters presented findings gathered from in-depth interviews and a survey instrument. The data demonstrated a disjuncture between partnered Baby Boomers' expectations and the current reality for couples in many residential aged care facilities (RACFs). Survey participants reported that they valued their intimate partner relationships and expected to be given the choice as to whether they continue to live and/or sleep with their partner should they require the services of a RACF. However, participants revealed that many aged care organisations did not cater to couples and, in some instances, actively discourage intimate relationships. This was supported by the research literature.

This chapter will discuss the study findings in relation to the research questions. It will then compare and contrast the findings with the broader literature and, lastly, will draw on relevant theories in an attempt to interpret the issues highlighted by the data. First, I will discuss valued aspects of Baby Boomers' relationships and their attitudes to institutional living environments followed by the current reality for intimate partners in residential aged care (RAC). Lastly, I will discuss theoretical explanations of institutional environments and present a conceptual model developed from the data to explore possible pathways to support partnered Baby Boomers to maintain their coupledom in RACFs.

8.2. Valued aspects of Baby Boomers' intimate relationships

The first research question in this study asks, which aspects of their intimate relationships do partnered Baby Boomers value and wish to maintain as they age? The majority of survey respondents indicated that they valued togetherness and wished to remain together. Survey questions asking about 'essential' and 'valued' features of participants' intimate relationships revealed that most found it difficult to separate important features of their relationship from the day-to-day business of living together. However, regardless of whether they cohabited, partners valued emotional closeness,

physical affection and sexual enjoyment. In addition, partners living together valued teamwork, intimate proximity and conducting their relationship in bed. Pleasure of all sorts was highly valued. Although couples' intimate behaviours have been investigated previously (Acitelli, & Antonucci, 1994; Andersen, Guerrero, & Jones, 2006; Gulledge, Gulledge, & Stahman, 2003; Stafford & Canary, 2006) this current study was the first to qualitatively investigate self-rated relationship features valued by partnered individuals within a single generational cohort, and by doing so, extends and adds value to the field of knowledge.

8.2.1. Togetherness

It was clear that the majority of survey participants were happily partnered. Sharing life with the person they love was an enjoyable experience that enriched their lives and contributed to their sense of wellbeing as individuals. Responses to questions on features of their relationship suggested that being together, being familiar with each other, and sharing life moments were essential relationship ingredients. Other important elements included regularly talking and being listened to, giving and receiving assurances of love, friendship, companionship, physical affection, kindness, playfulness, humour, laughter and sharing day-to-day tasks. Balancing individual needs, exercising tolerance, and building trust between partners was also important, as was a positive attitude.

These findings support previous literature on partner communication. Quantitative survey research conducted in the United States by Canary and Stafford (1994) and Dainton, Stafford and Canary (1994) found that couples maintained affinity with each other through re-assuring behaviours that were comforting and supportive. These included being patient, forgiving, co-operative and non-critical. According to them, relationship satisfaction was fostered by sharing day-to-day tasks and communicated using positivity (cheerfulness and optimism), assurances and physical affection. They described assurances and positivity as the best predictors of relationship satisfaction (Canary & Stafford, 1994; Dainton, Stafford & Canary, 1994).

Important self-reported relationship features identified in this current study are also consistent with an American study that relied on participant observation. Carstensen,

Gottman, and Levenson (1995) found that partners in happy unions displayed more humour, affection and joy and tended to listen, show interest and validate their partners more than unhappy partners. Carstensen et al. (1995) also found that older, long-term couples tended to show more mutual affection than middle-aged couples. This suggests that Baby Boomers' enjoyment of being together might increase with age and relationship duration.

Driver and Gottman's (2004) observational research found that, in the United States, partners who 'turned toward' each other in everyday interactions established more lasting friendships. Regular playfulness and humour exhibited by male partners played a significant role in reducing relationship conflict and increasing female partners' affection whereas men valued partners who displayed enthusiasm. These gender differences are not apparent in this current study (possibly due to the small sample size and skewed gender mix). However, in general, this current study supports the literature cited here.

Biomedical and population-based research in Europe, North America, Asia and Australia found that loneliness and social isolation were linked to negative health outcomes such as depression, anxiety and aggression, cognitive decline, stroke, obesity, elevated blood pressure, diminished immunity and premature death (Cacioppo, Grippo, London, Goossens, & Cacioppo, 2015; Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015; Matthews et al., 2016) whereas intimate relationships were found to have a protective effect (Cacioppo, Capitanio, & Cacioppo, 2014; Cacioppo et al., 2015). This current study contributes to the knowledge base on couples' intimate behaviours through the addition of rich, qualitative, self-reported data on relationship characteristics that sustain a sense of close connection between partnered individuals within a single generational cohort.

8.2.2. Emotional closeness

Emotional intimacy, closeness and affection were rated as important by study participants, demonstrating that people in happy unions had a high emotional investment in their relationships. Closeness was established through verbal expressions of love, caring actions, talking and listening to each other and laughing

together. Survey respondents valued 'looking out for each other'. They appreciated their partner's support and encouragement and the sense of *being cared for*. In participants' narratives, women referenced *being cared for* with greater frequency whereas men referenced *caring for* their partner.

These study findings on relationship maintenance strategies broadly reflect American research (Andersen & Guerrero, 1998; Floyd 2006). Graham's (2010) meta-analysis of 81 international studies found that selfless love, altruism, and putting the other before oneself signified commitment to maintaining the relationship. Montgomery reported that such behaviours predicted love, liking, and relationship satisfaction because non-verbal behaviours are "less strategic, more spontaneous, and, therefore, more honest" (Montgomery, cited in Taraban, Hendrick, & Hendrick 1998, p. 342).

Quantitative North American studies by Acitelli and Antonucci (1994) and Antonucci (1994) found that women were more attuned to their social environments than men and that, for them, relationship satisfaction and happiness in general was dependent on feeling supported, cared for, valued and appreciated by one's partner. Horan and Booth-Butterfield (2010) reported that, in heterosexual couples, *receiving affection* increased relationship satisfaction whereas *giving affection* communicated commitment to the relationship and tended to increase feelings of safety and security.

Prior research that supported Belle's (1982) support gap hypothesis (Steil, 2000), found that women tended to offer more emotional support to their partners than men. However, given that this dissertation reports on what men and women *valued*, as opposed to what they *received*, there may be no contradiction. Furthermore, a study by Verhofstadt, Buysse, and Ickes (2007) found that while participants' self-rated responses validated the support gap hypothesis, researchers' observational data did not. Xu and Burleson (2001) offered further insight when they reported that women's *desired* levels of emotional support exceeded their experiences. What this study adds to the literature is a suggestion that, in the Baby Boomer cohort at least, men tend to value *giving* more than receiving, whereas women prioritise *receiving* emotional support. This perhaps indicates reciprocal values, where men see value in offering assurances of their commitment in order to satisfy women's greater need to feel safe and secure.

8.2.3. Physical affection

For many in this study, close body contact and loving touch were essential ingredients that contributed to relationship satisfaction. Data from survey questions relating to physical intimacy showed that a large majority considered physical intimacy an 'essential' part of life. Cuddling and kissing were the most mentioned activities, followed by holding hands, touching/stroking, hugs, massage and affectionate squeezes. Men in this study placed a higher value on physical affection than women. These findings support survey research conducted by Heiman et al. (2011) in Brazil, Germany, Japan, Spain and the United States that found that, for men in particular, physical affection, especially kissing/cuddling and partner touch/caressing, predicted relationship happiness.

The results of this study also support quantitative research studies in the fields of communication, psychology, sexology and the biological sciences. One study of American college students by Gulledge et al. (2003) found that physical affection in couples, in the form of "backrubs/massages, caressing/stroking, cuddling/holding, holding hands, hugging, kissing on the lips, and…face" positively influenced relationship and partner satisfaction. Hertenstein's (2006) review of almost 100 international studies on the role of touch in humans and animals reported that hugging and kissing were fundamental means of communicating affection between partners. A review by Gallace and Spence (2010) of international literature in cognitive and social psychology, neuroscience and cultural anthropology found that touch was the most powerful form of interpersonal communication.

Studies in Switzerland (Debrot, Schoebi, Perrez, & Horn 2013) and the United States (Horan & Booth-Butterfield, 2010; Rancourt, MacKinnon, Snowball, & Rosen 2017) found that caring physical contact benefitted partnered individuals by regulating emotion, lowering stress hormones, promoting health and wellbeing, fostering long-term survival and quality of life. Ditzen, Hoppmann, and Klumb (2008) found that physical intimacy and closeness reduced the stress hormone, cortisol, in both partners. These studies, together with the findings in this current study, have significant implications for the health of partnered individuals in RACFs, where intimate physical contact is often discouraged by the physical environment and/or organisational culture.

What this study contributes to the literature is data that illustrates and reaffirms the meaning and value people attribute to their physical contact.

8.2.4. Sexual enjoyment

Sexual expression has been described as integral to intimate relationships (Butzer & Campbell, 2008). However, to date, sexuality research has predominantly focused on individuals, resulting in a paucity of research into the role partnerships play (Aubin & Heiman 2004; Das, Waite, & Laumann, 2012), especially in later life. Furthermore, while contextual effects on relationship satisfaction have been studied (Bradbury, Fincham, & Beach, 2000), their effects on sexual satisfaction have largely been ignored (Henderson, Lehavot, & Simoni, 2009), except in congregate settings (Rheaume, & Mitty, 2008).

Population-based survey research in Australia, France, Germany, Italy, the United Kingdom and the United States found that many people aged 50 to 70 continue to engage in partnered sexual activities (Hayes et al., 2007; Herbenick et al., 2010; Lindau & Gavrilova, 2010; Lyons et al., 2017; Moreira, Glasser, King, Duarte, & Gingell, 2008; Steinke & Bergen, 1986; Vanwesenbeeck, Bakker, & Gesell, 2010). Sexual problems, more prevalent in older age groups (DeLamater, 2012; Leiblum, Hayes, Wanser, & Nelson, 2009), included vaginal dryness and pain (Howard, O'Neill, & Travers, 2006) and erectile dysfunction (Lindau et al., 2007) among others. Lindau and Gavrilova, (2010) found that sexual problems were often associated with poor health and stressors rather than age *per se* (Laumann & Waite, 2008).

Three survey questions in the current study asked participants about their (1) attitudes to sexual pleasure; (2) levels of sexual satisfaction; and (3) sexual pleasure with their partner. They were also asked if they had any future plans to cease being sexual. Most participants indicated that they considered sexual pleasure an essential part of life, were sexually satisfied at least some of the time and did not think they would ever stop being sexual. Many described their sexual satisfaction and relationship satisfaction as being interdependent, indicating that regular and positive sexual interactions were essential ingredients for happiness and vice versa. This corroborates findings by Heiman et al. (2011). Participants who were sexually satisfied were more likely to

describe their relationships in positive terms. Women reported more sexual dissatisfaction than men, often attributing it to their partner's erectile dysfunction or their own fatigue. Sexual enjoyment was rarely mentioned in isolation by either gender, being one of several important ingredients in the relationship experience.

American research by McCarthy and Wald (2012) found that in a healthy relationship, sexual satisfaction constitutes approximately 15-20% of overall relationship satisfaction, findings corroborated by the current study. Furthermore, Two Australian studies reported that poor sexual and relationship satisfaction was associated with higher levels of psychological distress (Patrick et al., 2013). Smith et al. (2011) found that sexual satisfaction was influenced by sexual frequency (especially for men) and the quality of couples' sexual encounters (especially for women). While they found there was often a mismatch between partners' desired frequency of sex, women were more likely to be sexually dissatisfied. One possible reason, according to Australian researchers, Richters, de Visser, Rissel, and Smith (2006), was that women considered quality and variety in sexual activities more important. Rehman, Fallis and Byers (2013) attributed women's dissatisfaction to cultural influences that devalue female pleasure. Consistent with the current findings, Rosen, Heiman, Long, Fisher, and Sand's (2016) multi-national study66 found that: (1) female partners of men with sexual problems reported more sexual dissatisfaction; (2) men were more distressed by the impact that their sexual difficulties had on their relationships; and (3) many couples in long-term, committed relationships demonstrated relationship resilience by maintaining high levels of physical affection.

According to McCarthy and Wald (2012), sexual satisfaction relies on both partners creating pleasurable sexual interactions. They found that, in couples who nurture their sexual relationship and develop increasing emotional closeness, sexual pleasure may improve, rather than decline, over time. Frederick, Lever, Gillespie, and Garcia (2017) reported that taking time, setting the mood, sexual variety, and communication were important predictors of sexual satisfaction for both sexes.

In the current study, although some respondents reported a decline in sexual activity with relationship duration, others described adaptations they had made to keep their

66 Countries studied included Brazil, Germany, Japan, Spain and the United States

sexual relationship alive, including using sex toys and erotic imagery to facilitate their mutual pleasure. However, despite one account of a 'love hotel' room in a RACF[67], it is hard to imagine how 'setting the mood' and the use of sex toys might generally be received by RACFs at the current time.

In terms of factors that interfered with sexual pleasure, participants indicated that stress, fatigue, and illness, accompanied by reduced sexual desire, were significant issues that impacted on their sexual health. Erectile dysfunction and vaginal changes were also frequently mentioned. Significant interpersonal factors that affected personal enjoyment included ageist and discriminatory attitudes by others, privacy intrusions, and the challenge of maintaining privacy with other people nearby. Other peoples' attitudes were especially an issue for people in same-sex relationships. Key informant data gathered from staff, consumer advocates and aged care consultants reported that these interpersonal factors are issues that currently need addressing in RACFs.

The qualitative data in this study suggest an interrelationship between physical affection, sexual satisfaction, relationship satisfaction and personal wellbeing. This adds to the knowledge base (mostly from the United States) that found connections between: (1) relationship satisfaction with physical affection (Acitelli & Antonucci, 1994; Antonucci, 1994; Canary & Stafford, 1994; Dainton et al., 1994; Gulledge et al., 2003; Heiman et al., 2011); (2) physical affection with health and wellbeing (Debrot et al., 2013; Horan & Booth-Butterfield, 2010; Gallace & Spence, 2010; Rancourt et al., 2017); relationship satisfaction with sexual satisfaction (Heiman et al., 2011; McCarthy & Wald, 2012; Rosen et al., 2016); and (4) sexual and relationship satisfaction with psychological wellbeing (Patrick et al., 2013).

This current study extends the literature on sexual activity within dyads, its relationship to personal wellbeing and relationship satisfaction and contextual factors that can reduce sexual pleasure in mid to later life. The findings help debunk the myth that older women are asexual, given that 85% of survey participants were women and the majority did not expect to ever stop being sexual. The data provide a glimpse into the types of sexual challenges that increasing numbers of Baby Boomers will face in

[67] Reported in Chapter 7.

their old age, some of which may require specialist health services. Also, since pleasure played an important role for participants in this study, it is reasonable to assume that many Baby Boomers will continue to be sexually active and will continue to use sexual products and services to facilitate their sexual relationships. These findings sit at odds with current aged care provision, as reported by key informants. Furthermore, research inattention to the sexual health of residents, despite evidence of increasing rates of STIs in older age groups in countries such as Australia, the United Kingdom and the United States (Bourne & Minichiello, 2009; Center for Disease Control, 2012; Emannuel, 2014; Smith, Delpech, Brown, & Rice, 2010; Tavoschi, Dias, & Pharris, 2017), highlights an area in need of further research to establish the relative risk of residents arriving with, or subsequently contracting, STIs in RACFs.

8.2.5. Living together

Data from the survey question about living together indicated that cohabiting provided additional relationship benefits not mentioned by non-cohabiting partners - teamwork and intimate proximity. Teamwork incorporated a sense of partnership, equality and sharing responsibility. Intimate proximity described the intimacy and closeness created by partners being in close proximity, even when not interacting directly. These findings support previous research that found that sharing of day-to-day routines and household duties helped foster feelings of love, mutuality and friendship (Canary & Stafford, 1994; Dainton et al., 1994; Graham, 2010). Canary and Stafford (1994) reported that equitable relationships were more stable whereas inequity caused distress and reduced mutuality, trust, liking and commitment between partners.

There is a body of evidence from Europe, North America, Asia, Australia and Israel that married people are happier, healthier and less emotionally distressed than single people (Coombs, 1991; Gray, De Vaus, Qu, & Stanton, 2011; Williams & Umberson, 2004) and that marriage reduces mortality risk (Hughes & Waite, 2009; Manzoli, Villari, Pirone, & Boccia, 2007; Pienta, Hayward, & Jenkins, 2000; Rendall, Weden, Favreault, & Waldron, 2011; Wilson, 2002). Some scholars have claimed that these benefits result from the social support provided by cohabitation rather than marriage per se (Hagedoorn et al., 2006; Musick & Bumpass, 2012; Ross, 1995; Wu, Penning, Pollard, & Hart, 2003) whereas others reported that marriage was more protective than

de facto partnerships (Brown, Bulanda & Lee, 2005). Some attributed health benefits to interpersonal closeness, ongoing companionship, emotional gratification and daily support (i.e. teamwork) (Coombs, 1991). What this current study contributes is a greater depth of understanding of the subjective experiences of cohabiting couples.

8.2.6. Bed as a relationship setting

A few studies found that sleeping together is a social activity that contributes to individual wellbeing. Troxel, Robles, Hall, & Buysse. (2007) and Troxel (2010) reported that (1) social connections help people live longer, healthier, and happier lives; (2) healthy relationships promote good quality sleep by reducing vigilance; and (3) there is an inter-relationship between couples' sleep quality, relationship quality, and individual health and wellbeing.

The data from the survey question on sleeping together showed that the majority slept together and found it a comforting activity. Participants described their bed as an important relationship setting, regardless of whether they lived or slept separately. They described a range of bonding rituals that take place in bed. The double bed was a meeting place but not necessarily a sleeping place. Important activities that occurred in bed included talking, cuddling, spooning, being in close body contact while falling asleep, keeping warm, reading and sexual activities. Several respondents expressed how reassuring it was to be able to reach out and touch each other in the night. While many experienced sleep issues, they preferred to sleep together with their partner, instead taking proactive measures to improve their sleep. For those sleeping apart, reasons included personal preference, differing sleep patterns, partner disturbances, sharing the bed with pets, being their partner's carer, and illness. Amongst this group, sleeping separately did not necessarily mean that the relationship suffered. However, for some it was an indicator of relationship dissatisfaction.

This current study found that sleeping together is indeed a social activity and supports previous research that found links between relationship satisfaction and sleep quality in couples who sleep together. What this study adds is qualitative information about the social activities entertained by couples in bed together and the perceived

importance of sleeping together, including proactive measures taken to reduce sleep disturbances.

8.3. Baby Boomers' attitudes to institutional living environments

The survey instrument sought information about participants' experiences of RACFs to date and asked them to anticipate life in a RACF in relation to (1) maintaining their relationship; (2) sharing a bedroom; and (3) sharing a bed with their partner. Most were highly invested in maintaining their relationships and wished to remain together for as long as they choose, even in institutional settings. The majority (n=98, 64%) considered it 'vital' that they share a room and preferred to at least be given the option of sharing a bed with their partner. This section focuses on the answer to the second research question: what are partnered Baby Boomers' attitudes to residential aged care? Many study participants stated a preference for avoiding being institutionalised themselves. Some entertained alternative models of aged care when they are no longer able to look after themselves. This section will discuss key issues raised by survey participants based on their experiences of RACFs, which are: (1) quality of life; (2) fear of dying in an institution; (3) older people as sexual beings; and (4) privacy.

8.3.1. Quality of life

While a body of work exists on the resident experience *after admission*, Jeon (2016) found that Australian research into consumers' needs and expectations *prior* to entering RACFs is limited. None of the studies he reviewed identified needs specific to couples. He classified the Australian consumer experience of RACFs into eight domains, in order of priority: (1) choice; (2) respect and dignity (personhood, autonomy, private storage, privacy and confidentiality); (3) the physical environment; (4) the social environment; (5) the functional environment (rehabilitation, mobility and exercise); (6) staff actions and interactions; (7) the organisational environment and resources; and (8) clinical and personal care (Jeon, 2016; Wells, 2017).

Findings from this current study emphasised the importance of quality of life for people anticipating possible futures in RAC settings. Quality of life has been described as a subjective phenomenon that reflects a person's sense of happiness and

wellbeing, largely determined by one's attitudes, morale, and general satisfaction with life (McDonald, 2016; Skevington, Lotfy, & O'Connell, 2004). This subjectivity is said to be fluid, responding and changing according to personal circumstances (McDonald, 2016). For participants in this current study, quality of life meant thriving rather than merely surviving. Maintaining one's identity and individuality was a key theme, as was autonomy and choice. Aspects of life quality that were emphasised were being treated with respect; being able to continue being the person they have always been, doing the things they enjoy; maintaining a degree of independence and privacy; being able to develop and maintain meaningful social connections of choice, especially one's intimate relationships; having meaningful activities; and living in a safe, appealing, personalised, home-like environment.

In some participants' narratives, there were accounts of happy couples remaining together in RACFs which suggested there were visible emotional benefits to keeping happy couples together. However, participants who had witnessed the day-to-day lives of residents who had been involuntarily separated from their spouse/partner stressed the emotional harm they perceived this can do to both individuals. Some study participants expressed a fear that they themselves might experience forced separation from their intimate partner and may have to live out the remainder of their life alone. Among co-resident couples in RAC, participants perceived that the physical and social environments within RACFs were more likely than not to have negative impacts on couple relationships. Many questioned whether a good quality life was possible in RAC, making them fearful of RAC. A few expressed the opinion that, given a choice, they would rather choose euthanasia than RAC.

Previous research found that health is not the primary determinant of quality of life. Albrecht and Devlieger (1999) and McDonald (2016) reported that many healthy people did not perceive they have a good quality of life whereas others experienced happiness and wellbeing in spite of disease or disability. However, while poor health, disability, and frailty were generally not found to drive quality of life, acute illness or pain, bereavement and depression influenced the way life experiences were perceived (Degenholtz, Kane, Kane, Bershadsky, & Kling, 2006; Degenholtz, Rosen, Castle, Mittal, & Liu, 2008). Likewise, McDonald (2016) reported that the personal efforts by

residents to establish quality of life can be undermined by service providers who prioritise essential services, safety and risk management.

Extant gerontological literature from the United States and Europe cites the following important factors for positive life quality in aged care settings: (1) participation in meaningful activities to build social connections, improve functional capacity and increase enjoyment in life (McDonald, 2016; Raske, 2010); (2) involvement in self-care and health-promoting activities exercised through personal choice, free of duress from others (Elavsky et al., 2005; Hellstrom & Sarvimaki, 2007); (3) supportive relationships with people who care about the resident's happiness and wellbeing (Droës et al., 2000; Krause, 2010), including positive contact with partners, family and friends (Haggstrom & Kihlgren, 2007); and (4) feeling safe and secure in one's surroundings (Barnes, 2002; Kane, 2001).

This current study expands on these parameters by including the importance of one's physical and social environment being not just caring, safe and secure but also socially rewarding, comfortable, enjoyable, pleasing to all five senses and 'homelike', incorporating adequate levels of privacy. In the case of happily partnered residents, quality of life also meant remaining together as a couple. The literature on quality of life in RAC settings has exclusively focused on residents as individuals whereas the contribution this study makes relates to quality of life from the perspective of couples who see themselves as psychologically indivisible dyadic units.

Survey participants demonstrated that Baby Boomers are not a homogenous group. Each couple had subtly different relationship dynamics that required individually tailored services rather than a 'one size fits all' approach to accommodating their needs in RAC settings. Notable findings were that couples' subjective wellbeing can be enhanced by (1) organisational policies and practices that support couples; (2) staff with positive attitudes to couples in their care, who are willing to communicate with them to identify and action their specific needs; and (3) accommodation and furniture suitable for each individual couple. Furthermore, in order for couples' needs to be met in these ways, it was essential for providers and their employees to shift their priorities from being task oriented to treating each resident as a person, with the

continuing ability to make decisions, maintain their identity and live according to their personal preferences, doing the things they enjoy.

What this study contributes to the literature is evidence of consumers' needs and expectations *prior* to entering RAC from the perspective of partnered individuals. It also provides also important insights into partnered residents' quality of life from the perspectives of aged care staff. Some staff took pleasure in supporting couples in their care and some would have liked to do more to service couples but felt unsupported in their work setting. Others who felt time pressured, under-resourced or aligned with their organisation saw couple-centred care as an unrealistic fantasy and/or added burden in environments where staff were already struggling to provide basic clinical care.

8.3.2. Fear of dying in an institution

When discussing quality of life, fear of dying in an institution emerged as a strongly related theme for participants. More women than men expressed the fear of living or dying in an institution, which may indicate their awareness that women tend to outlive men and are more likely to die alone in RACFs (Australian Institute of Health and Welfare [AIHW], 2015c). Participants reported feelings of repulsion or disgust towards RACFs, reactions which were often triggered by having witnessed residents being infantilised or dehumanised or as a result of direct sensory perceptions, such as exposure to unpleasant sights and smells in RAC environments.

The reactions of disgust to unpleasant sensory stimulation in RACFs described in this study support previous research by others (Tofle, 2009). Rozin, Haidt and McCauley (2008) found that odours that evoked death and decay were particularly powerful triggers for the disgust response in most cultures. Sherman and Haidt (2011) described disgust as a mechanism of social avoidance, motivated by the avoidance of offensive things (such as dying). Rozin et al. (2008) found that it was natural for people to avoid thoughts or feelings elicited by death and dying. According to them, people expressed disgust as a means of rejecting or distancing themselves from circumstances they found personally distasteful. Sherman and Haidt (2011) theorised that feelings of disgust can lead to dehumanisation (treating people as less than human).

Participant responses in this and previous studies may be explained by Terror Management Theory (Greenberg, Solomon, & Pyszczynski, 1997), which posits that exposing people to reminders of death and dying triggers a need to erect psychological barriers in order to protect them from thoughts of their own mortality (Bodner, 2009). For Baby Boomers in this current sample, the psychological barrier manifested as a rejection of RAC environments in general.

Survey respondents' fears of dying in an institution reflected the current reality in Australia. Compared to other nations, Australians are the most likely to experience an institutionalised death, with approximately half of people over 65 dying in hospitals and a third in RACFs (Broad et al., 2013; Swerissen & Duckett, 2014). In 2014, 153,580 deaths were recorded in Australia, of which 81% were people aged over 65 years (Australian Bureau of Statistics [ABS], 2015). In the same period, 54,375 people died in RACFs, representing 35% of all deaths in Australia. According to one report, 43% of deaths in people aged over 65 occurred in RACFs (AIHW, 2015c) and Australians aged over 85 had a 62% chance of dying in a RACF (Australian Bureau of Statistics, 2015; AIHW, 2015c). As Baby Boomers age, the number of deaths in Australia will double annually, meaning that many Baby Boomers will die in institutions if current trends continue.

These statistics suggest that, on our current trajectory, most respondents in the current study are unlikely to die in the environment or manner they prefer unless they are prepared to initiate difficult but necessary conversations with the people they choose to have advocate on their behalf in their final years. To be effective, these conversations need to take place far enough in advance to plan and organise the support services they will need. According to Swerissen & Duckett (2014), due to lack of preparation, only 14% of Australians die at home despite it being the preferred option for most. The implications of this are that couples in particular will need to specifically state their relational needs, including whether or not they wish to cohabit and/or share a bed.

8.3.3. Older people as sexual beings

Data gathered from survey questions relating to (1) residential aged care generally; and (2) whether sexual health information, products and services should be available in RACFs revealed that two thirds of participants considered residents' sexual health to be important. What is noteworthy about these findings is that most participants did not express ageist attitudes to sexuality, which sits in contrast to the organisational cultures described by key informant data from staff, health professionals and aged care consultants. The fact that most survey respondents characterised older people as sexual beings who deserve to be treated as mature, capable adults supports evidence that sexual activity remains important throughout the life cycle (Carpenter & DeLamater, 2012; Das, Waite, & Laumann, 2012) and that sexual attitudes and identity change only minimally after early adulthood (Carpenter & DeLamater, 2012; Das, Waite, & Laumann 2012). The current findings suggested that participants were cognisant of this fact and/or took the perspective of projecting their present selves into the future.

The majority of survey participants asserted that aged care residents deserve the same access to sexual health services as the wider community. Respecting privacy, allowing residents to make their own choices, providing safe and private environments, and improving staffing levels and staff training were important themes raised. Protecting older people from sexually transmitted infections was also raised as an issue, which reflects increases in sexually transmitted diseases in older age groups (Bourne & Minichiello 2009; Emanuel 2014).

Previous research found that inadequate staff training played a role in perpetuating negative staff attitudes (Di Napoli, Breland, & Allen 2013; Villar, Fabà, Serrat, & Celdrán, 2015). Young people who had (1) ageist or stereotypic views; (2) limited experiences of orgasm; (3) came from religious backgrounds; and (4) believed sex is only for procreation, were found to hold negative and restrictive attitudes towards older age sexuality (Bouman, Arcelus, & Benbow, 2007; Allen, Petro & Phillips, 2009). Consequently, this study, together with previous research, points to the need for comprehensive sexuality training of aged care managers and staff to facilitate the sexual health needs of the next generation of aged care residents.

8.3.4. Privacy[68]

Although the *Aged Care Act 1997* (Cth) purportedly protects residents' privacy, without a universal definition (Australian Law Reform Commission, 2008; Leino-Kilpi et al., 2001), "the concept remains open to normative and subjective interpretations" (Rahn, Bennett, Jones & Lykins, 2017, p. 50). Studies from Australia, the United Kingdom and the United States reported that privacy was a significant issue for partnered aged care residents (Bauer, 1999; Hughes, 2004a; 2004b; Heron & Taylor, 2009; Petronio & Kovach, 1997; Salzman, 2006) and was the primary obstacle to maintaining intimate relationships (Berger, 2000; Edwards, 2003; Hajjar & Kamel, 2004). Common practices in RACFs included keeping residents' doors open, staff entering without knocking, ignoring 'do not disturb' signs, and gossiping about residents (Bauer, Fetherstonhaugh, Tarzia, Nay, Wellman, & Beattie, 2013). In extreme examples, Australian media have reported on staff sharing degrading photos of residents amongst themselves or on social media (Australian Human Rights Commission, 2015; Ornstein, 2015). Key informant and survey data presented in Chapter 6 provided evidence that the types of privacy infringements cited above continue to occur in the Australian aged care industry.

Rather than conceiving privacy as an end result, Altman (1976) conceptualised privacy as a constant process of boundary regulation undertaken in an attempt to achieve desired levels of social interaction. This territorial behaviour establishes comfortable limits to one's personal space, which he graded into four zones: intimate distance, personal distance, social distance and a public zone. According to Altman (1976), self-identity is the ultimate goal of confirming which aspects of the environment are part of the self and which are not. Where boundary regulation is strong, people personalise their space to reflect their personalities (Vinsel, Brown, Altman, & Foss, 1980). However poor boundary regulation results in undesirable levels of privacy - either too much (perceived as isolation) or too little (perceived as intrusions). Altman (1976) described privacy invasions as especially harmful because they destroy individual autonomy, self-respect and dignity. According to him, if none of the world is an acknowledged part of the self, then the person is literally 'nothing'. This has

[68] Extracts from this section have been peer reviewed and published as Rahn, A., Bennett, C., Jones, T., & Lykins, A. (2017). Couples' Privacy in Residential Aged Care. In *Digging for gold: Building success in ageing research: 16th national conference of Emerging Researchers in Ageing program & proceedings* (pp. 49-51). Perth, Australia: Curtin University.

particular pertinence in RACFs, where residents' personal space is rarely distinguished from the staff workplace.

Survey participants in this current study were asked (1) how much privacy they needed to feel comfortable relating intimately or sexually with their partner; (2) what types of privacy were important to them; and (3) how important it was for them to have internet access whenever they choose. A significant majority required 'as much privacy as possible' to feel comfortable expressing themselves intimately or sexually and considered internet access 'very important'. They ranked their privacy needs in the following order: (1) visual (seeing/being seen); (2) private space (territorial control of self, room and belongings); (3) bodily (includes nudity and procedures performed on one's body); (4) acoustic (hearing/being heard); (5) communication (talking, writing, internet access); (6) social (who one socialises with); and lastly, (7) personal information/data. However, when analysed by sex, men and women differed in the types of privacy they prioritised. Men identified communication privacy as their top priority and bodily privacy as a low priority.

Although privacy needs vary according to culture (Petronio, 2010), communication researchers found that men: (a) manage privacy differently from women (Petronio, 2010); (b) are socially conditioned to maintain tighter boundaries around personal information (Petronio & Martin, 1986); (c) are less inclined to disclose personal thoughts and feelings (Eadie, 2009); and (d) prefer to remain in control when communicating (Eadie, 2009). Men in this current study may have prioritised communication privacy because: (1) that is their natural tendency; (2) the semi-public setting of a RACF is perceived as unsuitable for protected communication; and/or (3) they may have anticipated the need to access online pornography or sexual information (McKee, Albury, & Lumby, 2008), which would require additional privacy to avoid derogatory labelling by aged care staff, such as "dirty old man" (Nuessel, 1982).

Female participants distinguished themselves by placing significantly more importance on bodily privacy, which referred to being undressed and having bodily procedures performed. This is perhaps indicative of women's experiences of indignity arising from bodily invasions in health and social settings, negative perceptions of body image, and acculturated discomfort with public nudity (Allen, 1988; Cook, 2011;

Cook & Brunton, 2015; Hoddinott & Pill, 2000). English research by Armstrong and Morris (2010) found that bodily invasions diminish women's sense of being a whole person - the breach is not only physical, it is metaphorical. Likewise, international research by Jacobson (2009) found that stripping, washing or 'toiletting' women without their consent, especially if done with indifference or rudeness, violated their dignity.

This current study fills a research gap on the anticipated privacy needs of future aged care consumers from the perspective of couples. This privacy data was based on seven domains of privacy identified in the literature. Respondents' attitudes to each privacy domain provide a basis for further discussion to develop clearer privacy policies for RAC.

8.4. Current challenges to maintaining intimate partnerships in residential aged care

In this section I will discuss the findings from this study in relation to the third research question: what are the challenges to maintaining intimate relationships in residential aged care settings? Most key informants described a culture in Australian RACFs that generally precludes discussing, assessing or servicing partnered residents' relational, privacy or sexual health needs. Six important themes that emerged: (1) old age in not valued and respected; (2) couples are routinely separated; (3) residents and their families need more emotional support; (4) residents' sexuality makes staff uncomfortable; (5) discussing older age sexuality is largely taboo; and (6) a culture of fear exists in RAC. Another important topic that was only touched on was staff attitudes to people with dementia. The unifying concept that underlies all of these themes was ageism. These findings sit in stark contrast with the data gathered on survey participants' expectations of how they would prefer to have their relationships and sexual health needs serviced if they were to enter a RACF.

Key informant data from health professionals and researchers described an overarching national culture that attempts to distance itself from ageing. This ageism is internalised by all the key players in the aged care sector, from politicians and bureaucrats to residents and staff. Many survey participants did not regard residential

aged care services as ‘caring’. They viewed entry into a RACF as a form of ostracism, society’s way of removing and concealing those it wishes to distance itself from. According to them, this attitude results in older people, and the people employed to care for them, being marginalised, disregarded, and stigmatised. In other words, the experiences of staff and residents represent different perspectives of the same social phenomenon. Participants identified that in order to improve partnered residents’ wellbeing it may be first necessary to improve the wellbeing of staff.

One way to interpret the findings is to use the lens of ageism. José and Amado (2017, p. 375) defined ageism as negative “stereotypes, prejudice and/or discrimination against” older people that can be “self-directed or other-directed, implicit or explicit”, “expressed on a micro, meso or macro-level”. Much of the data could be viewed as evidence of the way ageism manifests in the aged care domain and, to some extent, the causes and outcomes of ageism in specific contexts. Within the data are examples of explicit and implicit ageism at micro, meso and macro levels, which is predominantly other-directed.

8.4.1. Macro level ageism

Key informant data from aged care consultants described an Australian aged care sector that reflects societal ageism manifests it in both covert and overt ways. Participants described pervasive ageism at every level of decision-making – from politicians to bureaucrats, company directors, facility managers, doctors, nurses, care staff, families and even residents themselves. This ageism was said to affect fiscal policies, organisational structures, the design of aged care facilities, the education and training of health care providers, staff recruitment, staff working conditions and ultimately residents’ quality of care and quality of life.

Figure 8.1 illustrates the structural pathways through which ageism can be produced. Interviewees described the aged care system as a top-down, hierarchical structure. Beginning at the top of the diagram, individuals in government at federal and state levels are influenced by societal thinking in terms of (a) their own upbringing and beliefs; and (b) information communicated to them by advisers, lobbyists,

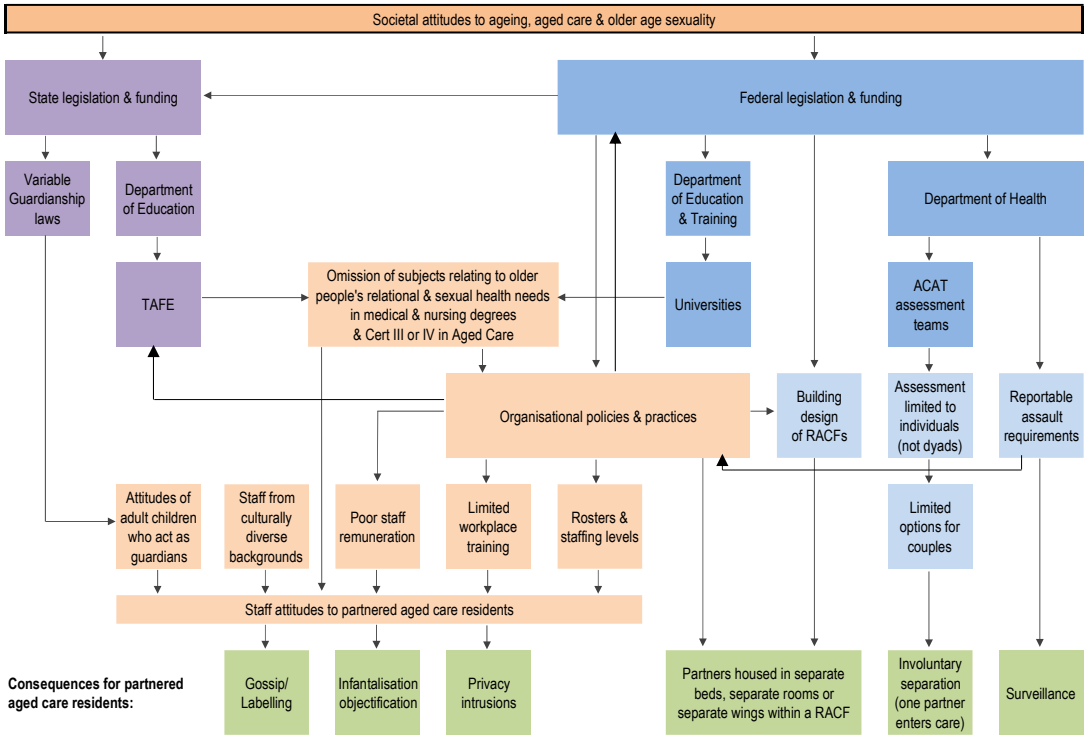

Figure 8.1. Structural pathways for ageism in the aged care sector

constituents, the news media, various self-interested groups and concerned individuals. Historically, when federal aged care legislation has been debated, interest groups have included religious organisations, lobby groups representing aged care organisations, nurses' associations and consumer advocates. One of the most hotly contested topics in those debates related to aged care residents' sexuality and sexual expression. Australia's current aged care legislation largely reflects the dominant voices at the time of its enactment[69] . That legislation, and the bureaucracy that implements it, determines national policies, funding instruments and procedures that must be followed.

[69] The findings discussed here were peer reviewed and published as Rahn, A., Jones, T., Bennett, C., & Lykins, A. (2016). Conflicting agendas: The politics of sex in aged care. *Elder Law Review, 10*, 1-24. Retrieved from https://www.westernsydney.edu.au/elr/elder_law/elder_law_review_elr

8.4.1.1. The *Aged Care Act 1997*

It is evident that both lawmakers and policymakers who drafted the Australian *Aged Care Act 1997* (Cth) and its resultant regulations and policies had a blind spot where older couples were concerned. This lack of regard for older people's primary relationships could be described as implicit, or unconscious, ageism (José & Amado, 2017), in that couples appear not to have been considered. Furthermore, terms used in the accreditation standards (that form part of the Act) to protect residents, such as privacy, dignity and homelike, are not defined, leaving them open to interpretation.

As the literature review for this study identified, there was a distinct absence of policy referring to the specific service needs of partnered older people or indicating whether or not the government's preference was to keep members of a couple together at home if that is their choice. A common situation that was not covered by public policy was where (a) only one member of a couple required aged care services; and (b) the assistance required by that individual exceeded the capacity of their caregiving partner and/or local community care organisations. Public policy relating to the sexual health needs of aged care residents was also notably absent, as identified by Kirkman, Kenny and Fox (2013).

Furthermore, the processes established to determine the aged care services that older people receive was found to explicitly target individuals. Whether deliberately intended or not, this policy often results in couples becoming separated when only one partner is deemed eligible for entry into a RACF. I refer specifically to processes implicit in the *National Screening and Assessment Form* [NSAF] (Department of Health [DoH], 2017a) administered by Aged Care Assessment Teams [ACAT] and the *Aged Care Funding Instrument* [ACFI][70], (DoH, 2018) which determines the level of aged care funding applicable to each individual requiring aged care services.

Despite a government policy which favours 'ageing in place', a strategy that implicitly relies on informal caregivers (often spouses or partners), ACAT processes have been criticised for focusing on the needs of the individual rather than directing additional support to the struggling partner who provides that informal care (National Aged Care

[70] At the time of writing, the ACFI was undergoing a review by the Department of Health.

Alliance, 2017). By focusing on the health needs of one partner while ignoring the couple's relationship status, these ACAT processes can result in couples being unnecessarily and involuntarily separated, which may in the long term increase the burden on the aged care system. Although beyond the scope of this dissertation, this phenomenon requires further research

Rather than offering the caregiving partner the necessary additional supports he/she may require (because this is not the individual being assessed), inevitably the care-receiving partner is placed in a RACF and the caregiving partner remains in the couples' home. In cases where couples would have chosen to remain together if offered another alternative, I refer to this as involuntary separation. This study corroborates Tilse's (1995) findings that separated partners grieved for each other, for the loss of their togetherness, their support person and for their role loss. The partner placed in care experienced the additional grief of being removed from his/her home and community and losing personal autonomy. It was evident in the data that rarely was either partner offered grief counselling to help them adjust to these losses, in fact several interviewees said they cried when I asked about this, which indicates how distressing it was for others beyond the immediate family unit.

The practice of separating partners (referred to in key informant and survey data) ignores a body of research that has identified that happily cohabiting dyads provide each other with mutual care and support (Day & Day, 1993; Gove, Briggs, Style & Hughes, 1990; Kitson, Babri, Roach & Placidi, 1989; Wenger, 1990), where partners experience greater subjective wellbeing (Gray, De Vaus, Qu, & Stanton, 2011; Kamp Dush & Amato, 2005; Ross, 1995; Waite, 2000; Waite & Gallagher, 2000) and better physical and mental health than individuals (Hagedoorn et al., 2006; Levenson, Carstensen, & Gottman, 1993; Musick & Bumpass, 2012; Ross, 1995; Stokes & Moorman, 2017). The current policy focus on individuals is short-sighted and may in fact place greater burden on the health and aged care systems in the longer term.

During the course of this study, correspondence with government agencies[71] revealed that aged care and/or census data that linked dyadic partners was unavailable. This

[71] The absence of this data became evident in correspondence with the Minister for Aged Care, the Australian Institute of Health and Welfare and the Australian Bureau of Statistics. Copies of this correspondence are included in the appendices.

makes it impossible to track how many Australian couples become separated by bureaucratic processes in the progression from home care to residential aged care. Given that one third of aged care residents are partnered (AIHW, 2015b), the lack of government attention to this topic suggests that it is not perceived to have any significant public importance. It begs the question: why is it that census data is gathered on separation and divorce in the wider community but the most vulnerable elders separated by bureaucratic forces remain invisible in the data? Longitudinal studies are required to monitor the ongoing physical and mental health of couples separated in this manner to provide evidence of the real cost for federally funded health and aged care systems. Such an investigation is beyond the scope of this study.

8.4.1.2. The impact of mandatory reporting rules

The data indicated that the *Aged Care Act*'s (Cth) rules governing mandatory reporting of sexual assault in aged care facilities has bred a culture of fear. There were accounts of providers adopting the view that prevention of sexual activity was preferable to any negative attention they would receive from the Department and the media if an assault was to occur. Key informant data in Chapter 6 described aged care provider's approaches to assault prevention, which generally consisted of segregating the sexes, maintaining surveillance by keeping residents' doors open and, in some cases, medicating residents to inhibit their sexual urges. Facilities with adequate staffing levels and well trained staff were perceived as adept at observing resident interactions and instigating non-confrontational diversionary tactics to redirect potentially non-consensual behaviours. However, there was little evidence that aged care staff received training in how to distinguish between consensual and non-consensual sexual encounters. Many of the risk management approaches adopted by providers created an environment that discriminated against couples, making privacy difficult to achieve.

8.4.1.3. The *Guardianship Act 1987* (NSW)[72]

A legal expert who participated in this study drew attention to the explicitly ageist wording of the *Guardianship Act 1987* (NSW), which classifies a person of advanced

[72] This Act is under review by the NSW Law Reform Commission at the time of writing.

aged as a person with a disability, regardless of whether they are cognitively sound and able to communicate clearly. Section 3.2 of the Act states:

> In this Act, a reference to a person who has a disability is a reference to a person:
> (a) who is intellectually, physically, psychologically or sensorily disabled,
> (b) who is of advanced age,
> (c) who is a mentally ill person within the meaning of the Mental Health Act 2007, or
> (d) who is otherwise disabled, and who, by virtue of that fact, is restricted in one or more major life activities to such an extent that he or she requires supervision or social habilitation.

8.4.1.4. Education and training

There is a body of evidence that health professionals commonly hold negative ageist attitudes towards older people (Sneed & Whitbourne, 2005), especially where sexuality is concerned (Fileborn, Lyons et al., 2017; Gott, Galena, Hinchliff, & Elford, 2004; Gott & Hinchliff, 2003b; Gott, Hinchliff, & Galena, 2004). This current study also identified ageist attitudes among aged care employees in relation to residents' sexuality. Study participants attributed this to a systemic inadequacy within the university and TAFE (Tertiary and Further Education) curricula. They identified that nurses and care workers required much greater understanding of issues of consent and human rights in relation to older age sexuality, especially in people with dementia, in order to guide them in how to respond when residents exhibit sexual behaviours.

The absence of these topics in the field of education was again an example of implicit ageism. It perhaps indicates that some educators either (1) subscribe to the asexual stereotype attributed to older people; (2) do not feel comfortable raising this topic; or (3) do not think students will feel comfortable learning about this. Students' ignorance was found to be further compounded in the workplace, where sexuality training was the exception rather than the norm.

8.4.2. Meso level ageism

8.4.2.1. Differential treatment of couples

Data in this study provided accounts of the differential treatment of couples in cases where both partners were admitted into a RACF. The survey data presented in Chapter 5[73] indicated that some organisations had explicit policies that discriminated against couples known to be sexually active (by refusing to admit them). Others took a task-oriented approach, dividing their facilities according to service levels by placing individuals with low care needs in separate parts of the facility from those with high care needs, irrespective of whether they arrived as a dyadic unit and wished to remain together. Others did not have buildings with rooms large enough to house couples together, so partners were allocated single beds in separate rooms (sometimes adjoining or adjacent to each other and sometimes not).

Where room sizes were large enough and the organisational policy allowed for couples to share a room, sometimes they were permitted to have their single beds pushed together and other times not. Rarely was a double bed provided and sometimes only after insistence by families. For couples who shared a room, some were permitted to close their doors however reports were that none were able to lock them. There were accounts of some finding ways to make the best of their circumstances whereas for others their primary relationship and sense of wellbeing were negatively affected, sometimes resulting in depressive symptoms or angry outbursts. These examples suggest that implicit and explicit ageism may play a part in the policies and practices of organisational cultures and in the commissioning and design of buildings and the ways they were subsequently furnished.

8.4.2.2. The aged care workplace

The findings presented in Chapter 6 indicated that working in aged care was not viewed as a promising career move. According to key informant data from aged care consultants and health professionals, care work was widely characterised as a menial, dead-end job. Compared to other jobs, staff were poorly paid, undervalued, and held in poor repute by the wider community. For some employees, aged care work was a

[73] See Section 5.4.1.4.

job of last resort and, as a consequence, the sector tends to attract a poorly skilled workforce. Of particular concern was an increase in workers who were either previously unemployed or on migrant visas who sought aged care positions simply to find employment, rather than being motivated by a desire to care for others. For care staff, the work was often demanding and unrewarding. Some staff felt undervalued, which sometimes resulted in them directing their frustrations at residents. Managers of aged care facilities also had stressful jobs. There were accounts of facility managers having their employment terminated when mistakes were made. Interviewees suggested that some aged care organisations tended to direct blame at the easiest target, which resulted in a high turnover of managers throughout the industry.

These findings reflect workplaces where employees are not held in high esteem and which operate within a national culture that stigmatises ageing and those who care for the aged. In a predominantly female workforce, there is the additional cultural overlay of conditioned gender role expectations. As such, aged care workplaces appear to be shaped by sexism as well ageism, since care work is predominantly a female domain where the majority of employees (Richardson & Martin, 2004) and residents are women (AIHW, 2017b) and both groups appear to be discriminated against compared to service providers and consumers in other sectors.

The pay and prestige associated with one's occupation reflects societal values (Magnusson, 2008). Previous research supports the concept that care work in general, and aged care in particular, is devalued by society. Clear associations were found between female dominated industries, particularly care-related industries, and lower remuneration (England, Allison, & Wu, 2007; England, Budig, & Folbre, 2002). Aged care nursing was found to be less prestigious and poorly paid compared to nursing in public health services (Buchanan & Considine, cited in Chenoweth, Jeon, Merlyn, & Brodaty, 2010; Marquis, Freegard, & Hoogland, 2004).

Findings in this current study support findings in a few larger-scale investigations into the Australian aged care workforce. Aged care work continues to be perceived as an occupation of low pay and low status (Mavromaras et al., 2017; Tune, 2017) In the same study, although job satisfaction was found to be generally high, there was widespread dissatisfaction throughout the aged care sector in relation to excessive

workloads, inadequate staffing levels and poor rates of pay. They also identified a trend in unemployed people being directed by employment agencies to undertake aged care qualifications irrespective of whether they had the personal attributes to undertake care work. This resulted in poor quality care and high staff turnover.

Richardson and Martin (2004) found that care workers were significantly more likely to be unhappy with their salaries than female Australian employees generally. Care workers with the longest service records were found to be the most dissatisfied (Healy & Moskos, 2005; Richardson & Martin, 2004). Mavromaras et al. (2017) found that managers experienced difficulties recruiting suitable applicants with the desired skills, qualifications, experience, and values. Approximately a quarter of care workers lacked qualifications in aged care. According to Healy & Moskos (2005, pp. 23-24), "without the prospect of a higher wage in exchange for their commitment to the job, workers slowly lose interest and the incentive to attain higher skills".

Staff expressed frustration at being unable to spend enough time with each resident (Richardson & Martin, 2004). Given that employees have daily contact with residents and act as the interface with the aged care organisation, they have the greatest influence on residents' quality of care and life quality. It is evident from both the current findings and previous research that issues of staff satisfaction and retention need to be addressed. However, what this current study adds is evidence of a concerning industry-wide turnover of managers. Consistency in management is needed to maintain consistency in workplace policies and practices in order to oversee the implementation of long term goals, including the cultural change that will be required to implement consumer-directed care. These findings point to the need for stronger organisational support of managers.

8.4.3. Micro level ageism

The most conspicuous accounts of ageism presented in this study were at the micro or interpersonal level. A litany of negative staff behaviours towards residents were described in detail in Chapter 6. Prejudicial attitudes and discriminatory practices took the form of rudeness, condescending language, labelling, gossip, privacy intrusions, objectification and dehumanisation, using power and control to restrict residents'

choices or limit access to their own bodies, and, in some cases, abuse. This supports Nussbaum, Pitts, Huber, Krieger, & Oh's (2005) contention that ageist language and behaviour is rife in residential aged care settings. According to them, ageist attitudes are taught in educational settings and then "further reinforced in healthcare settings" (Nussbaum et al. 2005, p. 299).

According to interviewees in this study, older people's sexuality made many staff uncomfortable. Upon admission into a RACF it was rare for a couple to be asked about their relational, privacy or sexual health needs or to subsequently have them assessed or documented. Except in moments of crisis, discussing residents' sexual needs was still largely taboo and tended to be avoided where possible. As a consequence, staff either failed to consider couples' needs, considered it rude to enquire, or assumed partnered residents were asexual. It was suggested that staff were largely unprepared and untrained to respond in cases where they perceived there to be 'inappropriate' behaviours and, in the absence of organisational training, tended to act according to personal values. Some could not tell the difference between consensual sexual activity and sexual assault, especially in cases where one or both parties had dementia and some employees believed that any sexual contact between residents was a reportable offence.

8.5. Theoretical explanations of institutional environments

One theory that helps explain the contribution of the socio-physical environment apparent in the findings is Socio-Environmental Theory (Gubrium, 1972; 1973), a general theory which explores the impact that the environment exerts on social interactions (Lawton 1983; 1985; Nussbaum, 1983) as well as the resources that individuals bring to their environment (Gubrium, 1972; 1973; Marshall, 1986). These ideas have been developed further to explain healthcare settings. Green, Poland and Rootman (2000) promoted an ecological and context-specific 'settings-based' approach to healthcare. Harris and Grootjans (2012) developed Green et al.'s (2000) work further by designing ecological framework to explain resident wellbeing in aged care settings based on evidence gathered from residents and staff. It incorporated the

social and physical settings, governance models and residents' activities of daily living.

Environments are viewed as more than just physical structures. They include social and psychological constructs (Gubrium, 1972; 1973; Lawton 1983; 1985), which are inter-related and intrinsically linked. Other people are equally important elements in the older person's immediate environment. Their attitudes and values shape the communication (and subsequent relationships) that is possible in any given context (as was evident in this study findings). Features such as age segregation, where older citizens are housed in RACFs often without access to the wider community, place constraints on the older person's social world.

Residents' relationships are either facilitated or constrained by their environment and their 'successful' ageing relies on the active maintenance of relationships and continued involvement in meaningful pursuits (Neugarten, 1964). Nussbaum, Pecchioni, Robinson, and Thompson (2011, p. 28) asserted that the socio-physical environment in which older people live "mediate[s], structure[s], and even dictate[s] the communication within its context", which in turn defines the quality of their relationships (Nussbaum et al. 2011). The environmental impacts on each resident's relational world influence how well they adapt to their environment and their corresponding sense of life satisfaction (Nussbaum,1983).

According to Nussbaaum et al. (2011), aged care residents' interpersonal communication depends on their unique personal and sociodemographic characteristics and life experiences, in combination with the constraints or opportunities in their environment (Nussbaum et al. 2011). Older people living in RACFs, where social opportunities are often controlled and minimised, may experience "forced disengagement" (Nussbaum, 1983). While the social isolation of aged care residents is well known (Aartsen & Jylha, 2011; Braithwaite, 2002; Gladstone, 1995; Lundh, Sandberg, & Nolan, 2000; Tilse, 1995; Victor & Bowling, 2012), research indicates that social isolation and loneliness increase depression and hasten death (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015; Matthews et al., 2016), suggesting that older people do not willingly withdraw from society but disengage because they are socially isolated.

In cases where RACFs quarantine older people from the rest of society, they effectively impose social restrictions on them. This reflects the concept of society withdrawing from its older citizens that is inherent in Disengagement Theory (Cumming, Dean, Newell, & McCaffrey,1960). Disengagement Theory supports the notion that proximity to friends and family is an important determiner of residents' abilities to sustain relationships. Given that the data in this current study demonstrate that happy couples wish to remain together in late life, these findings raise the question of how partnered Baby Boomers would fare if separated, especially if separated involuntarily, and what impact that might have on health and social services (a question is however beyond the scope of this study).

Social-environmental theorists have tended to concentrate on the "pragmatic, functional impact of the environment on communication for elderly individuals" (Nussbaum et al. 2011, p. 29). For instance, Nussbaum (1990) observed that architectural features common to nursing homes that were reminiscent of Foucault's panopticon, together with "tightly scheduled" activities (p. 156), were "key macro-level ingredient[s]" (Nussbaum 1990, p. 166) with which to control social interactions in the nursing home. In his view, RACFs designed with residential wings converging on a central nursing station tended to limit communication between frail residents located in separate wings, thereby limiting their opportunities to form friendships. This highlights the importance of proximity, which is of particular importance to intimate partners who become involuntarily separated within an institutional setting.

An important finding in Nussbaum's (1990) research was that the social aspect of the aged care organisation can compensate for the physical limitations of the built environment. However, Andrade, Lima, Devlin and Hernández (2016) contend that the physical environment plays a powerful role in communicating the quality of care than can be expected. As was evident in this current study, where care workers report feeling an affinity for residents, conversations of a more personal nature are possible between staff and residents (Nussbaum 1990), which results in residents receiving increased "emotional care" (Nussbaum 1990, p. 164).

Kahana's (1982) congruence model of person-environment interaction effectively explains and predicts aged care residents' satisfaction within their socio-physical

environments. An important role of RACFs is to accommodate, where possible, the changing needs of residents. However, providers' ability to minimise residents' stress levels and slow further decline depends on their ability to accommodate residents' needs. Kahana's (1982) model provides an excellent guide for this purpose.

Kahana's Person-Environment Congruence Model [PECM] considers two sets of factors: (a) how successfully people's needs are met by the environment in which they live; and (b) how successfully the individual can meet the demands of that environment. These two factors can be compared across multiple dimensions including, but not limited to, (1) segregate dimensions (the results of segregating people from their homes, the community and each other according sex, physical and mental functioning); (2) congregate dimensions (the results of having so many people congregated together, which raises issues such as privacy and individuality); (3) issues of institutional control and the degree to which autonomy is tolerated; (4) structural dimensions such as the clarity/ambiguity of rules and role expectations; (5) the desirable amount of stimulation in the environment; and (6) affect (whether emotional expression is encouraged or avoided) (Kahana, 1982).

According Kahana, the congruence of individual needs and characteristics of the setting, also known as 'person-environment fit' (Kaplan, 1983), should result in residents' sense of wellbeing, satisfaction and adequate functioning of the institution. Adapting to mismatches relies on adjusting individuals' expectations and/or modifying the environment. Depending on the success of these adaptive strategies, wellbeing or lack of wellbeing may result.

Kahana found that congruence between environmental characteristics and individual needs was most important where options were limited, such as in RACFs. Three factors that limit individuals' options are: (1) restrictive environments; (2) limited individual freedom; and (3) an internal perception of limited individual freedom. She found that residents' morale was most affected by incongruence between (1) institutional control and personal autonomy; and (2) the congregate setting and private time alone.

8.6. Possible pathways to creating couple-centred residential aged care

This section explores insights provided by the data to the final research question: what initiatives are necessary to support partnered Baby Boomers' coupledom in residential aged care settings? The data described a range of circumstances experienced by couples in RAC settings that clearly demonstrated that providers varied greatly in their approaches to intimate relationships. This applied at both the meso level (systemically within organisations) and the micro level (at the level of individual staff members). The social environment (the organisational structure of RACFs and its individual staff members) and the built environment (the physical environment indoors and out) presented a range of opportunities and constraints for partnered residents living in RACFs. So too did each couples' familial relationships. These influences also applied in the case of visiting intimate partners who resided elsewhere.

The core variable in these interrelated spheres of influence was found to be communication (verbal and non-verbal, direct and indirect), mediated by (1) attitudes towards older people; (2) availability of resources (staffing levels, time and money); and (3) employees' experience, confidence and comfort levels with sexual subjects. Interpersonal communication, particularly between staff and residents, was found to influence couples' experiences by either transforming or reinforcing the structural influences of the RACF. Furthermore, the key element in that communication was found to be the active presence or absence of respect, defined as "having due regard for the feelings, wishes, or rights of others" (Oxford Dictionaries, 2017).

8.6.1. A conceptual model developed from the data

In the absence of an existing framework that adequately explains the study findings, one outcome of this study is a new conceptual model. Figure 8.2 provides a visual representation of the complex interplay between the social, physical and interpersonal influences on partnered aged care residents within broader industry, bureaucratic and societal contexts. The diagram shows four intersecting spheres of influence (three social and one physical) that together create a fifth zone called the *couple life-space,* which are in turn nested within three spheres of influence - the aged care sector, the bureaucratic environment and societal attitudes. The spheres of influence may vary in

size, according to the relative degree of influence they exert within individual RACFs. The arrows represent two-way communication and the relationships between groups/environments. All arrows point towards the *couple life-space* in the centre, which is affected by every sphere of influence and is the subject of this study.

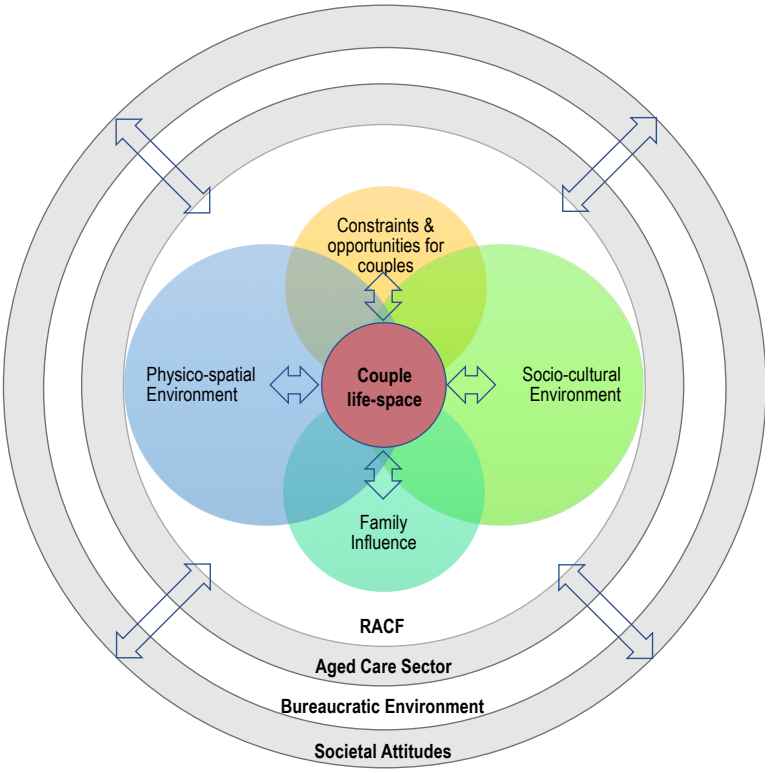

Figure 8.2. A microcosmic-macrocosmic model of influences on partnered residents in RACFs

In the diagram, the arrows bridging the outer rings represent bi-directional influence and communication. *Societal attitudes* towards older adults (and their care needs) are depicted in the outer ring as the over-arching background influence. These in turn affect political decisions and associated bureaucratic processes. The *bureaucratic environment* that has developed from public policy decisions and legislative changes is the major influence on the *aged care sector*. However, regular input from the sector (via organisations such as ACSA and LASA[74] in Australia), in tandem with social change at a societal level, has influenced legislative and policy changes over time[75]. Residents' needs are represented in this process (by proxy) via government

[74] ACSA and LASA are lobby groups that represent the interests of member aged care organisations. ACSA stands for Aged & Community Services Australia. LASA stands for Leading Age Services Australia.
[75] See Chapter 6.

submissions from advocacy groups such as COTA, National Seniors Australia[76] and others. Subsequent policy changes then filter down to individual RACFs which are, in effect, a microcosm of the larger scale forces at work.

In this model, the *socio-cultural environment* refers to the people within RACFs, the social culture they construct and are in turn constructed by. It includes the residents, staff, volunteers, managers and visiting health professionals together with the organisation's policies and practices, staff attitudes, beliefs and behaviours. In Chapter 7, key informants highlighted the features that differentiated service providers who were couple-centred from those who were not. At the level of staff-resident interactions, couple-centred care relied on (1) positive regard; (2) empathy; (3) open, non-judgemental communication and (4) the development of mutually beneficial staff-resident relationships. However, in order to create a couple-centred organisation, the data showed that a healthy workplace culture was necessary, one which nurtures staff, fosters a culture of openness and creates a sense of community between residents, employees, managers and families.

The *physico-spatial environment* refers to the built and natural environments. It includes spatial relationships, light and air quality and sensory stimulants (noise, odours, colours, patterns etc.). Key informants and survey participants referred to the absence of choice in relation to privacy; room sizes; bed sizes; homelike qualities and access to garden areas as factors that could support or infringe upon partnered residents' coupledom.

The *constraints and opportunities for couples* resulted from the interplay between (1) partnered residents' relational needs; (2) the *socio-cultural environment*; and (3) the *physico-spatial environment*. According to key informants, the parties to the relationship and their relational dynamics, together with whether or not their needs were met by the accommodation and furniture provided, the attitudes of staff and the organisational culture, determined the person-environment fit of each couple. According to the data, a couple-centred organisation would focus their efforts on

[76] COTA and National Seniors Australia are lobby groups that represent the interests of Australians aged over 50. COTA stands for Council on the Ageing.

servicing the needs of partnered residents. This would include developing and training a workforce sensitive to couples' relational needs.

Family influence refers to residents' family members, including non-resident partners. It includes the interpersonal dynamics between them and their relative(s), their attitudes and behaviours towards staff and the person/couple in care. Key informant data indicated that family members acting as guardians, or who had Power of Attorney, had a role to play in supporting or interfering in the relational needs of partnered residents. Family support could be enlisted by staff who acted as advocates on residents' behalves. Similarly, family members acting as advocates had a role to play in educating staff about their loved ones' needs.

The *couple life-space* refers to the quality of the couple relationship that is possible within the RACF as a result of the four interrelated spheres of influence already described. The social and physical environments of RACFs communicate to couples, in both direct and indirect ways, such things as whether their relationships are valued; where their needs sit in relation to the organisation's other priorities; and the degree to which staff and management are comfortable with couples conducting their relationships. Whatever is communicated can affect a couple's relationship positively or negatively depending on the level of congruence with their environment. This in turn influences the type of intimate communication (verbal, non-verbal, physical or sexual) that is possible between partners within their couple domain.

Where couples experience inhibiting influences, the findings showed that interpersonal communication between staff and residents was the key variable. Even in socio-physical environments that were not designed with couples in mind, direct and open communication between staff members and partnered residents (or their families) can lead to modification of the socio-physical environment to achieve greater congruence. Examples of such changes include the re-purposing of rooms, allowing a couple's bed to be brought from home, pushing single beds together, training staff to knock, installing 'do not disturb' signs, hoisting partners into positions in bed that allow them to be intimate, scheduling social events with couples' needs in mind and so on. Conversely, the absence of difficult but necessary conversations between staff

and residents appears to be the key driver that results in residents' sexuality becoming problematic.

8.6.1.1. Communication in residential aged care facilities

The built environment of RACFs symbolises or communicates to residents the attitudes and priorities of the people who commissioned, designed and operate the interior and exterior environments. Buildings are concrete representations of the prevalent socially constructed beliefs about older people and their care that become frozen in time (Andrade et al., 2016). Such environments provide cues to couples as to how to conduct their relationships while one or both partners reside in the facility.

The layout and furnishings, the lighting, smells and sounds throughout the facility influence whether or not the building feels home-like and/or welcoming, as does access to outside garden areas. Floor plans and finishes indicate whether or not visual and acoustic privacy in residents' rooms was considered and deemed important, as does the presence (or not) of a door at the entry to their room. Room sizes dictate whether or not a couple can continue enjoying their bed size of choice. Likewise, the provision or not of their own private sitting area influences a couple's ability to conduct private conversations and continue some of the routines they established over many years to maintain and sustain their relationship, which may include entertaining guests.

At an organisational level, the aged care provider's official policies and practices, or lack of them, communicates to staff and residents whether or not the needs specific to couples in their care have been considered and are supported. Upon admission, whether or not couples are asked how their privacy or sexual needs can be supported and whether or not the organisation has policies on such matters indicates to couples the level of permission they have to ask for what they need. Likewise, the organisation's commitment to resident-focused staff training becomes evident to partnered residents through their interactions with staff and managers. From the perspective of couples, practices such as accommodating partners in separate beds, separate rooms or separate wings of a facility clearly communicate the implicit and explicit attitudes of the organisation. Conversely, the provision of couples' suites or

larger bed sizes for residents whose partner resides elsewhere convey a more welcoming message.

In terms of the daily interactions between staff and residents, the people with the greatest direct influence on residents are the direct care staff. The actions of each employee are informed by the organisational culture of the workplace. Staff, in turn, perpetuate or modify that culture through their actions. Each staff member comes with their own personal history, including their cultural or religious beliefs. This influences their attitudes and behaviours towards partnered residents, particularly their sexual expression. A combination of personal attributes, life experience, professional training and organisational policies influences how comfortable each staff member is with the more intimate aspects of couple relationships and whether or not they are equipped to put aside their personal views in order to be professional, objective and person-centred in their interactions. This is both the responsibility of each employee and the organisation as a whole. However, as the findings indicate, organisational culture, recruitment processes, in-house training and managerial guidance play a significant role in how staff conduct themselves.

8.6.1.2. Examples of person-environment fit

Much of the data in this study described negative outcomes for partnered aged care residents. However, it was the exceptions in the data (where residents' relationships were handled better) that suggested that the personal attributes of individual care workers and managers, their proactive efforts to communicate with residents and their style of communication increase the likelihood of positive outcomes for residents. Positive narratives described employees who (1) had a positive attitude; (2) showed interest and took the time to have open two-way communication (where the residents' needs were elicited and actioned); and (3) were comfortable discussing sexual matters. This combination of attributes appears to establish a workable relationship between individual staff members and residents and acts as a bridge between the couple and the organisational environment. Some have termed this 'relationship-centred care' (Nolan, Davies, Brown, Keady, & Nolan, 2004). This has implications for aged care organisations in terms of their recruitment, training and staff supervision policies as well as policies and practices they might adopt in relation to partnered residents.

Nussbaum et al. (2011, p. 32) define communication as "an individual emitting cues in the presence of another individual and the meaning that those cues produce". According to them, that communication defines their relationship. In other words, developing and maintaining relationships relies on communication and the quality of those relationships is dependent on the quality of communication. According to Hargie (2010), effective interpersonal communication depends in part on the degree of warmth in the interaction and the level of 'noise' or interference present during the exchange. Noise includes factors such as personal prejudices held by either party, which can act as a filter that distorts the message and changes its intended meaning.

All communication takes place in a context. Socioemotional Selectively Theory (Carstensen, 1991; 1992), a social exchange theory, suggests that contextual factors play a larger role in older people maintaining emotional closeness than do personal attributes (Nussbaum et al., 2011). According to Hargie (2010), the socio-physical context determines how much privacy is available and moderates the extent to which each party feels safe to be open and honest in their communication, which is highly relevant in aged care contexts. Time is another factor. Key informant interview data from aged care staff and consumer advocates suggested that many facilities were understaffed, limiting the time that care workers had available to attend to individual residents. This perceived sense of time pressure fuelled task-oriented organisational cultures where clinical care was prioritised over social care. This study suggests that such an environment limits the opportunities for relaxed, open communication between staff and residents. The implications of this are that staff in these establishments have limited opportunity to develop mutually meaningful relationships with residents. This in turn severely limits the possibility of relationship-centred care.

8.7. Conclusion

This study specifically contributed knowledge to the fields of communication, family studies, psychology and gerontology germane to the understanding of (1) couples' intimate behaviours; (2) the benefits of physical affection and the subjective experiences of cohabiting couples; and (3) the importance of a couple's bed as a relationship setting. It also extended knowledge in the fields of psychology and sexology in relation to dyadic sleep arrangements, sexual activity and their effects on

individual wellbeing and relationship satisfaction, including contextual factors that reduce sexual satisfaction.

The study confirmed and further detailed international findings, making them transferable to other English-speaking countries. These included ageist attitudes towards older people's sexual expression (including the 'asexual stereotype'), lack of privacy and constraints on sexual freedom in RACFs identified in the literature review. However, this study modified the gerontology literature in three ways: (1) the data questioned researchers' dominant representation of spouses/partners as 'caregivers' by representing them instead as intimate sexual partners; (2) the paradigm of the 'asexual' older woman was effectively subverted by the data provided by a largely female survey sample; and (3) the paradigm of social control in RACFs highlighted in the literature review was challenged by the survey data, which demonstrated that Baby Boomers valued happiness and personal wellbeing, autonomy, choice and the maintenance of intimate relationships more highly than traditional institutional models of care.

This study is novel for four reasons. It is the first to adopt a macro, meso and micro perspective to studying the phenomenon of partnered aged care residents. Other novel features are that: (1) it sought the views of a generational cohort prior to entering care; (2) the information sought specifically targeted intimate partners, a group not represented in aged care policy; and (3) it contributed a theorisation of the environmental influences on partnered residents in RACFs. This conceptual model is easily transferable to other Western countries with similar institutional arrangements. The study also identified that Baby Boomers are calling for change. The Australian aged care system is structurally modelled on implicit ageism and, in order to create a functional system that meets the needs of Australian citizens and the broader community, the system needs a radical redesign.

This chapter has discussed the findings in relation to each other, the literature and relevant theory and has presented a conceptual model to help guide successful integration of couples into residential aged care. The next chapter will present the study limitations, conclusions drawn from this study, directions for future research and recommendations for policy and practice.

Chapter 9. Conclusions

9.1. Introduction

This thesis has highlighted the complexity of issues affecting couples' intimate relationships in residential aged care. While there has been a heavy focus in Australia in recent years on 'person-centred' care[77], this thesis contends that focusing on individuals does not adequately address the needs of couples. This study instead shifts the focus onto needs that are specific to partnered aged care residents. As a result, what is recommended is an adaptation of the person-centred model to a complementary one that is 'couple-centred' for this group of residents. Such an approach must respond to (a) the needs of *both* partners as individuals; and (b) their ongoing relationship as a dyadic family unit.

Chapter 1 began by outlining the problem that this thesis is concerned with, together with the aim of the study, which was to investigate measures to support partnered Baby Boomers to retain their coupledom in residential aged care settings. Chapter 8 subsequently presented a discussion of the study findings detailed in Chapters 4-7 and illustrated how they reiterated, expanded or challenged paradigms within the extant literature. To demonstrate how the aims of the study were met, this chapter will draw together conclusions generated from the issues raised in the previous discussion of the findings. Firstly, I will present an overview the major conclusions from this study. Then I will discuss the implications of this research for the aged care sector, Baby Boomers and the wider community. Lastly, I will identify the study limitations and suggest areas for future research to further expand the knowledge base on this subject matter.

The individuals who participated in both phases of this study were highly motivated to contribute and gave generously of their time. In many cases it took courage for them to speak either about the intimate personal details of their lives or perceived injustices within aged care settings. The key informants represented a broad range of people embedded in aged care (including scholars, educators, public servants, consultants, company directors, administrators, nurses, aged care workers, consumer

[77] Refer, for instance, to Victorian Government Department of Human Services (2011).

advocates, health professionals, a legal expert and a sex worker) who each felt passionately about their work. All of these people demonstrated compassion for older people and concern for their welfare. Some had worked tirelessly for 20 years or more, in multiple roles, to improve the delivery of aged care services. Furthermore, the nurses, care workers and care managers who participated worked long hours in complex and difficult environments in an effort to help older people maintain a quality of life, often without adequate support, recognition or remuneration and at the expense of their own health and wellbeing. Participants provided multiple perspectives on service delivery that fell along a continuum from best to worst practice, highlighting accounts of some motivated individuals and innovative organisations who actively supported the relationships of partnered residents in their care.

However, despite the best efforts of those providing such services, five significant conclusions can be drawn from this study about the industry as a whole. Firstly, the ageist attitudes to older peoples' sexual relationships that are prevalent in Australian society (in the form of implicit and explicit stereotypes, prejudice and discrimination) are pervasive at every tier of the aged care system, from government policy and legislation through to staff attitudes and behaviours. Secondly, the data suggests that the current system is failing the needs of older couples in a variety of ways, ranging from privacy invasions and inadequate couple accommodation to couples becoming involuntarily separated. Thirdly, these issues are not unique to Australia; the challenges faced by partnered aged care residents are endemic in individualistic English-speaking societies internationally. Fourthly, there is currently a significant disjuncture between partnered Baby Boomers' needs and expectations and the priorities and capabilities of the Australian aged care industry. As a consequence, their needs are unlikely to be met by current aged care policies and practices. In order to reconcile these contradictions, widespread cultural change within the aged care sector will be needed in relation to residents' relational, privacy and sexual needs. Lastly, Baby Boomers' awareness of the consequences of ageism in RACFs is already influencing some to reject current models of residential aged care and explore preferred alternatives.

This research is the first to present the views and preferences of partnered Australian Baby Boomers with regard to their future aged care service needs. Their expectations

of being able to exercise the choice to remain living together, share a bed, and physically express their affection in their own private domain, while simultaneously receiving care services, has enormous implications for national policy, government agencies, educators, service providers and Baby Boomers themselves. Importantly, the challenges identified in the findings do not lie solely with individuals and organisations. Aged care is a whole-of-society problem. Nonetheless, there is no simple solution to the many problems identified in this (and other) research. In order for Australian society to find a more holistic approach to servicing the aged care needs of happily partnered older couples in the short, medium and longer terms what is required is a radical re-think and re-prioritisation that positions the dyadic nature of couple relationships as central to their wellbeing and designs services around that.

In essence, what this thesis is arguing for are three fundamental principles: (1) respect for older people and their relationships; (2) acknowledgement of the value of those relationships; and (3) genuine and courteous communication/consultation about those relationships. Whilst there has been much scholarship on person-centred care (Edberg et al., 2008; Edvardsson, Fetherstonhaugh, & Nay, 2010; Nay, Bird, Edvardsson, Fleming, & Hill, 2009), this approach does not appear to have been extended to couples in theory, policy or practice. 'Couple-centred' aged care has scarcely been mentioned outside the context of dementia care (Bielsten & Hellström, 2017a; 2017b). The central tenets of the client-centred counselling model developed by Rogers (1951; 1961), later adapted into person-centred dementia care by Kitwood (1997), relies on the service provider and the client both developing a relationship of mutual trust and genuinely being themselves. To be effective, the relationship relies on the service provider practising active listening and communicating his/her positive regard and empathy for the client. Such an approach allows the professional to learn from the client what is needed rather than imposing rules on the client. This approach could be adapted to suit couples by framing the couple relationship as the 'client' and listening to the needs of both partners in order to understand the needs of the relationship.

A central message arising from the data in this study was that constructing older couples' sexual relationships as 'taboo' created problems both for couples and their service providers. The absence of conversations that some individuals and institutions may find difficult is necessary in that this avoidance serves to maintain the status quo

whereas direct consultation with residents can create opportunities for improvements in service delivery. If, as the data suggest, the solution to incorporating the principles of respect and acknowledgement into aged care service delivery lies in better communication, what are the implications of this? What now follows is a summary of the key findings in relation to each research question and an exploration of the implications of this for (1) people and organisations directly engaged in the aged care sector; (2) Baby Boomers themselves; and (3) the wider community. I will then make recommendations to address each of these areas.

9.2. Summary of key findings and their implications

The Discussion Chapter was structured around answering the four research questions: (1) which aspects of their intimate relationships do Bay Boomers value and wish to maintain as they age?; (2) what are the challenges to maintaining intimate relationships in residential aged care settings?; (3) what are the challenges to maintaining intimate relationships in residential aged care?; and (4) what are the possible pathways to creating couple-friendly age care services for partnered Baby Boomers? Tables 9. 1 to 9. 4 summarise the key findings in the Discussion Chapter for each of the research questions, together with their implications.

Comparing rows 1, 2, 3 and 7 in Tables 9.1 and 9.2 with rows 12 and 17 in Table 9.3 shows that the relationship features that happily partnered Baby Boomers value, such as remaining together and conducting their relationship in bed, are unlikely to be supported in situations where couples are unable to enter care together or where aged care providers accommodate couples in single beds, separate rooms or separate wings of a facility. Likewise, a comparison of rows 5, 9 and 10 with rows 14 and 15 demonstrates a disparity between Baby Boomers' expectations of remaining sexually active and the preparedness of aged care organisations and their staff to respond appropriately to sexual relationships. On the topic of privacy there is also a disjuncture between Baby Boomers' needs (in row 8) and current practices that limit privacy in RACFs (in rows 14 and 17). Privacy infringements contravene aged care legislation and policy however it would seem that compliance checks fail to adequately address this issue (see row 11). This indicates a need for more precise wording in aged care legislation and policy.

Table 9.1

Summary of key findings and their implications in relation to research question 1

Research Question 1: Which aspects of their intimate relationships do Baby Boomers value and wish to maintain as they age?			
	Data Source	**Key Findings**	Implications
1	Survey question on 'essential' aspects of being partnered	• Partners valued being together; emotional closeness; physical affection; sexual enjoyment; and caring for each other.	• When choosing aged care services, there is a need for older couples to be offered: • the choice as to whether or not they remain living together, and • the services necessary to enable that choice.
2	Survey question on 'valued' features of living together	• In addition to the above, living together provided greater opportunity for teamwork and intimate proximity.	
3	Survey question about sleeping together	• The couples' bed is an important relationship setting regardless of whether partners sleep together. It provides opportunity for discussion, sexual activity and physical affection. • Compatible partners derived comfort from sleeping together. • Sleeping together required that individual needs be balanced. Adaptations included larger (king size) beds and de-camping to separate beds during the night.	• Within RACFs, there is a need for older couples to be offered choices in relation to (a) sharing a room or suite of rooms; (b) sharing a bed; and (c) bed sizes and their locations. • The built environment of RACFs needs to be designed to accommodate these choices.
4	Survey questions about physical intimacy	• Physical intimacy was associated with relationship satisfaction. • Valued activities included cuddling, kissing, holding hands and touching/caressing. • 79% (n=130) thought physical intimacy is an 'essential part of life'. • 57% (n=96) were 'very satisfied' and 20% (n=33) were 'somewhat satisfied' with their current levels of physical intimacy.	• There is a need for aged care service providers to provide the conditions necessary for happily partnered couples to maintain their physical intimacy and sexual pleasure. This requires: • policies that support physical expressions of affection between partnered residents; • adequate education and training of aged care staff; • the provision of double beds for resident couples; and • the provision of larger than average single beds, large enough for two people to lie side by side, for residents with visiting partners.
5	Survey questions about sexual pleasure	• Sexual pleasure was associated with relationship satisfaction. • 57% (n=96) said they did not think they would ever stop being sexual. • 51% (n=80) thought sexual pleasure is an 'essential part of life'. • 39% (n=65) were 'very satisfied' and 25% (n=42) were 'somewhat satisfied' with their current levels of sexual pleasure. • Impediments to sexual pleasure included: ill health; stress and fatigue (resulting in lack of desire); age-related changes (such as stiff joints, dry vaginas and unpredictable erections); lack of privacy / intrusions by others; and relationship disharmony.	

Table 9.2

Summary of key findings and their implications in relation to research question 2

Research Question 2: What are Baby Boomers' attitudes to residential aged care?			
	Data Source	**Key Findings**	**Implications**
6	Survey question about past or current experiences of RACFs	• A good quality of life was considered a high priority and Baby Boomers questioned whether this is possible in RACFs. • Participants feared living or dying in an institution. • Autonomy and choice was highly valued.	• There is a need for aged care services to adapt to future consumers' needs if consumer-directed care is to become a reality.
7	Survey questions about maintaining intimate relationships in RACFs	• 55% (n=92) considered it 'vital' and 25% (n=42) said it was 'somewhat important' to maintain their relationship in a RACF. • 58% (n=98) considered it 'vital' and 15% (n=26) said it was 'somewhat important' to share a room with their partner. • 39% (n=65) considered it 'vital' and 29% (n=49) said it was 'somewhat important' to share a bed with their partner.	• Within RACFs, there is a need for older couples to be offered the choice of (a) sharing a room or suite of rooms; and (b) sharing a bed. • The built environment of RACFs needs to be designed to accommodate these choices.
8	Survey questions about privacy in RACFs	• 79% (n=133) said they would need 'as much privacy as possible' to conduct their relationship in a RACF. • Visual privacy was ranked most important by 82% (n=138), followed by (2) private space (82%, n=137), (3) bodily privacy (76%, n=127), (4) acoustic privacy (73%, n=123), (5) communication privacy, (6) social privacy (70%, n=117) and (7) data privacy (65%, n=110). • Men placed a higher value on communication privacy (88%) than women (67%). • Women placed a higher value on bodily privacy (78%) than men (63%).	• Terms such as privacy need to be defined in aged care legislation. • Legislation and policies need to incorporate clear measures of success (or failure) in relation to resident privacy. • A more effective means of accreditation compliance checking in relation to resident privacy is needed. • Aged care providers need more effective written policies and staff training programs on resident privacy consistent with the legislation and accreditation standards. • Privacy needs to be designed into the built environment of RACFs. • Residents need to be asked what their privacy needs are.
9	Survey questions about sexual relationships in RACFs	• 73% (n=122) thought it was important for families and care workers to respect residents' sexual choices.	• Aged care providers need written policies on how they will support the sexual expression of consenting adults. • Older age sexual expression needs to be normalised within tertiary education of health and aged care providers. • Education and training of care staff needs to include nuanced understanding of older people's sexual behaviours, issues of consent and how to respond humanely and appropriately.
10	Survey questions about sexual health information, products and services in RACFs	• Older people were described as sexual beings with the same rights as all Australian citizens. • 65% (n=109) thought sexual health information, products and services (delivered by trained professionals) should be available in RACFs.	

Table 9.3

Summary of key findings and their implications in relation to research question 3

Research Question 3: What are the challenges to maintaining intimate relationships in residential aged care settings?			
	Data Source	**Key Findings**	**Implications**
11	Key informant interviews discussing aged care legislation and policy	• By excluding explicit provision for couples, current aged care legislation and policy fails to protect couples as family units. • The *Aged Care Act 1997* does not provide definitions of 'privacy', 'dignity' or other terms used in the *Quality of Care Principles 2014* and *User Rights Principles 2014* contained within it. This leaves such terms open to interpretation and prevents objective measurement of providers' compliance with accreditation standards. • There are no measures in legislation or policy to support residents' sexual expression in RACFs.	• There is a need to include protections for older couples in aged care legislation. For this to happen, a consultation and feedback process with partnered aged care recipients is required. • Terms defined in the *Quality of Care Principles 2014* and *User Rights Principles 2014* need to be clearly defined so that (a) providers clearly understand their obligations; (b) consumers understand their rights; and (3) nationally consistent and objective compliance assessment tools can be developed. • More rigorous compliance checking of aged care providers is required to enforce accreditation standards. For this to happen, aged care policies, including accreditation standards, need to incorporate objective measures of success (or failure).
12	Key informant interviews discussing aged care funding policy and practices	• There were accounts of couple distress caused by involuntary separation when couples perceived their only available choice was to place one partner in a RACF. Aged care funding rules and providers' interpretation of those rules were implicated as the primary causes. The extent of this problem is not documented. Also unknown are the long-term health impacts of this on partners and the associated economic impacts on public funding.	• In the case of couples, there is a need for consumer-directed aged care policy to frame dyadic family units as the 'consumer'. • A whole-of-government approach to the health and aged care services for older people is needed. • Further research is needed into the involuntary separation of couples and the long term social, health and financial implications. • Industry education on the needs specific to couples needs to be rolled out by government.
13	Correspondence with government agencies	• Data that tracks the aged care pathways taken by dyadic partners is not publicly available.	• There is a need for government agencies to collect data that links dyadic partners and tracks their aged care pathways.
14	Key informant interviews discussing the impact of federal policy on aged care practices	• A culture of fear in the aged care industry was attributed to rules around mandatory reporting of sexual assault, resulting in some providers limiting residents' privacy in order to maintain surveillance and prevent sexual contact, whether consenting or otherwise. Lack of privacy was described as a one of the greatest impediments to maintaining intimate relationships in RACFs.	• Aged care providers need industry-wide support and training in how to respond appropriately to both consensual and non-consensual sexual activity in RACFs.

15	Key informant interviews discussing education and training of aged care staff	• Tertiary education and vocational training of health practitioners and aged care staff does not appear to adequately prepare them to provide appropriate services to sexually active older people. • There were reports that the complex needs of people with dementia (and related issues of capacity to consent to sexual activity) are not adequately understood by staff. • The absence of policy and training on sexual expression by aged care providers can result in staff adopting personal rather than professional values towards partnered residents.	• There is a need for comprehensive, nationally consistent and mandatory course content in the tertiary and vocational education of aged care staff that equips them to respond appropriately to the sexual expressions of older people. • Aged care providers need to develop policies on residents' sexual expression and train staff in accordance with them.
16	Key informant interviews discussing the aged care workforce	• There were reports of aged care staff being under-appreciated, underpaid and overworked which, in some cases, negatively influenced their attitudes and behaviours towards residents. • Inadequate staffing levels were cited as contributing factors in staff being task-oriented rather than person-centred in their approach to residents. • Some staff were deemed by key informants to be unsuited to care work.	• Improvements in working conditions and job satisfaction are needed for aged care employees. • Staffing levels in RACFs may need to be increased if 'person-centred' care is to be achieved. • There is a need for RACFs to recruit staff with personal attributes suited to care work.
17	Key informant interviews discussing the treatment of couples and the survey question about Baby Boomers' experiences of RACFs	• It was reported that couples rarely reside together within RACFs. • In the case of couples who both resided in residential aged care, there were accounts of some providers placing partners in separate beds, separate rooms or separate wings of a RACF. • There were accounts of the built environments of RACFs being inadequate to provide shared accommodation for couples. • There were accounts of privacy invasions that included staff entering without knocking, doors being kept open and gossip about resident couples.	• There is a need to include dyadic family units in the 'special needs' category within the *Aged Care Act 1997*. • A 'couple-centred' model of aged care policy, funding and service delivery needs to be developed for dyadic family units. • When building or refurbishing RACFs, adequate accommodation for couples needs to be included. This first requires further research to establish an optimum ratio of couple suites.

Table 9.4

Summary of key findings and their implications in relation to research question 4

Research Question 4: What initiatives are necessary to support partnered Baby Boomers' coupledom in residential aged care settings?			
	Data Source	**Key Findings**	**Implications**
18	Key informant interviews discussing the treatment of couples in RACFs	Accounts of some providers actively catering to couples' needs included: • providing double beds or interlocking single beds for couples; • providing adjoining rooms large enough to house a double bed in one room and a sitting room in the other; • providing 'do not disturb' signs and training staff to respect them; • providing a discreet booking service for a 'love hotel' suite; • arranging regular activities for single residents away from couples' rooms to facilitate couple privacy; • designing couple-friendly activities; and • hoisting disabled partners into comfortable positions to assist them to engage sexually with their partner. Each of these examples were facilitated by: • at least one staff or family member who was comfortable discussing with residents what their relational, privacy and/or sexual needs were; • a care manager who was willing to action couples' requests.	• Peer-to-peer learning in the aged care sector needs to be strengthened. There are many positive examples that could be used as learning opportunities. • There is a need for aged care managers to have a positive attitude towards couples. • Appointing staff who are comfortable discussing sexual subjects is important when dealing with couples. • Staff attitudes to their own relationships may be useful as a guide to their comfort levels with sexual subjects.
19	The survey question about Baby Boomers' experiences of RACFs	• There were accounts from people in the aged care industry who were comfortable with the sexual expression of couples. These people tended to be sexually satisfied in their own relationships.	
20	Key informant interviews discussing what individuals can do to prepare for their future age care needs	• Most people do not prepare for their old age. • There was a sense that aged care residents do not have the energy to demand that their needs be met and that one's personal preferences instead need to be discussed and documented well in advance of needing aged care services.	• Partnered Baby Boomers need to plan ahead, especially financially, for their future aged care needs. • These plans need to be discussed well in advance with their future representatives so that they can act as advocates. • Decisions need to be recorded in Advance Care Directives well before aged care services are required. Such documents should include how they wish to be treated as a couple.

The contrasting findings demonstrate (a) the contested nature of residents' rooms - being both personal space for residents and workplaces for staff; (b) the problematic ways in which couples' rooms are designed and furnished; and (c) the lack of distinction made between partnered and single residents in terms of organisational policies, building design and staff training. The different answers provided in the tables highlight the complexity of providing consumer-directed aged care for Baby Boomers that is 'couple-centred', or even person-centred for that matter.

Table 9.4 summarises glimpses of 'best practice' presented in the data that provide possible pathways to successfully integrating partnered Baby Boomers within residential aged care services. In the Discussion Chapter, these exceptions within the data, together with an assessment of all the findings, resulted in the creation of a conceptual model. This model illustrates the intersecting influences of the couple, their family, aged care organisations and the built environments of RACFs in constructing the daily life of partnered residents and how they experience their relationships. These constraints and opportunities can be altered by the attitudes and communication styles of each party.

9.3. Implications

9.3.1. Implications for Australia's aged care system

9.3.1.1. For lawmakers

One third of residents have partners either residing with them in a RACF or separately elsewhere (Australian Institute of Health and Welfare [AIHW], 2015b). This study demonstrates that aged care policy can directly harm older couples' relationships, which implies that aged care recipients' primary relationships need to be acknowledged and, wherever possible, their needs ought to be explicitly addressed in any legislation and/or regulations that pertain to them. In order to adequately represent their needs, a mechanism needs to be created to give them direct input in the process, thereby giving them a voice in the legislation. One possible means of achieving this is through a modified version of a recently piloted consumer experience survey developed for the Australian Aged Care Quality Agency (AACQA) (Wells, 2017). Inclusion of one additional question that offered an opportunity for partnered residents

to identify unfulfilled needs would facilitate the creation of an ongoing database of issues which could be drawn on by lawmakers.

With respect to current legislation, while the *Quality of Care Principles 2014* (Cth) and *User Rights Principles 2014* (Cth) contained in the *Aged Care Act 1997* (Cth) include protections for the human and civil rights of aged care residents, this study found that these rights are not adequately regulated or enforced. An inherent flaw in these documents is the absence of definitions for the terms contained within them, such as 'privacy and dignity' and 'homelike environment' for instance. What do these terms mean and how are they measured? Precise definitions would facilitate (1) service providers' understanding of their obligations; (2) residents' understanding of the treatment they are entitled to; and (3) enabling the development of objective assessments tool to measure each domain and rate the relative performance of individual RACFs, the results of which could then be shared with the public.

The under-provision of couples' rooms in the findings implied that legislation does not currently address this issue. In order to achieve the optimum balance of couples to singles, an evidence base is first required to identify how many couples enter care together (as outlined later in this chapter). In the interim, the *Aged Care (Transitional Provisions) Principles 2014* (Cth) could be modified to provide for couples. This document currently stipulates that all aged care facilities built since 1999 have an average of no more than 1. 5 residents per room, which equates to a maximum of 25% of rooms catering to two occupants. In advance of accurate statistics, a modified version of the Transitional Provisions could provisionally specify that 10% to 25% of rooms in every RACF be double rooms designed in such a manner that would allow two occupants to occupy the room as a couple, in a shared bed, with an ensuite bathroom. It could also include a minimum recommended floor area of 20 square metres for double occupancy bedrooms, along with a sitting room and ensuite bathroom, in order to achieve this outcome.

9.3.1.2. For government

The findings imply that government agencies may inadvertently fail older couples by sometimes playing an instrumental role in separating them. The social, health and economic benefits to the whole of society that flow from happy couples remaining

together and spousal caregiving are ignored. So too are the social, health and economic costs to caregivers that arise directly from caregiving. This lack of awareness has resulted in contradictory policies that work against each other. On the one hand, Baby Boomers' desire to age at home is supported by government-funded community care services. On the other hand, the *Aged Care Act 1997* (Cth) is narrowly focused on directing funding to aged care providers on behalf of *individuals*. This is compounded by a lack of adequate community care services in some regions. These combined factors can result in one member of a couple being directed into residential aged care (an option that significantly increases government expenditure) while the other remains at home or, in some instances, is rendered homeless.

It is evident in this study that the Australian Government's siloed approach to services for older people lacks the holistic perspective that is required. A more integrated approach would involve care recipients and their resident caregiving partners being acknowledged as dyadic family units, rather than as individuals, when assessing their entitlements to services. Framing dyadic units as the 'consumer' would require a reorientation and re-wording of the legislation to truly make it 'consumer-directed' in the case of couples. This may require that separate funding that is already directed to each partner by the Departments of Health, Social Services and Veterans' Affairs be pooled and managed jointly. The person-centred approach used in the United Kingdom's *National Service Framework for Older People* (Department of Health, 2001) could be used as a model for this shift in thinking. If such an approach were to be taken, longitudinal studies would be needed to identify the cumulative public cost of health and aged care services to members of a dyad over time according to whether they are provided with adequate supports to remain living together; or become physically separated as a result of one entering a RACF.

9.3.1.3. For data collection agencies

Publicly available data tracking the paths that couples take on their aged care journey is lacking, making it impossible to accurately identify the extent of partner separations or the economic cost to the community. Collection of this data could be facilitated by (1) *naming* the co-resident spouse/partner on the *National Screening Assessment Form (NSAF) Client Record* (Department of Health, 2017a) administered by Aged Care

Assessment Teams; (2) linking each *NSAF Client Record* to their aged care admission data; (3) collating the outcomes for each couple into a database; and (4) de-identifying individuals named in the data. A database such as this could then be used as a resource for internal and external research.

9.3.1.4. For tertiary education and vocational training

The findings imply that where staff were knowledgeable and comfortable discussing residents' relational and sexual needs there were improved outcomes for partnered aged care residents. However, accounts of staff reactions to sexual behaviours also implied that staff education and training in relation to the privacy and sexual needs of older couples is not necessarily offered, nor is it nationally consistent, for those working in residential aged care settings. Furthermore, staff did not necessarily understand residents' legal rights generally nor those of sexually diverse residents (Cartwright, Hughes, & Lienert, 2012).

Educational inconsistency applies to undergraduate medical, nursing, and allied health degrees, post graduate gerontology training and vocational Aged Care Certificates III and IV. Immigrant workers also appear to receive no training in normative Australian cultural practices for each generational cohort. In many cases, care workers enter employment with no aged care training whatsoever (Mavromaras et al., 2017). Aged care employees and healthcare providers may also benefit from ageism awareness training to gain an understanding of the assumptions they make and how these affect residents. These educational gaps need to be addressed if uniform 'best practice' standards for the care of couples are to be achieved.

9.3.1.5. For aged care organisations

Evidence of aged care providers' ad hoc approach to residents' privacy, sexual relationships and sexual health in the findings may have been due to any number of reasons. Providers' responses imply either a lack of (a) knowledge; (b) staff guidelines, training and support; (c) funding and resources; (d) power; and/or (e) will to implement policy, systems and staff training to ensure compliance with the *Quality of Care Principles 2014* (Cth) and *User Rights Principles 2014* (Cth) in the *Aged Care*

Act 1997 (Cth). Compliance with the Act would be facilitated by defining the terminology in these documents (as suggested earlier in this chapter).

The fear based, risk-averse culture described in the findings that has developed in some RACFs in response to mandatory reporting of sexual assault suggests that aged care providers need more support and guidance in relation to mandatory reporting of sexual assault. Access to peer-based learning of 'best practice' from within the industry may prove more effective than threats of punishment by the Department or negative exposure in the media. This needs to extend beyond AACQA's annual Best Practice Awards and their publication, *Quality Care*, to include regular workshops offering peer-to-peer learning from industry leaders.

The study findings have important implications in terms of 'consumer-directed' care for partnered Baby Boomers. Service providers can prepare for this next generation of consumers by: (1) developing publicly available policies on privacy, sexuality and couples' relational needs; (2) creating a culture of mutual rapport and respect between staff and residents through careful staff selection, in-house training and a positive work culture; (3) developing industry-wide building design guidelines and staff training to clearly demarcate the boundaries between residents' private space and the staff workplace, especially in the contested space of residents' rooms; (4) designing built environments that are more homelike, with couples' suites designed for visual and acoustic privacy, large enough to accommodate king size beds; (5) offering the option of bed sizes of choice; (6) conducting individual privacy, relational and sexual needs assessments of residents upon admission; and (7) addressing those needs in resident care plans.

A useful resource to help guide aged care providers in their approach to couples is *The Sexuality Assessment Tool (SexAT) for residential aged care facilities* (Bauer, Fetherstonhaugh, Nay, Tarzia, & Beattie, 2013a). Aged care providers also have a valuable role to play in guiding family members in how to respond to their loved ones' sexual expression. It may prove helpful for them to distribute a copy of *Sexuality and People in Residential Aged Care Facilities: A Guide for Partners and Families* (Bauer & Fetherstonhaugh, 2016). Alternatively, it could be made available on the government's *My Aged Care* web portal.

In addition, staff need to be trained to have awareness in (1) identifying ageism and understanding its effects; (2) the cultural needs of different generational cohorts; (3) needs specific to couples; and (4) the full spectrum of sexual expressions in older people. Useful resources for staff sexuality training are listed in Table 9.5. Providers must also plan how they will cater to the relational and privacy needs of residents whose partners live offsite. However, at the present time, the aged care sector appears to have limited capacity, willingness and/or economic resources to embrace such measures on an industry-wide scale.

Table 9.5

Useful sexuality resources for training aged care staff

Resources	**Website links**
Dementia Training Australia's *'Sexualities and Dementia*' workshops presented by Dr Cindy Jones from Griffith University.	https://www.dementiatrainingaustralia.com.au/
Alzheimer's Australia. (2010). Quality Dementia Care Series: Understanding Dementia Care and Sexuality in Residential Facilities.	https://www.dementia.org.au/
Steele, D. (2012). Intimacy and Sexuality in Long-Term Care. A guide to practice-resource tools for assessment, response and documentation. PRC: Lanark, Leeds & Grenville Long-Term Care Working Group.	http://brainxchange.ca/Public/Files/Sexuality/Intimacy-SexualityLTCResourceTool_LLGDraft22.aspx

9.3.1.6. For architects and designers

The findings related to inadequate privacy, rooms too small to house couples' beds and un-homelike environments imply two things: (1) that aged care organisations (architects' clients) are providing inadequate or restrictive design briefs and/or (2) architects are not factoring couples into the design of aged care facilities. To overcome the issue of inadequate briefs, the Victorian Government's *Aged Care Residential Services Generic Brief* (Victorian Government Department of Human Services, 2000), modified to incorporate design guidelines for couples' suites, could be developed to guide both providers and architects.

Since part of an architect's role is to educate the client and advocate for the best possible environment for building users, course content on the needs of older people in undergraduate and postgraduate degrees is needed. A useful reference book, *Design for Dementia: Volume 1 - A Guide* (Halsall & MacDonald, 2015), could become required reading. Similarly, for architects engaged in designing aged care facilities,

ongoing professional development and design guidelines that keep pace with changes in resident demographics and cutting-edge ageing research need to be offered by the Australian Institute of Architects to professionals working in this field. A useful resource for this purpose is the Victorian Government's *Residential Aged Care Services Built Environment Audit Tool Part 3: Resource Review* (Department of Health, 2012). Within such training, architects would benefit from being made aware of the possible consequences to older couples of ageist prejudices that some still hold (Buse, Nettleton, Martin, & Twigg, 2016).

9.3.1.7. For the aged care workforce

The study findings have implications in terms of recruiting suitable staff with the personal attributes and training to care for older people, and improving job satisfaction for employees. These issues have significant implications for the quality of the care residents receive. Issues of low pay, understaffing, strict schedules, heavy workloads and inadequate training (Tune, 2017; Healy & Moskos, 2005; Mavromaras et al., 2017; Richardson & Martin, 2004) need to be addressed since they limit meaningful staff-resident interactions that help establish resident trust. However, this may be the most challenging area to address without additional funding sources, since most of these issues have significant financial implications.

One possible means of improving staff wellbeing may be through industry-wide adoption of person-centred care. This model disrupts the 'top-down' approach of service delivery by centralising decision-making with the client and their care staff. Evidence has shown that this approach can help staff feel more supported and appreciated, increasing creativity and job satisfaction and reducing staff burnout (Nay et al., 2009). However, for this model to be successful, it requires a whole-of-organisation commitment to making it work, which may require considerable cultural change in some organisations since it is premised on RACFs adapting their routines to suit residents (Edvardsson, Fetherstonhaugh, & Nay, 2010).

9.3.2. Implications for Baby Boomers

The implications of this research for partnered Baby Boomers themselves is that they can't simply assume that their needs to live together, sleep together or continue being

sexual will be met in aged care settings in the future. They must start planning their future aged care options; discuss and document their preferences; and (3) identify the models of aged care they prefer. Lastly, there is the potential for future friction between Baby Boomers and aged care service providers.

Bringing about the desired changes may require political activism by Baby Boomers while they are still healthy enough to do so. This may involve participating in organisations such as COTA (Council on the Ageing) or National Seniors Australia that already lobby government and raise public awareness on issues specific to older people. There is evidence in the current study that Baby Boomers are already advocating on their parents' behalves directly with aged care providers. Writing letters and sending signed petitions to federal and state ministers in aged care, health and social services portfolios is another option.

Some Baby Boomers could use their positions of seniority as political platforms to raise awareness of issues. This has already begun in the political[78], media[79], film[80] and aged care sectors[81]. Innovative Baby Boomers on the boards of directors of several aged care organisations (including Benetas, ACH Group, ECH Incorporated[82] and Synovum Care Group) are already developing more homelike models of residential care. Another example is the film, *Together*[83], just released in the United States (2018) based on the story of a couple separated by the British aged care system after more than 60 years of marriage.

9.3.3. Wider implications

9.3.3.1. For researchers

The findings indicated that older couples' intimate relationships have largely been devalued, obscured and sanitised in the research literature. Aged care researchers, it

[78] For example, see Minister for Aged Care, Ken Wyatt's speech to the National Press Club on loneliness in older people: http://www.abc.net.au/news/2017-10-25/aged-care-residents-suffering-from-loneliness,-ken-wyatt-says/9085782.
[79] See Paul Barclay's program on ABC Radio entitled "Disrupting Ageing" (http://www.abc.net.au/radionational/programs/bigideas/disrupting-ageing/9145690) for example.
[80] See Paul Duddridge's 2017 film, "Together": https://www.youtube.com/watch?v=NrEHPXxw0E8 for example
[81] For example, see these news interviews of COTA Chief Executive, Ian Yates, Age Discrimination Commissioner, Kay Patterson and Attorney General, George Brandis on elder abuse: https://www.sbs.com.au/news/landmark-report-calls-for-better-protection-of-elderly.
[82] Representatives from ACH and ECH, Jeff Fiebig and David Panter, were interviewed for this study.
[83] See footnote no.3 and http://www.imdb.com/title/tt6111634/.

seems, have been predominantly focused on the caregiving aspect of couples' relationships. As a consequence, partners/spouses have frequently been termed 'informal carers' or 'spousal caregivers', which obscures the true nature of their relationships. This lack of attention to the personal and intimate dimensions of couples' relationships has enormous implications when it comes to using research to argue for change. Researchers also need to avoid being ageist themselves. While some contend that terms such as 'senior', 'elder' and 'veteran' have positive connotations (Palmore, 2000), derogatory use of the word senior (as in 'senior moment') (Gendron, Welleford, Inker, & White, 2016) has caused it to fall out of favour. An evidence-based language guide written by the International Longevity Centre USA recommends descriptors such as 'older people' and 'older adults' in preference to terms deemed by Americans Baby Boomers to be "laden with stereotypes" (Dahmen & Cozma 2009, p. 27). They recommend against using terms such as 'elderly', 'seniors' and 'senior citizens', some of which are now prohibited by some academic journals[84]. These terms, while perhaps acceptable in the twentieth century (Baars, 1991; Bauer, 1999; Ehrenfeld, Tabak, Bronner, & Bergman, 1997), still remain in usage by scholars (Flamion, Missotten, Marquet, & Adam, 2017; Loe, 2004a; Kenner, 2008; Manzoli, Villari, Pirone, & Boccia, 2007). The implications for an agenda for further research are outlined in a separate section in this chapter (see section 9.5).

9.3.3.2. For the broader community

This research found that ageist attitudes to older couples' relationships are endemic in Australia and elsewhere. This has implications for the entire community. Research suggests that frequent but, more importantly, positive contact with grandparents in childhood and adolescence reduces negative views towards older people (Allan, Johnson, & Emerson, 2014; Bousfield & Hutchison, 2010; Flamion et al., 2017; Luo, Zhou, Jin, Newman, & Liang, 2013; Robinson & Howatson-Jones, 2014). Within families, this may be achieved through regular family gatherings, family holidays, or living as extended family units.

[84] The Australasian Journal on Ageing prohibits the use of the term 'elderly'.

Early childhood teachers have a role to play, such as inviting older couples to share their stories with students and school visits to places or events where older people gather. Innovative programs already exist in isolation. Some schools have regular visits to their local RACF. One Australian RACF incorporates a pre-school[85] where each child develops a relationship with a 'grandfriend' (Low, Russell, McDonald, & Kauffman, 2015). In Japan, day care centres cater to the old and young within the one facility (Anderzhon, Hughes, Judd, Kiyota, & Wijnties, 2012) and, in the Netherlands, free student accommodation is offered within one RACF[86] in exchange for developing relationships with residents.

Politicians and the media also have a role to play. Ageist attitudes are perpetuated by politicians who present older people as 'the problem' and media representations of older people as decrepit, useless, asexual or targets for ridicule. Older people are not a homogenous group. Older adults need to be represented in all their variety, including the myriad ways in which many continue to contribute society. Dahmen and Cozma's (2009) guide, *Media Takes: On Aging* is an essential reference for journalists for this purpose.

9.4. Study limitations

This study has required the negotiation of several challenges. Firstly, the subject matter of the study posed the challenge of how to obtain meaningful data from Baby Boomers about their anticipated aged care needs, given that they lacked direct lived experience of the phenomenon in question (living in residential aged care with or without one's partner). The mixed methods design of the study was an attempt to partially overcome this limitation by providing multiple perspectives of the phenomenon. Given that it is not possible to predict Baby Boomers' actual needs in 20 or more years from now, this study concerns only anticipated needs. Nonetheless, these anticipated needs provide insight into the anxieties some partnered Baby Boomers have regarding their future care and wellbeing. Nor are the results representative of all Australian Baby Boomers, given the small sample sizes and the skewed gender mix. Instead what is presented is a sample of Baby Boomers' current

[85] See http://rsllifecare. org. au/little-diggers/ and http://www.littlediggerspreschool.com.au/.
[86] See http://www.abc.net.au/radionational/programs/drive/dutch-retirement-home-lets-students-live-rent-free/6351450; https://www.youtube.com/watch?v=V7TCatTjjjs; and https://www.youtube.com/watch?v=PZgGb4p0xo0.

experiences, their perceptions of their future needs and their current attitudes to residential aged care, contrasted with accounts of aged care practices at the time of the research. These findings are indicative of a range of attitudes that aged care providers may encounter once Baby Boomers begin needing aged care services.

The findings in this study may be transferrable to other individualistic Western democratic nations with similar aged care systems, where their Baby Boomer cohort has similar values and life experiences, such as in New Zealand, the United Kingdom, Canada, the United States and, to a lesser extent, northern European and Scandinavian countries. The applicability of this study to Mediterranean countries or collectivist cultures such as Japan, China and other south-east Asian nations, where respect for older people is higher (Olson, 2001), where families tend to care for older relatives at home and where cultural values in relation to expressing sexuality may differ, is much more limited.

Research gaps identified in the literature review that were not addressed by this study include: (1) the absence of sexual health policy for older Australians; (2) a lack of epidemiological data on sexual problems in aging populations; (3) research into community-dwelling same sex couples in older age groups; (4) Baby Boomers' expectations of their needs in old age generally; (5) how ageist attitudes, beliefs and practices impact older people's relationships and sexuality in and out of aged care settings; and (6) the role partnerships play in shaping sexual experience throughout life. Lastly, this thesis did not address the need to develop practical guidance for Australian aged care staff in how to respond appropriately when residents express themselves sexually, as exemplified by a Canadian model (Steele, 2007). Nor did it consider matters concerned with funding aged care services.

Topics identified in this study that require further in-depth exploration include: (1) the issue of couples becoming involuntarily separated, its prevalence and outcomes for those individuals; (2) the impact of staff attitudes and aged care practices on couples, from partnered residents' perspectives; (3) the cultural sensitivities of staff from culturally diverse backgrounds towards residents' sexual expression; (4) the experiences of same sex couples and other sexually diverse aged care residents; (5) the views of culturally diverse aged care residents towards sexual relationships in aged

care settings; and (6) the experiences of couples where one or both partners have dementia. Lastly, the study findings raise the question of how partnered Baby Boomers would fare if separated, especially if separated involuntarily, and what impact that might have on health and social services. The answer to this question is however beyond the scope of this study.

9.5. Agenda for further research

This study suggested that there has been a gap in scholarly attention to the specific needs of partnered aged care residents. There appears to have been a lack of attention to couples in person-centred models of aged care and a lack of transference of the progressive emerging work on sexually diverse aged care residents (Barrett, 2008; 2011; Barrett, Harrison, & Kent, 2008; Barrett, Whyte, Comfort, Lyons, & Crameri, 2015), including those with dementia (Barrett, Crameri, Lambourne, Latham, & Whyte, 2015; Birch, 2009), and heterosexual couples living with dementia (Adams & Gardiner, 2005; Bielsten, & Hellström, 2017a; 2017b) to extending support to all partnered aged care residents. More broadly, a lack of research focus on older couples generally in the fields of sociology, psychology, sexology and gerontology is evident. There is a need for deeper scholarly thinking and theorisation of the roles of togetherness, privacy and sexual expression for older couples and the consequences of services withdrawing or limiting their access to these fundamental needs. The gaps on these themes have meant there is limited practical advice available for aged care employees or couples entering residential aged care.

Further work by scholars needs to focus on guiding aged care policy and practice in relation to couples, including curricula for tertiary education and vocational training of aged care staff; educational materials to guide professional practice in the fields of law, architecture, interior design, medicine and nursing; generic policies to guide aged care organisations on resident relationships, privacy and sexual expression; and publicly available educational materials for couples and their families that spell out their rights and provide guidance on how to select an aged care service and what questions to ask. Attention also needs to be given to an education campaign to help guide Baby Boomers in how to prepare in advance for their needs in old age.

This study offered a new model of the socio-physical influences on partnered aged care residents developed from the data. This model presents for the first time a way of conceptualising the intersecting influences of the physical environment, organisational policies and practices, residents' families and couples themselves on partnered residents' experiences of living in RACFs. It could be used as a framework to guide further analysis of the couple-friendliness of the built environment, staff practices and the role of families within individual RACFs. Such an approach could be used to inform best practice by generating data that links features of the built environment, organisational responses and measurement of couples' quality of life with feedback from families and partnered residents. It would be particularly useful to have more conceptualisation work done on the model's practical application to aged care services in order to develop an industry guide to couple-centred care of partnered residents.

This study identified six key areas requiring further research attention:

1. The first area relates to the unavailability of aged care data from Australian government agencies that links individual partners in dyadic family units and enables researchers to track partnered individuals' pathways through the aged care system. At present, there is only anecdotal evidence on the prevalence of involuntarily separated couples however linked data would enable researchers to tease out the mechanisms by which couples become separated, whether it be due to bureaucratic processes, institutional policies, the attitudes of individual managers or other causes.

2. Public policy would benefit from using the suggested linked government data to undertake longitudinal and/or retrospective population-based research to identify individual partners' use of health and aged care services according to their aged care pathway. Until such research is undertaken, the potential long term economic impacts of supporting couples to remain together compared to the costs of involuntarily separating partners remain unknown.

3. There is a need to collect qualitative data from involuntarily separated couples to identify the direct impacts on their personal wellbeing and the

quality of their couple relationship as well as the ongoing ramifications of being separated. This data could be used to better inform legislators and policymakers when drafting aged care measures that affect couples.

4. There is a need to develop alternative aged care models that (1) meet partnered Baby Boomers' expectations of autonomy, choice, togetherness, privacy and ongoing sexual expression; (2) assuage the fears expressed by Baby Boomers; and (3) are designed with the wellbeing of couples in mind, both in terms of bureaucratic funding models, organisational practices and the built environments in which aged care services are provided. Such research may involve studies of alternative international models and/or Australian interventions designed to improve conditions for couples.

5. Variable interpretations of aged care legislation by aged care organisations and their employees need to be standardised. In order to improve compliance, action research is needed to develop training programs and educational materials to make aged legislation more accessible and understandable by all aged care employees, including those with limited education and/or English as a second language.

6. Future comparative data collection efforts could also be useful in the long term to understand the gaps and differences between Baby Boomers' anticipated aged care needs as reported in this particular study, and their needs when actually in aged care.

9.6. Conclusion

This chapter has demonstrated how the aims of the study were met, drawn conclusions from the issues raised in the discussion of the findings and presented an overview of the major conclusions. It then outlined the implications of this research for the aged care sector; Baby Boomers and the wider community. Lastly, it identified the limitations to the study and suggested areas requiring further research.

If approximately three in seven annual deaths in Australians aged over 65 occur in aged care facilities (AIHW, 2015c), this indicates that a considerable proportion of older adults use residential aged care services. One third of those residents are partnered (AIHW, 2015b). It is, therefore, critical that all aged care services treat older couples humanely, in ways that respect their integrity as family units. This requires catering to the needs of partnered residents if they are to have an acceptable quality of life.

Once Baby Boomers reach the stage of requiring aged care services they will need support to voice their sexual and relationship needs in residential aged care settings. The evidence set out in this thesis suggests that the beliefs and attitudes of others, especially those of staff and family members, will influence their ability to exercise autonomy and choice when conducting their intimate relationships. Privacy (Altman, 1976; Doyal 1997) and expressing one's sexuality (Barrett et al., 2012; World Health Organization, 2002) have been identified as fundamental human needs at all stages of life. RACFs need to foster a culture where residents' wellbeing, including their privacy, sexuality and relationship choices, is a high priority. This research has proposed a number of recommendations that could assist aged care providers to prepare for the integration of partnered Baby Boomers into residential aged care settings. Central to these recommendations are the principles of respect, acknowledgement and communication. This study, together with previous research, suggests that the initiatives outlined have the potential to create more positive outcomes not just for partnered Baby Boomers but for future generations in aged care settings in Australia and, to some extent, other Western democratic nations where family are not necessarily the primary carers of older people.

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Appendices

Appendix A. Key Informant Interview Guide

This is a semi-structured interview with open-ended questions intended to open up further conversation. Prior to the interview, ensure each participant has received the *Participant Information Sheet* and signed the *Consent Form for Participants*.

Thank you for agreeing to participate in this study. Some of the questions I will be asking relate to the sexuality of older people. Are you comfortable discussing this topic? If there are any questions you are not comfortable answering please let me know and we will skip that question. If there are additional topics you'd like to discuss there will be an opportunity at the end of the interview.

7. How would you like to be referred to? What is your formal position title? Do you prefer to be called …. Mr / Mrs / Ms / Dr / Prof / Other
8. What generation do you consider yourself to be a part of?
    - Federation Generation / Oldest Generation
    - The Builders / The Lucky Generation
    - Baby Boomers / Hippies
    - Generation X / Baby Busters
    - Generation Y/ Boomerang Generation
    - iGeneration/ Generation Z/ Millenials
    - Other – please describe:
    - None of the above
    - I don't know
9. What do you consider to be core characteristics of this generation? [Prompts: wild vs. conservative, open-minded vs. closed minded)]
10. In relation to your field of expertise what do you think are the main needs of the population you're servicing?
11. What do you think are the 3 key needs of the current generation in care?
12. Do you think this might change for Baby Boomers, and if so, how?
13. What do you see as the 3 key needs of the next generation (Baby Boomers)? [Probe further into answers to this question]
14. What do you think Baby Boomers will require in aged care?

15. From your position, how can these needs best be met?
16. How might current or future aged care policies affect Baby Boomers?
17. From a policy perspective, what do you perceive will be needed for the successful integration of the next generation into aged care?
18. If funding is cut to aged care services, compared to what exists now, how do you think it might affect Baby Boomers?
19. What kind of counselling services are currently provided to residents in aged care?
20. Is grief counselling offered to couples who are separated by a partner entering aged care?
21. What kind of sex education and sexual health services are currently provided to residents in aged care?
22. What do you perceive to be the sexual health needs of Baby Boomers in residential aged care?
23. Do you have any policy or registration documents from your organisation that you can give me?
24. Does [name of organisation] have a policy on residents' sexual expression?
25. What policies and training are provided to help staff distinguish between consensual and non-consensual sexual activity in residential aged care?
26. What measures are in place to prevent non-consensual sexual activity?
27. Without identifying anyone, what stories can you share about 'inappropriate' sexual behaviours by aged care residents?
28. How is this managed?
29. Again, without identifying anyone, what stories can you share about 'appropriate' sexual behaviours by aged care residents?
30. What is [name of organisation]'s position on assisted sexual expression?
31. This is the personal question I'd like to ask you. If you choose to answer it, you will not be quoted by name. You do not have to answer it if you don't want to.

    When you think of your own old age, what kind of residential aged care would you like?
32. Is there anything you'd like to add that we haven't discussed?
33. Is there anyone else that you'd recommend I speak to in relation to what we've talked about?

Appendix B. Sample Survey

What follows is a copy of a completed online questionnaire, including the information given to participants prior to them giving implied consent, as it appeared to participants on the Qualtrics website:

Q1.

Information Sheet for Participants

I wish to invite you to participate in my research project, described below.

My name is Alison Rahn and I am conducting this research as part of my PhD in the School of Behavioural, Cognitive and Social Sciences at the University of New England. My supervisors are Dr Tiffany Jones, Dr Amy Lykins and Dr Cary Bennett.

Project Name:
Baby Boomer Sexuality: Exploring the Wants, Needs and Available Options for Partnered Individuals and Couples in Australian Residential Aged Care

Aim of the research
This research seeks to identify the sexual and intimacy needs of couples born 1946-65 (Baby Boomers) in the event that they become consumers of residential aged care and to identify potential conflicts between their wishes and the current delivery of aged care.

Questionnaire
I would like you to participate in an anonymous online survey. The questionnaire will take between 20 and 45 minutes to complete.

Confidentiality
Your participation is completely anonymous. You will not be asked your name or any identifying details to ensure that the answers you provide remain confidential.

Participation is Voluntary
Please understand that your involvement in this study is voluntary and I respect your right to withdraw from the study at any time. You may discontinue the questionnaire at any time without consequence and you do not need to provide any explanation if you decide not to participate or withdraw at any time.

Questions
The questions are designed to enhance my knowledge of what people look for when choosing an aged care facility. Some of the questions are of a sensitive nature. If you are uncomfortable answering any question at any time, please skip that question and go on to the next one.

Use of information
I will use information from the questionnaire as part of my doctoral thesis, which I expect to complete in August 2017. This information may also be used in journal articles and conference presentations before and after this date. I will safeguard your identity by presenting the information in way that will not allow you to be identified. The results of this research will be made available online at UNE's online thesis repository at http://e-publications.une.edu.au. Early findings will be posted on Facebook at http://www.facebook.com/couplesinagedcare.

Upsetting issues
If this research raises any personal or upsetting issues you may wish to contact Lifeline on 13 11 14 or your local healthcare centre.

Storage of information
Information you provide will be stored as electronic data, kept on a password-protected computer and password-protected external storage device in a locked office in the researcher's home. Only the research team will have access to the data.

Disposal of information
All the data collected in this research will be kept for a minimum of five years after successful submission of my thesis, after which it will be disposed of by deleting relevant computer files, and destroying or shredding hardcopy materials.

Approval
This project has been approved by the Human Research Ethics Committee of the University of New England (Approval No. HE15-171, Valid to 9/6/2016).

Contact details
Feel free to contact me with any questions about this research by email at arahn3@myune.edu.au or by phone on 0432 599 812. You may also contact my supervisors.

My Principal supervisor's details are as follows:
Dr Amy Lykins - alykins@une.edu.au or 02 6773 5014.

My co-supervisors details are as follows:
Dr Tiffany Jones - Tiffany.Jones@latrobe.edu.au or 03 9479 8773.
Dr Cary Bennett - cary.bennett@une.edu.au or 02 6773 2992.

Complaints
Should you have any complaints concerning the manner in which this research is conducted, please contact the Research Ethics Officer at:

Research Services, University of New England, Armidale, NSW 2351
Tel: (02) 6773 3449 Fax: (02) 6773 3543
Email: ethics@une.edu.au

Thank you for considering this request and I look forward to your participation.

Regards,
Alison Rahn

Q2.

Online Implied Consent for Participants

Research Project: Baby Boomer Sexuality: Exploring the Wants, Needs and Available Options for Partnered Individuals and Couples in Australian Residential Aged Care

I have read the information contained in the *Information Sheet for Participants* (above) and any questions I have asked have been answered to my satisfaction.

I agree to participate in this activity, realising that I may withdraw at any time.

I agree that research data gathered for the study may be published, and my identity will be unidentifiable due to the strict confidentiality explained in the information sheet.

I am over 18 years of age.

In preservation of anonymity, I understand that no name or signature is required of me to give consent. By proceeding to the next page I am agreeing to participate in this study.

PROCEED TO STUDY

Q3. Thank you for agreeing to participate in this survey. This is an opportunity for you to have your say about what is important to you and what you would like service providers to know, in order to better provide for you in old age.

Q4. 1. Where do you live? Please mark the circle that best applies.

- (•) New South Wales
- ( ) Victoria
- ( ) Queensland
- ( ) Western Australia
- ( ) South Australia
- ( ) Tasmania
- ( ) Australian Capital Territory
- ( ) Northern Territory
- ( ) Remote Australian territory or island
- ( ) Outside of Australia
- ( ) Other

Q5. 2. What is your home postcode?

2484

Q6. 3. What year were you born?

1963

Q7. 4. What country were you born in?

Australia

Q8. 5. Are you an Australian Aboriginal or Torres Strait Islander?

- ○ Yes
- ◉ No
- ○ Not sure

Q9. 6. What sex are you?

- ☑ Female
- ☐ Male
- ☐ Other - please describe

Q10. 7. What is your sexual orientation?

- ○ Same sex attracted
- ◉ Opposite sex attracted
- ○ Attracted to both sexes
- ○ Not attracted to either sex
- ○ Other - please describe

Q11. 8. What is your current relationship type?

- ○ Married
- ○ De facto
- ◉ Single
- ○ Other - please describe

Q12. 9. Please describe your current personal income level (please do not include income earned by other people).

- ○ Up to $20,000 p.a. ($385/week)
- ◉ $21,000 - $40,000 p.a. ($386-769/week)
- ○ $41,000-$60,000 p.a. ($770-1,154/week
- ○ $61,000-$80,000 p.a. ($1,155-1,538/week)
- ○ $81,000-$100,000 p.a. ($1,539-1,923/week)
- ○ $101,000-$150,000 p.a. ($1,924-2,885/week)
- ○ $151,000-$200,000 p.a. ($2,886-3,846/week)
- ○ $201,000 p.a. or more ($3,847/week or more)

Q13. The following questions are to better understand your current intimate relationship(s):

Q14. 10. Please describe your current intimate partner relationship(s), including whether you live together, any traditional or non-traditional features, and the gender of your partner(s).

In monogamous relationship with male for past nine years

Q15. 11. Please describe aspects of your intimate partner relationship(s) that are essential to you.

Physical intimacy Emotional support Companionship and friendship

Q16. 12. If you live together, what is it about **living with your partner(s)** that you value?

Don't live together.

Q17. 13. Please tell us about your experience of **sleeping in the same bed** (or not) with your current partner(s).

Comforting, but also sometimes challenging when he snores.

Q18. 14. Please tell us about the **physical intimacy and closeness** you experience with your current partner(s)
(e.g. kissing, cuddling, holding hands, non-sexual touching).

Cuddling, holding hands, kissing.

Q19. 15. Please tell us about the **sexual pleasure** you experience with your current partner(s).

Intercourse, fellatio, use of vibrators.

Q20. 16. **What sorts of things interfere** with your intimacy or sexual pleasure at this stage of your life?

Anorgasmia without vibrator. Reduced libido with onset of menopause.

Q21. 17. Do you consider physical intimacy and/or sexual pleasure **essential** parts of life?

	Yes	No	It varies
Physical intimacy	◉	○	○
Sexual pleasure	◉	○	○

Q22. 18. **How satisfied are you** with your current level of physical intimacy and/or sexual pleasure?

	Very satisfied	Somewhat satisfied	Not satisfied	It varies
Physical intimacy	◉	○	○	○
Sexual pleasure	○	◉	○	○

Q23. 19. Do you think you'll ever stop being sexual?

- ○ Yes
- ◉ No
- ○ It depends - please explain

Q24. 20. What experiences have you had with residential aged care facilities (nursing homes) and what impact did they have on you?

Have visited many nursing homes in professional role as a counsellor, and in another role as I do after-hours body transfers for a funeral director. My impression of the homes are that they are places where bodies go to be housed until physical death occurs. I witness much learned helplessness, loss of sense of purpose within their communities. A sense of rejection by their families. However the residents I have spoken with are fully functioning (i.e no dementia) The only exception to this situation I have witnessed is in an apartment block designed to provide aged care support while enabling true independent living. Each apartment is complete (i.e full kitchen, bathroom, laundry) and yet includes an emergency button for immediate on-site support. Couples live together. You would not know it was an aged care support facility unless someone told you.

Q25. If you and/or your partner(s) ever need to move to a residential aged care facility for health reasons:

Q26. 21. How important is it to maintain your intimate partner relationship(s)?

- ◉ Vital
- ○ Somewhat important
- ○ Neither important nor unimportant
- ○ Somewhat unimportant
- ○ Not at all important
- ○ It depends - please explain

Q27. 22. How important is it to sleep in the same room with your partner(s)?

- ◉ Vital
- ○ Somewhat important
- ○ Neither important nor unimportant
- ○ Somewhat unimportant
- ○ Not at all important
- ○ It depends - please explain

Q28. 23. How important is it to sleep in the same bed with your partner(s)?

- (•) Vital
- ( ) Somewhat important
- ( ) Neither important nor unimportant
- ( ) Somewhat unimportant
- ( ) Not at all important
- ( ) It depends - please explain

Q29. 24. How much privacy would enable you to feel comfortable relating intimately or sexually with your partner(s)?

- (•) As much as possible
- ( ) A little
- ( ) It's not important
- ( ) It depends - please explain

Q30. 25. What kinds of privacy are important to you? Please tick any or all that apply.

- [x] Visual privacy (I choose if I can be seen)
- [x] Acoustic privacy (I choose if I can be heard)
- [x] Communication privacy (e.g. when talking, writing, emailing, skyping, and viewing websites)
- [x] Bodily privacy (my consent is required before undressing me or performing bodily procedures)
- [x] Private space (my own bed, room and storage space - where I can lock the door and my consent is required before others can access me or my belongings)
- [x] Personal information (my personal and medical details may only be shared with my consent)
- [x] Social privacy (e.g. I choose who I am seated next to and who I do/do not spend time with)
- [ ] Other - please describe

Q31. 26. Do you think sexual health information, products and services should be available in residential aged care facilities?

- (•) Yes
- ( ) No
- ( ) It depends

Q32. 27. Please explain your answer to the previous question.

Sexuality is part of life. If not discussed then people can assume that their inherent sexuality is invalid after a certain time of life.

Q33. 28. How important would it be for you to go online whenever you choose?

- (•) Very important
- ( ) Somewhat important
- ( ) Not important

Q34. 29. In residential care facilities, sometimes family or carers make decisions on behalf of an older person. How important is it to you that your sexual choices be respected by your family or carers?

	Very	Somewhat	Not important
Family	(•)	( )	( )
Carers	(•)	( )	( )

Q35. 30. What steps have you taken to communicate your wishes about your sexual choices to your partner, your family or future carers?

None.

Q36. 31. Are you aware that you can document these wishes in detail when you appoint someone to be your Enduring Guardian?

- ( ) Yes
- (•) No
- ( ) Don't know

Q37. 32. How do you think the development of dementia might affect your intimate and sexual relations with your partner(s)?

- ( ) No difference
- ( ) Small difference
- ( ) Large difference
- (•) Unsure

Appendix C. Correspondence

From: Selma Mujagic-Horvat <selma.mujagic-horvat@abs.gov.au>
Date: Thursday, 31 August 2017 3:59 pm
To: alison rahn <arahn3@myune.edu.au>
Subject: Census data: University of New England - Alison Rahn

Dear Alison,

thank you for your recent enquiry to the Australian Bureau of Statistics (ABS) regarding Census data for married couples at nursing homes.

Unfortunately, we do not have what you are after as we do not ask for a marital status on the form for non-private dwellings. Such individuals are enumerated on a personal form basis rather than a household form.

Kind Regards

Selma M Horvat

Information Officer

Customised and Microdata Delivery I Dissemination BranchI Australian Bureau of Statistics

(P) 1300 135 070 (W) www.abs.gov.au (E) client.services@abs.gov.au

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Name: Alison Rahn
Business Name: University of New England
Email: arahn3@myune.edu.au
Phone: 0432 599 812
Location: New South Wales

Hello
I'm seeking data on the number of cohabiting couples residing together within nursing homes throughout Australia. Is it possible to obtain census data that identifies how many people with married, de facto or same-sex couple status lived together with their partner as residents in a nursing home (non-private dwelling), Australia-wide?
This information is not available from the Australian Institute of Health & Welfare, so I hope you can help.
Yours sincerely,
Alison Rahn
PhD student

29/08/2017 16:23:26 ZE10

AI

Appleby, Ian <ian.appleby@aihw.gov.au>
Alison Rahn; Aged Care Data Clearinghouse
Wednesday, 19 October 2016 at 2:26 PM
Show Details

You forwarded this message on 19/10/2016, 4:17 PM.
You forwarded this message on 16/11/2017, 3:52 PM. Show Forward

Dear Alison,

Thank you for your request for aged care data relating to couples entering residential aged care. Sorry we haven't got back to you before now. Unfortunately we are unable to assist you with information on the topic you enquired about. This is because information that would enable the linking of residents to determine couple relationships is non-existent or inadequate, as is information on previous residence prior to entering residential aged care.

If you would like to discuss this with me further, please call on the number below.

Regards

Ian Appleby
Team leader
Disability and Ageing Unit
Australian Institute of Health and Welfare
02 6244 1253

Australian Government

Department of Health

Ref No: MC17-005513

Alison Rahn
School of Behavioural, Cognitive and Social Sciences
University of New England
ARMIDALE NSW 2351

Dear Ms Rahn

Thank you for your correspondence of 16 March 2017 to the Minister for Aged Care and Minister for Indigenous Health, the Hon Ken Wyatt AM, MP, regarding the request to access ACFI data relating to couples in residential aged care facilities. The Minister has asked me to reply.

The Aged Care Funding Instrument (ACFI) is designed to assess the relative care needs of residents and has three funding categories: Activities of Daily Living, Behaviour, and Complex Health Care. The Department does not monitor couples entering a residential aged care facility and de-identified ACFI data does not track how many older couples remain together once in residential aged care.

The Australian Aged Care Quality Agency (AACQA) has a key role in monitoring facilities and their performance against the Accreditation Standards. Accreditation Standard 3, *Care recipient lifestyle*, aims to ensure care recipients retain their personal, civic, legal and consumer rights and are assisted to achieve active control of their own lives within the residential care service and in the community. More information can be found on AACQA's website: www.aacqa.gov.au

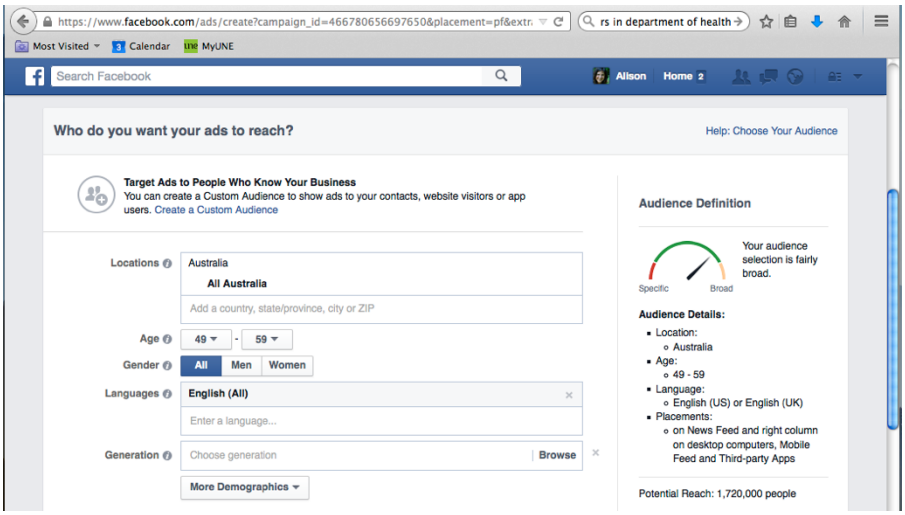
[redacted]

Nick Hartland [redacted]
First Assistant Secretary
Aged Care Policy and Regulation Division
Ageing and Aged Care Group
Department of Health
[redacted]pril 2017

GPO Box 9848 Canberra ACT 2601
Telephone: (02) 6289 1555

Appendix D. Baby Boomers on Facebook

Australian audience aged 49-59: 1.72 million



Australian audience aged 59-65+: 1.4 million