'Still a couple?'

A study of sexuality and intimacy concerns in residential care from the perspective of residents' partners and care staff

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ABSTRACT

Sexuality and intimacy are recognised as crucial aspects of being human. Our sense of self and identity is maintained through our relationships with others, and existing literature suggests that concepts of sexuality and intimacy are important throughout the lifespan. Whilst sexual liberty has increasingly been seen as a basic human right, this view has tended to exclude people with disabilities, compromised cognitive abilities and people who live in residential care settings. The debate over the last 40 years has tended to view these groups of people as vulnerable and requiring protection, despite the literature suggesting that later life relationships are focused towards intimacy rather than sexual behaviour, and that maintaining relationships is a key aspect of quality of life for older couples.

The situation for older people is compounded by the evidence which suggests that it is difficult for Westernised societies to consider their sexuality and intimacy needs in general, and that Residential Care Facility (RCF) staff are not exempt from this discomfort. Staff may fail to recognise the differences in later life relationships, which can then impact on the provision of holistic care.

In order to examine this situation in a contemporary New Zealand care setting, in-depth qualitative interviews were held with twelve home-based partners of RCF residents, and three focus groups comprised of sixteen RCF staff were held across Otago and Southland. A thematic analysis revealed that grief and loss was a significant factor for partners, and finding ways to maintain connections with their partner within the RCF setting was seen as a way to manage this in a practical way. Continuing to offer aspects of care, having privacy to talk with their partner and being able to maintain physical proximity and closeness, for example, by occasional bed- sharing, was valued highly by partners as an important way to continue an intimate connection. Whilst many staff recognised grief responses, ways to maintain intimacy and connection and the needs of later- life relationships were not well understood. Privacy requirements were commonly interpreted as associated with sexual behaviour rather than with intimacy and connection, which then raised concerns about surveillance and protection which were not confirmed by the data from partners. In general staff found it difficult to assess the intimacy and sexuality needs for RCF residents and community- based partners and therefore to consider this aspect of care.

ACKNOWLEDGEMENTS

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CHAPTER ONE
SETTING THE SCENE

Sexuality and intimacy are crucial aspects of being human (Gott & Hinchliff, 2003), and impacts on our identity, our self-concepts and self-worth, as well as our relationships, our mental health, and quality of life (Heath, 2011). Our sense of self and identity is maintained through our relationships with others, especially in later life, and long-term close relationships can assist older people with life changes and loss (Heath, 2002). Yet, respecting and supporting the intimate relationships and sexuality expression of individuals who live in residential care is not simple and straightforward. Most residents have a number of co-existing health conditions which makes it not only difficult for people to live at home, but also impact on their closest relationships (Bowman, Whistler & Ellerby, 2004). Whilst sexual liberty has increasingly been regarded as a basic human right (Oriel, 2005) this right has previously excluded people with disabilities, compromised cognitive abilities and people who live in institutional settings. The debate over the last 40 years has tended to view these groups of people as vulnerable and requiring protection (Appel, 2010), and many Residential Care Facility (RCF) staff maintain these concerns, especially if there is any suggestion that an individual has cognitive decline (Tarzia, Fetherstonhaugh, & Bauer, 2012). This situation is compounded by the considerable evidence which suggests that it is difficult for Westernised societies to consider the sexuality of older people (Bauer, McAuliffe, & Nay, 2007; Bouman, Arcelus, & Benbow, 2006; Gott, 2005). Staff within RCFs are not exempt from this discomfort (Hajjar & Kamel, 2004; Heath, 2011), which adds to the difficulties that older people who live in a RCF may experience. Most of the literature focuses on sexuality expression either between residents in the same facility, or attitudes toward self-expressions of sexuality (Bauer et al., 2007), rather than long–term relationships, and the changes experienced when one in the partnership is placed in residential care. This study aims to examine this situation from the perspective of the partner who remains at home. The perspectives of home-based partners are not well represented in the literature, particularly in the last ten years (Bauer et al., 2007). This thesis examines the experiences of home-based partners of people who have moved to a RCF in Otago and Southland, and their perceptions of their relationships and aspects of intimacy and sexuality. The views of residential care staff were also sought to ascertain their perceptions of the needs of residents and their views of resident relationships. The underlying reason for examining these perspectives is because

of the link between relationships (including aspects of intimacy and sexuality) and the quality of life (QoL) of residents (Tolson, Dewar, & Jackson, 2014).

Later–life relationships – a shared identity, a shared life

People in long term relationships have a longer life expectancy than people who have not been in long-term relationships or are divorced or widowed (Cole, 1984). Advancing age brings an increase in the interdependence between a couple and this is accompanied by increased reciprocity and altruism (Kahana & Young, 1990). If people live longer, then there is an increased likelihood that at least one in the partnership will require residential care, as partners are both contending with declining health and other age-related issues and will not always be able to care for one another. Moss et al. (2001) describe that the loss of a partner in later life creates a loss of shared identity and shared life roles. Whilst the death of a partner is one way for this loss to occur, the loss of a shared life where the couple live together is significant and similar to the experience of an actual death (Farkas, 1980). The home-based partner's experience may not relate to a single 'cause': there may be a number of factors that the person may be contending with at the same time, such as loss of their own health as well as the relocation of their partner (O'Bryant & Hansson, 1995). It is common for home-based partners to describe feelings of loneliness and this is well recognised in the literature (Lopata, 1996), and visiting the partner and assisting in care tasks is one way to maintain some aspects of a shared life (Brubaker, 1990). A significant loss can be the loss of human contact and touch, often everyday expressions of intimacy such as being able to hold a partner's hand, or enjoy an early morning conversation or cuddle when first waking (Heath, 2002). This study explores these aspects of partner relationships and firstly requires us to consider the ways that intimacy and sexuality are viewed within society and then to consider the exceptions that are made for older people.

The attitudes and values within society toward sexuality are complex and can seem contradictory. It is often a taboo subject (Bouman et al., 2006), where people's attitudes, values and beliefs are influenced through social, religious, political and cultural values, as well as values portrayed within the media (Bouman et al., 2006). The contrasting view holds that sexual self-determination is a fundamental human right within Western societies and whilst there is legal protection against coercion for children, young people and people who are considered to be vulnerable, adults can generally expect to enact sexual behaviour with whom they choose, when they choose (Tarzia et al., 2012). When individuals have cognitive limitations or declining cognitive function, Appel states that this has raised 'vexing and

unpalatable questions… and an easy solution was to view sex as off limits for those with impaired IQs" (Appel, 2010, p. 152). When we consider the portrayals within society, it seems difficult for sexuality to have any place in the lives of older people, or people with disabilities or ill-health. Newson (2007) describes how we are bombarded with images of sex and sexuality but it is only acceptable if people are young, beautiful and have no sign of disability. In comparison, the sexuality of older people, and people with ill-health tends to be seen negatively (Bouman et al., 2006; Weeks, 2002; Yai & Hynie, 2011). There is an assumption within society that equates sexuality with sexual function and intercourse (Horden & Curnow, 2003). Teifer (2004) describes this as a 'bedrock' of sexuality education where sexuality textbooks usually start with a chapter explaining the genitals and how they work, therefore creating a focus on genital function. Hostad (2007) provides a simple and workable definition in delineating sex and sexuality by defining sex as something we do, and sexuality as something we are.

Giddens (1992) uses the term 'plastic sexuality' to describe the changing and malleable nature of relationships, sexuality and intimacy in contemporary Western society, and its impact on individual and social constructions. Despite this broadening of perspective, it does not mean that sexuality is an easy topic for people to talk about (Levy, 2005). It is likely that older people who grew up in the 1930s, 40s and 50s, may find this topic even more taboo (Bauer et al., 2007). When we consider that the media portrayals of older people and sexuality are usually positioned as unacceptable, humorous or sexually non-existent, it is not surprising that older people may struggle with this topic area (Gott, 2006).

Intimacy can be described as a private and personal communication of feelings, personal information, emotional support and empathy (Giddens, 1992; Searle, 2005). MacKinlay (2012) described that people need a depth of relationship and intimacy across their lifespan, and that it is an aspect of spirituality. Parr (2002) clarifies whether sexual behaviour is a defining characteristic of intimacy by stating that intimacy may be a part of sexuality but that it is not restricted to sexual acts, and whilst some individuals would not wish to have a sexual relationship, most people desire a level of intimacy.

Residential care – origins and current dilemmas

As this study explores the relationship experiences of couples where one partner is living in residential care, this places the relationship within a specific environment, with its own culture and practices. The couple are no longer living in a familiar environment where they invite people in, but are in an unfamiliar environment where the home-based partner is invited

in. There will be a new environment to adjust to, as well as changes of staff, a shift-orientated routine, as well as the need to understand the specific roles of staff. For many people, this may be their first experience of living collectively, depending on their cultural background, family situation and work experience.

Much of the development of residential care services in New Zealand has been linked to Christian and European philosophies of care, which differ from traditional whānau-based care for older Māori (Te Ara, 2014). The institution-based concept of care for older people was brought to New Zealand by settler communities and this included the link between church governance and the provision of care for older people (Brandeis & Oates, 2007). This link remains, with many residential care facilities in New Zealand functioning as medical facilities run by charities with a religious affiliation (Te Ara, 2014).

Old-age pensions were introduced in New Zealand in 1898. Prior to that, elderly people who became ill or unable to work had to rely on family support or charity. New Zealand had attracted numerous single male immigrants in the mid-1800s who were seeking work opportunities, and this gender imbalance meant that many never married. By 1900 there were numerous elderly men without family. Those who could no longer work or live independently often became residents of benevolent institutions, set up by provincial charitable aid boards from the 1860s. They provided care for people with physical ailments, but if older men were suffering from dementia, they were placed in mental institutions (Te Ara, 2014).

From the early 20th century, homes for former soldiers, who were recognised for their war service started to open. One of the first examples of this was the Ranfurly Veterans' Home in Auckland which opened in 1903. The number of church-run and private rest homes increased after the Second World War, when women began to outnumber men in older age groups. By the mid-1970s New Zealand had one of the highest rates of rest-home residency in the Western world (Te Ara, 2014).

In 2010, the New Zealand Aged Residential Care Review Steering Group published the Aged Residential Care Service Review which identified the increased need for RCF provision, because of the projected increase in older people within the New Zealand population. It also identified the need for additional workers within the sector. Since then there has been an increase in the number of facilities being developed, and an increasing presence in the sector of national and international companies, such as BUPA and Rymans Healthcare (New Zealand Aged Residential Care Services Review [NZARCSR], 2010). Following on from a recommendation in this review, standardised assessment criteria were developed and

implemented across the country which defined the criteria for recommending residential care. Needs Assessment and Service Co-ordination (NASC) services were established by district health boards in order to examine a person's ability to manage self-care and home care tasks. If the person lives with a partner or a spouse, then they are assessed together in order to take account of the needs of both people. If their needs are considered to be high and not able to be managed at home, then long-term residential care is recommended (NZARCSR, 2010). Some people with limited finances qualify for a government subsidy, but other residents meet the full costs themselves. If the person concerned has a partner, their assets are considered jointly (Te Ara, 2014).

Whilst residential care has become an established part of care provision in New Zealand, and the circumstances that warrant a person being placed in a RCF have become clearer, there are still uncertainties about the required skills and numbers of staff that are necessary to provide care in RCFs. For staff in RCFs who are registered either as enrolled or registered nurses, the Registration Board specifies and regulates training (including post-graduate training for registered nurses) and defines a specific scopes of practice. However, for unregulated care-workers, there is a continuing debate over the level of training that they require. Current estimates suggest that 46% of staff in RCFs have no formal training at all, and this has implications for the delivery of care and the emphasis of care. (Human Rights Commission, 2012). The Human Rights Commission (HRC, 2012) report entitled 'Caring Counts Tautiaki tika' identifies that "this leads to a care focus on completing tasks and staff need considerable reassurance and training to accept a shift in mind set from what the staff prefer to what residents would like" (p. 74). There are wide-ranging and opposing opinions between stakeholders and providers, and these opinions range from the recognition and impact of poor pay rates and poor training opportunities for care-workers on one hand (HRC, 2012), compared with business models that question the value in staff training and prioritise a drive to "further substitute cheaper labour for expensive labour" (NZARCSR, 2010, p.111). The gap between opinions is significant and is unlikely to be bridged readily.

Internationally, there has been an increasing focus on ensuring that RCFs deliver compassionate evidence-informed care that optimises a resident's quality of life (QoL), including care at the end of life (Tolson, Rolland, & Andrieu, 2011). Despite this aspiration, there is evidence that this remains a challenge to provide partly because there no common set of outcome measures for nuanced quality care and therefore the default standards are the measures required for facility registration (Tolson, Rolland, & Katz, 2013). The link between quality of care and QoL is interrelated but it cannot be presumed and it would be simplistic to

assume that good quality care is the key contributor to QoL (Tolson et al., 2014). The individual preferences of the resident, their mood, their access to meaningful relationships, the activities they engage in, and their ability to have privacy and autonomy will all impact on their QoL (Abrahamson, Clark, Perkins, & Airling, 2012). Kim, Park, and Kim (2014) identify that 'quality' is defined mainly through how residents and their families feel about the RCF and this does not appear in standardised indicators (Nolan, Davies, & Grant, 2001).

This study broadly explores the two aspects of QoL that are identified by Abrahamson et al. (2012) and Kim et al. (2014) - the perspective of partners about their relationship, and also how they feel about the RCF where their spouse now lives.

Thesis aims and structure

The aim of this study was to establish how partners of residents in RCFs perceive their intimacy/sexuality needs and those of their partner, and how staff in RCFs perceive these needs. It aims to critically explore the perspectives of partners as they undergo the transition and relationship changes that RCF placement entails, and includes an exploration of the ways that connections are maintained within a residential care setting.

The study sets out to answer the following research questions:

- How do partners of residents in RCFs perceive their intimacy/sexuality needs, and the needs of their partner?
- How do staff in RCFs perceive intimacy and sexuality needs for residents and their partner?
- What are the differences and similarities in the perceptions and views of these two groups?

In the following chapter, the current literature is reviewed and includes the current knowledge of sexuality and intimacy for older people, the impact of ill-health on the relationship and the relationship impact for the home-based partner following placement into a RCF. The literature on the attitudes and perceptions of RCF staff to resident sexuality and intimacy and the attitudes of health professionals more generally towards older people's sexuality and intimacy is also reviewed.

In chapter three, the theoretical approaches which have informed the research process are reviewed, and a rationale provided for the approach used. The methods used in the study are

described and the chapter concludes with a reflexive exploration of the research process, taking into account the limitations of the study.

The following chapters, four, five and six explore the main findings from the process of thematic analysis of the data, with reference to relevant theoretic frameworks where appropriate. The final chapter – chapter seven - draws conclusions from the findings, discusses the implications and proposes recommended actions arising from these.

CHAPTER TWO
LITERATURE REVIEW

This literature review was carried out by searching electronic databases, and also using a snowballing principle – finding other articles of relevance from the references of a relevant article. CINAHL, Google Scholar, MEDLINE, EMBASE, Pro Quest, Pub Med World Cat, Psych Info, and the Cochrane Library were the databases that were searched. The search criteria was *sexuality* (and associated terms- intimacy, sex, sexual behav* sexual concerns) *partner* (and associated terms- spouse, husband, wife, sexual partner) AND *health care worker* (and associated terms- care worker, "residential care worker", caregiver, nurses) AND *residential care facility* (and associated terms- aged residential care facility, nursing home, hospice, care home, homes for aged, assisted living) AND *perspectives* (associated terms- attitudes, values, beliefs, attitudes of health personnel, practice). The palliative care literature was searched in this topic area where it was relevant to partner perspectives in residential care.

In the last 10-20 years there has been an abundance of research dealing with older people's sexuality, and also sexuality related issues within RCFs but there are fewer sources in the literature that examine partner perspectives. I have therefore, narrowed the focus for this literature review in order to address the research questions for this study. Firstly, I examine the literature that examines partner relationships, intimacy and sexuality in later life and when ill-health occurs. Secondly, I review research that examines the impact on the home based partner during and after RCF placement, and partner views about the relationship after placement. As an outcome of the literature on partner reactions, I review the literature on grief and coping models. Following this, I review literature that examines the attitudes and beliefs of health professionals about sexuality and intimacy in later-life, and then examine the literature that explores the attitudes and beliefs of RCF staff about intimacy and sexuality for RCF residents and partners. I conclude by providing an overview of research on surveillance and autonomy within residential care where it relates to intimacy and sexuality.

The literature that examines how older couples conceptualise later-life relationships (either living together or separately because of RCF placement) are relatively few in number, tend to be at least ten years old and are situated in the sociological and allied health literature. Despite the length of time since publication, these studies remain highly relevant because of their focus on partner perspectives. These studies examine inter and intra-personal relationship/role

changes both before and after the partner or spouse moved into a RCF. Additionally, these studies also examine RCF practices and staff attitudes are addressed from the perspective of partners and families, which highlights examples of profession-based group behaviour and norms which are less evident in more recent studies. However, one of the limitations in these studies is that most examine couples where the RCF based partner has dementia and there are very few studies where the RCF-based partner has another health condition.

There are a considerable number of recent studies with a focus on the attitudes and perceptions of older people's sexuality by health professionals in community, primary health and from the RCF sector. These studies are found in the nursing and medical journals and have a focus on workforce education, development and RCF practice issues. These studies also explore which staff are most likely to have negative or adverse attitudes towards sexuality and intimacy concerns for patients or residents. The research explores a number of training approaches for staff, including awareness raising and specific information on sexuality issues for an older population. In comparison with the older literature, these studies do not address inter-personal factors for couples or the development and perpetuation of professional group norms to the same depth as the earlier studies.

Examining later - life relationships, intimacy and sexuality

The literature discusses the considerable changes in life expectancy and health in the decades following the Second World War for older men and women in the Western world (Gilleard & Higgs, 2007), and the impact on later life relationships. Older age is considered within the research as the years following retirement and further defined as a 'green' old age following retirement when people are more likely to be fit and active, and a 'frail' old age when the situation changes as health declines (Gilleard & Higgs, 2007; Laslett, 1989). Empirical evidence recognises that women live longer than men and have often married men who are older, but life expectancy for both men and women has increased (Ade-Ridder & Kaplan, 1993; Hudson & Gonyea, 2012; Laslett, 2000).

There is a consensus in the literature that relationships in later life undergo a significant amount of change and these changes often bring about an increased inter-dependence between the couple. It is further argued that a focus on communication and companionability means that the couple increasingly rely on each other socially, in part because external activities become harder to maintain with age and health changes (Ade-Ridder & Kaplan, 1993; Kahana & Young, 1990). Research findings also signal that this

effect is compounded because a similar pattern is also occurring in their friendships with same-age peers (Kelley, 1981).

Johnson (1985) describes that couples who have experienced much conflict in earlier stages of their relationship can find they are drawn together by the problems of ageing and ill-health, and concludes that when people are old, being in a long term relationship provides a significant benefit for which there are no adequate substitutes. This finding is balanced against the research evidence showing that marriage and intimate relationships are changed by ill health because it creates a burden of care which inevitably falls on the partner (Badr-Hoda, 2003; Barker, Pistrang, Shapiro, & Shaw, 1990; D'Ardenne, 2004). This burden becomes more critical when both partners are ageing and contending with changed health. Significantly, the research suggests that when one partner moves into residential care, the burden of care is altered but is not necessarily alleviated as partners still retain a sense of responsibility for care and experience guilt that they have no longer been able to provide it (Fengler & Goodrich, 1979; Pearlin, Mullan, Semple, & Skaff, 1990). This highlights the importance of considering the impact on the couple, rather than an individual problem with a person who happens to live with or separately from the partner. This will be explored later in the chapter.

Empirical evidence shows that sexuality and intimacy continues to have a part to play for older people as they reap the advantages of greater longevity, overall improved quality of health, and of increased access to education (Bouman et al., 2006; Starr & Weiner, 1982). The literature has suggested through several large scale studies that it is a stereotype to conclude that older people do not have a sexual component to their lives or have negative views towards it (Diokono, Brown, & Herzog, 1990; Marsiglia & Donnolly, 1991). Sexuality and intimacy are found to be linked to an individual's quality of life (Heath, 2011), and there are a number of studies have contributed to the understanding of this previously under-recognised aspect of older people's relationships (Bauer et al., 2007; Bouman et al., 2006; Gott, 2005; Gott & Hinchliff, 2003; Starr & Weiner, 1982). The literature cautions against drawing conclusions that homogenise older people and sexuality (Gott, 2005), as some older people (in a similar way to younger people) may choose not to be sexually active and people may re-prioritise other aspects of life. The evidence suggests that intimacy gains importance in the couple relationship and this is expressed through gestures such as close body contact and holding of hands. Sexuality has also been shown to encompass an individual's perspectives about inner sexual experience, rather than sexual behaviour (Gott & Hinchliff, 2003; Starr & Weiner, 1982). Maintaining outward

aspects of appearance (such as having one's hair styled or maintaining choices of clothes) has been concluded be an important aspect of sexuality for older women (Gott, 2005).

Later-life relationships are poorly understood by society in three important ways: Firstly, there is a notion within society that everyone must maintain a discreet silence about older people and sexuality, which effectively silences older people's experience. Secondly, there is a narrowness or tunnel vision, which sees sexuality in heterosexual, intercourse-focussed ways, when the breadth of sexuality includes intimacy and core sense of self (Bouman et al., 2006; Weeks, 1989). Thirdly, younger people carry a sense of distaste toward older people and sexuality, perceiving it as grotesque and incongruous (Hajjar & Kamal, 2004).

Attitudes within society may add to the difficulties for older people in seeking help for sexual concerns in later life. Empirical evidence suggests that older people are inhibited in asking for help for sexual concerns as they are likely to feel embarrassed, or to attribute the difficulties they experience to 'getting older' (Hinchliff & Gott, 2011). Gott (2006) concludes that this is gradually changing, but is likely to take time. This finding is supported by Farrell and Belza's (2012) quantitative study of RCF residents. Nearly half (47.1%) reported that they were comfortable to discuss sexual health with a health professional and were not embarrassed or offended. The understanding of later-life relationships creates a foundation from which to examine the impact of illness on couple relationships.

Examining relationship changes when illness arises

Much of the research relating to illness and sexuality has been carried out with couples coping with cancer and focuses on sexual function as well as sexuality more broadly. There is a smaller body of work that relates to couples with chronic illness. Whilst some of these studies include people under the age of 65, it has been argued that this does not detract from the findings as the changes that younger people experience replicate the changes that are experienced by older people (Weeks, 2002). Three qualitative studies carried out in Australia examine the impact of illness and sexuality with subsets of the same study group. Hawkins et al. (2009) examine the perceptions of partners of people with cancer. Three quarters (76%) of partners described an adverse impact in the relationship and that there are four main areas that change: an absence of desire for their partner, experiencing exhaustion associated with caring tasks, repositioning the person with cancer as being asexual and beliefs that it is unacceptable to be sexual in the context of cancer caring. The authors report that there were no differences

in the perceptions for partners across gender or cultural background. A further study (Hawkins et al., 2009), confirms the re-positioning of the relationship with cancer related illness, with the majority (59% to 79%) of partners reporting considerable changes to their relationship. Fewer than twenty percent (14% to 19%) of partners reported that they were able to renegotiate sexuality and intimacy in the relationship. Men were more likely than women to develop sexual alternatives after the cancer treatment, and importantly, cessation of sexual behaviour was associated with cessation of all physical or affection-based intimacy (Hawkins et al., 2009). The final study from this population (Gilbert, Ussher, & Perz, 2010) explores the issues raised in the previous study in more detail and describes the ways that sexuality and intimacy are renegotiated following cancer, and what assists or limits this process. Just over half (11 participants) stated that it was not possible to renegotiate other ways of being intimate when intercourse was no longer possible. Just under half (9) were able to renegotiate sexual intimacy to include practices that would have previously be seen as secondary to intercourse. Two factors assisted renegotiation: alternative sexual practices and the couple's communication and relationship context. Difficulties in renegotiation were linked to a difficulty in changing perspectives away from intercourse, communication difficulties which pre-date the cancer diagnosis, and repositioning the person with cancer as asexual or childlike. This group of studies provides useful data to clarify the factors that influence change possibilities for couples.

For older couples who have contended with ill health before a move to residential care, the evidence concludes that the process of re-positioning the relationship continues to occur during and after the move takes place. Gladstone's (1995) study of community-based spouses identified four key relationship changes because of dementia and a move to RCF. Nearly half of partners saw the marriage as a memory (48%) because their spouse was not able to be companionable or responsive to them. Twelve percent described their marriage as illusory, seeing themselves as being in the challenging position of not being either married or widowed. Fifteen percent of spouses perceived that they had a changed marriage, often describing this in parent-child terms, or as a very dear friend. However, a quarter of partners described their marriage as unchanged or continuing, either perceiving that nothing had changed, or that the current circumstances were another stage in their marriages and did not influence the feelings they had for their partner. Gott and Hinchliff (2003) draw similar conclusions, finding similar perceptions of a 'changed marriage' when older couples face ill-health.

If we contrast the literature relating to older couples facing health changes with couples facing with cancer, they differ in two aspects. Firstly, the literature suggests that there is no gender difference in the ways couples facing cancer re-position relationships, but there is some evidence in the literature for a gender difference in the way that older people re-configure relationships (Gilbert et al., 2010; Miller, 1987; Pruchno & Resch, 1989). The research concludes that women were more likely to see their relationships as changed (and therefore within the first three categories in Gladstone's (1995) definitions) and men were more likely to see the relationship as unchanged. Several researchers suggest this is because older men conceptualise caregiving for a partner as a workplace role or 'job' which allows the relationship to remain unchanged, whereas women are more likely to conceptualise care-giving in a similar way to childrearing which is more likely to create a re-positioning of the relationship (Boylstein & Hayes, 2012; O'Rourke & Wenaus, 1998). The second difference between couples facing cancer and older couples facing illness was the absence of evidence in the studies of later-life relationships to suggest that the cessation of sexual intimacy also signalled the end of any affection or intimacy between partners. This seems important as it challenges the assertion that the experience of younger couples facing illness are the same as older couples (Weeks, 2002). Drawing on the literature, it can be concluded that older couples have had to navigate gradual changes in sexual practice and to replace this with a focus on intimacy through the ageing process (Gott & Hinchliff, 2003; Starr & Weiner, 1982). Younger couples facing cancer-related illness may be contending with sudden changes at a time that is out of context for their life stage, leaving them less prepared to manage this situation.

The palliative care literature around sexuality and intimacy is consistent with the literature on later-life relationships. As RCFs have an increasing role to play in palliative care for older New Zealanders (Naylor, 2013) this finding is relevant. Several studies suggest that people who have serious health conditions still consider sexuality and intimacy to be very important even if they are in the last weeks or days of life. The empirical evidence from these studies has a similar broad perspective on sexuality, intimacy and emotional connection with partners (Cort, Monroe, & Oliviere, 2004; Gilbert, Ussher, & Hawkins, 2009; Gilbert et al., 2010; Hawkins et al., 2009; Horden & Street, 2007; Lemieux, Kaiser, Pereira, & Meadows, 2004; Vitrano, Catania, & Mercadante, 2011). An additional finding is that health professionals misunderstand sexuality and intimacy in these broad terms, perceiving this in functional or intercourse terms only. This will be explored in more detail in the next section of the chapter. The finding runs contrary to the dominant belief within society (and within the minds of many health and care staff) that older people lose interest

in sexuality, because of their age and changes in health status (Gott & Hinchliff, 2003). Furthermore, there is also the belief that once a person is faced with a life threatening illness, their focus will be directed at fighting the disease and they will lose interest in intimacy altogether (Horden & Street, 2007; Little, Jordens, Paul, & Sayers, 2001).

There is evidence in the literature which concludes that grief and loss feature strongly in these relationship changes. Changing health creates a sense of loss and the couple can be expected to experience emotions comparable with bereavement (D'Ardenne, 2004). The experience of loss can be experienced in many ways, including anger and resentment and this can be a considerable source of stress for both parties in a relationship (Revenson & Majerovitz, 1991). The 'ill' partner experiences anger as they contend with loss of function and illness symptoms and the 'well' partner experiences anger and resentment as their life is curtailed by carer expectations as well as contending with their own health needs. The research suggests that carer anger is not related to an objective amount of work that they carry out but is instead related to quality of life, social supports and loneliness, leaving them with a similar risk for psychological distress as the identified patient (Coyne & Downey, 1991). Overall, the research findings confirm that grief is unlikely to be due to a single cause for older people, as there may be many factors that the person may be contending with at the same time, such as loss of independence, loss of life roles, ill-health and disability (O'Bryant & Hansson, 1995).

When we consider the literature collectively, the evidence suggests that older people describe clear changes in their relationships in later life and with ill-health. These changes both draw the couple together and create stress in the situation. If the couple are separated by the requirement for residential care, this alleviates some of the care tasks but further alters the relationship. The recognition of loss seems fundamental when we consider the changes to relationships in later-life through ageing and other health changes.

The impact on the home-based partner when the spouse moves into a RCF

There is a paucity in the literature on the impact on marriages and long term relationships when one person moves into a care facility, because the assumption is made that one of the reasons that people move into a RCF is because they live on their own, either because they are single or widowed (Ade-Ridder & Kaplan, 1993). This assumption is described by Shanas (1979) as the 'principle of substitution': husbands are looked after by their wives, and when wives are widowed (as they tend to have longer life expectancy), they are cared for by their adult children until they require residential care. There are a small number of studies that examine the situation for the home-based partner (often through a case study design) which

allows the issues to be examined in depth. These studies reveal the complexity of the situations that partners find themselves in, concluding that the home-based partner is now faced with redefining their role once their partner has been placed in residential care. Schmidt's (1987) ten-year study finds that tensions and misunderstandings arise with RCF staff when the resident's partner attempts to maintain an unchanged role in changed circumstances, even though the research suggests that the spouse's new role is unclear (Schwartz & Vogel, 1990). This may offer an explanation for the contradictory findings in the literature about whether RCF placement reduces stress for partners. Some studies conclude that is does not (Fengler & Goodrich, 1979; Pearlin et al., 1990), because home-based partners still have to navigate a continued but changed role. Other evidence suggests that partners can feel relieved as the main burden of caring is diminished (Yaffe et al., 2002). The changing role of the partner includes maintaining specific care tasks and acting as a case-manager and advocate for their partner (Ade-Ridder & Kaplan, 1993; Brubaker, 1985; Kaplan & Ade-Ridder, 1991; Schmidt, 1987). The role of advocate is of interest and may be in the realm of 'contested territory' within the literature and in practice. Nursing as a profession (both historically and contemporarily) often describe themselves as holding an advocacy role with patients and residents (New Zealand Nurses Organisation, 2012).It is possible that RCF nursing staff could find advocacy from a family member challenging. Buckwalter and Hall (1987) conclude that assuming an advocacy role whilst also being a direct provider of care is a complicated scenario and could be seen as a sense of ownership of the resident.

When we examine the literature across this process of ageing, deteriorating health and a move to residential care, the experience of grief is a constant motif (D'Ardenne, 2004; O'Bryant & Hanson, 1995; Revenson & Majerovitz, 1991). The home-based partner has to renegotiate life roles, grieve the changed relationship and picture the losses that lie ahead (Ade-Ridder & Kaplan, 1993; Rollins, Waterman, & Esmay, 1985). Ade-Ridder and Kaplan (1993) describe this by stating "whilst the spouse in the nursing home clings to family members, the family (especially the community-dwelling spouse) may be involved in grieving, adjusting to the separation, and facing the challenges of life after nursing home placement" (p. 19). The concept of 'married widowhood' is used in several studies to describe this experience of grief without the clear, delineated demarcation that death brings (Rollins et al., 1985; Sommers & Shields, 1987). The research acknowledges anger and frustration as part of the experience of grief, and whilst feelings of sadness are readily accommodated by RCF staff, feelings of anger are not (Schmidt, 1987). Further studies conclude that if partners express these feelings towards staff, they can become marginalised or be avoided (D'Ardenne, 2004; Schmidt, 1987).

The literature which examines the perceptions of home based partners recognise the experience of grief, but does not examine it in depth. Therefore, the research which specifically examines grief and coping was considered. The literature is extensive and covers stress and trauma models (Horowitz, 1986; Lazarus & Folkman, 1984; Pennebaker, 1995), general theories of grief (Bowlby, 1980; Freud, 1917/1957; Parkes, 1996), as well as models of bereavement-related coping (Bonnano, Wortman, & Nesse, 2004; Worden, 1982/1991). Stroebe and Stroebe (1987) define grief as "the emotional (affective) reaction to loss, which includes a number of psychological and somatic reactions" (p. 7). Most definitions see grief as a 'private emotional experience with a predictable symptomatology' (Fowlkes, 1990, p. 636). Whilst it is acknowledged that grief is experienced in situations other than death, there has been less attention paid to this in the literature. The Dual Process Model (DPM) developed by Stroebe and Schut (1999) integrates the empirical findings of previous models and therefore appears most relevant for this study, as the researchers acknowledge life events asides from death which create grief (Stroebe & Schut, 2010). The DPM posits that people who are grieving have two broad stressors to contend with: firstly a loss orientation where the person is aware of the losses they have faced, continue to face and will likely face in the future. There is also an opposing restoration orientation which forces attention to the consequences of loss and change and addressing these in a practical way. The model envisages this as a set of balance scales where it is necessary to (in turn) place oneself in either position or the other in order to cope (Stroebe & Schut, 1999). A key conclusion of the model is the finding that people oscillate between each side of the scale, and also have times that they move away from the process all together, therefore having times away from coping with grief. Whilst the DPM is not referenced in the literature in association to the experience of partners, there appears to be an alignment. Empirical evidence acknowledges the dual dilemma home-based partners face in mourning the loss of the partner relationship in its prior form, as well as the need to find a new way to configure the relationship and manage with living alone (Ade-Ridder & Kaplan, 1993; Kaplan & Ade-Ridder, 1991; Schmidt, 1987).

Similarly, it is relevant to examine the scientific research about ways that home-based partners cope with this situation. Studies show that caregivers vary in their abilities to cope as they need to employ a broad range of resources (ranging from ways to manage feelings, solve problems practically and maintain resilience) in order to cope over a long period (Gottlieb & Wolfe, 2002). Most studies utilise the Stress and Coping Model (SCM) developed by Lazarus & Folkman (1984), or the SCM integrated into the Dementia Caregiver framework developed by Pearlin, Mullan, Semple, and Skaff in 1990 (Baker, Robertson, & Connelly, 2010; McGonaghy & Caltabiano, 2005; O'Rourke & Wenaus, 1998). As it was envisaged that this

study would recruit participants from couples who were coping with dementia and other conditions, focussing on the Stress and Coping model (Lazarus & Folkman, 1984) seemed most appropriate. The model identifies stress as being comprised of four interconnected factors: the context in which care is provided, primary stressors (which result from the diagnosis or health condition), secondary stressors (which result from the demands of a carer role) and potential mediators. Potential mediators are considered in three aspects of coping: managing the situation, managing the symptoms, and managing meaning – which can result in changed expectations, being able to make positive comparisons to the situation and finding a 'bigger sense' or meaning to the experience. The research which examines caregiver burden (Macleod, Skinner, & Low, 2012; Van den Hoonaard, 2010) ties in to the SCM by identifying the supports that carers find useful. This research concludes that individuals require instrumental support (such as home care), emotional support (e.g. a supportive person to talk to) and informational support (e.g. educational resources).

RCF culture, and couple perspectives towards intimacy and sexuality

Before examining relationship aspects within RCFs, it is important to examine the literature which explores the culture within facilities. Tolson, Dewar, and Jackson (2014) state that the central tenet behind international RCF development is to deliver compassionate, evidence-based care which optimises a resident's quality of life (QoL) including care at the end of life. Whilst few people would argue against this aim, the Royal College of Nursing (2012) has called for a more nuanced examination of what this means in practice, suggesting that the ways that quality of care is considered and measured are flawed. There is also growing evidence in the literature to suggest a gap between the care that residents receive and things that would make their lives better, partly because staff and residents may value different aspects of care (Abrahamson et al., 2012; Kim, Park, & Kim, 2014). The empirical evidence suggests that the nature of relationships between care givers and care receivers (and their families) in RCFs are crucial in shaping and defining resident-centred care (Owens & Meyer, 2012; Wilson, Davis, & Nolan, 2009). The reasons for promoting resident-centred care is to encourage residents' rights and perspectives, and enhance their ability to make decisions in all areas of life, including their sexual life (Brooker, 2004; Kitwood, 1997). Resident-centred care requires effective relationships and communication between staff, residents and families. Tzeng, Lion, Shyr, and Wen (2009) found that resident-centred care can also be challenged by the residents' adult children with the finding that if the resident and their children have different views, family wishes can become paramount (even if these contradict the resident's wishes). Furthermore, this study found that it was common practice for staff to keep

residents' families informed of all aspects of a resident's life, even without the resident's consent (Tzeng et al., 2009). This evidence is particularly significant when sexuality and intimacy are concerned, as resident's families can present an additional barrier. The literature concludes that it is difficult for many adult children to accept sexual or intimacy needs of their parents or see them as sexual beings. Therefore adult children and other family members may be inclined to say no to sexuality and intimacy wishes, especially with new relationships for widowed residents (Gilmer, Meyer, Davidson, & Koziol-McLain, 2010).

Schmidt (1987) utilises Goffman's model of Institutional Totality (1961) to explore the culture and practices of RCFs, where care needs are determined by staff and applied to a resident group rather than for individuals. Goffman's (1961) model differentiates between benign totality (which exists in RCFs, children's homes and boarding schools) and punitive totality (which exists in penal systems), but the surveillance over the lives of residents remains. A defining characteristic of a total institution is that a group of people reside, eat, work and socialise in the same place and are under a formal administrative system. The administrative system defines routines for the institution, determining when and how people within the facility carry out their daily lives. Whilst RCFs have undoubtedly changed since this model was developed in 1961, many of these defining characteristics can still be seen to apply today. RCF residents spend most of their lives in one building and will reside, receive care, eat, socialise and sleep within that environment. Current audit and quality structures reflect a focus that remains on the physical environment, efficiency, safety and routine care tasks rather than examining quality of life or individualised care (Kaplan & Ade-Ridder, 1991; Schmidt, 1987; Tolson et al., 2011; Tolson et al., 2013; Tolson et al., 2014). The literature suggests that one way that this becomes apparent is when home-based partners communicate their knowledge of individual residents care needs, and this is perceived by care staff as a criticism of care (Hennon, Brubaker, & Kaplan 1991; Kaplan & Ade-Ridder, 1991; Schmidt, 1987). This suggests that implicit attitudes can also influence staff/partner relationships, particularly staff assumptions that home-based partners have 'not coped' with care requirements when their spouse moves to a RCF. These assumptions may disempower partners and lead to a situation where their suggestions towards care are minimised (Schmidt, 1987).

The culture within RCFs is important to consider as it shapes the ways that resident and partner sexuality and intimacy is recognised and responded to. There are a considerable number of studies that examine sexuality and intimacy issues for RCF residents but most examine relationships that develop between residents, rather than within long-standing partner

relationships. Most studies also address relationship issues for residents who have dementia rather than conditions where there is no cognitive decline. The studies which examine the situation from a partner perspective (Gibson, Bol, Woodbury, Beaton, & Janke, 1999; Høgsnes, Melin-Johansson, Norbergh, & Danielson, 2014; Kaplan, 1996), conclude that the loss of a shared life together for couples is very significant. Other findings identify the loss of a shared identity and a loss of shared life roles, such as companion, life-partner and their 'other half' (Moss et al., 2001). Other evidence confirms the enormity of the home-based partner's loneliness, which is again attributed to the loss of a shared intimate life together (Lopata, 1996). The literature concludes that visiting partners and assisting with care tasks is a way for the home-based partner to maintain aspects of a shared life. The literature that examines later life relationships is utilised in these studies, recognising that intimacy between couples in long term relationships may be less reliant on sexual acts and more focussed on touch and emotional connection (Shaw, 1997; Weeks, 2002). All of the studies, therefore, describe intimacy in relational terms rather than through the presence or absence of physical acts. There is an acknowledgement that the RCF residents have unrecognised sexual needs within a RCF and become members of a forgotten neglected population; perceived as sexless (Chandler et al., 2004; Hajjar & Kamel, 2004; Kaplan, 1996; Reingold & Burros, 2004). There are descriptions in the literature where spouses of a resident continue to experience intimacy with their partner, even when the resident has dementia. This research finding confirms the continued importance of the relationship for home-based partners and affords an opportunity to see the person which remains behind the disease (Høgsnes, Melin-Johansson, Norbergh, & Danielson, 2014). The authors quote the following excerpt from one participant:

> 'it's strange – even when we're sitting in the living room [at the RCF] talking and joking, and I get an impulse to kiss him on the cheek… then he shows his mouth, it's like he's thinking we…. it's like that kind of contact is there' (p. 157).

Most studies conclude that RCFs are geared to institutional efficiency rather than the specific needs of residents. This echoes Schmidt's (1987) earlier work citing Goffman's (1961) model of institutional totality (Chandler et al., 2004; Hajjar & Kamel, 2004; Kaplan, 1996; Mahieu, Van Elssen, & Gastmans, 2011; Roach, 2004). The literature draws attention to the processes of change for home-based partners (Gibson et al., 1999; Høgsnes et al., 2014; Kaplan, 1996). Kaplan (1996) describes is an adjustment process, which necessitates the acceptance of grief and loss more generally in the relationship. This study also draws on the author's prior (co-authored) work which demonstrates the complexity of this issue (Kaplan & Ade-Ridder, 1991). Their finding is that even if RCFs work hard to support couples in their intimacy and sexuality needs, the couple may still not take advantage of this. This research highlights a

gender difference with the authors stating that if the home-based partners were women, they rarely took this up. The authors postulate that wives may take on a parental role with their RCF-based husbands rather than vice versa. This confirms and links to earlier discussion in this review. Relationships are re-shaped with illness and gender differences exist in how men and women reshape relationships (Gilbert et al., 2010; Gladstone, 1995; Gott & Hinchliff, 2003; Miller, 1987; Pruchno & Resch, 1989). Kaplan (1996) suggests that staff may have a role to support couples by communicating that sexuality needs may change and can be substituted by emotional focused intimacy such as holding hands or touch.

It is important to understand some of the underlying assumptions that are part of the discussion about intimacy and sexuality relating to RCFs. Gibson et al. (1999) articulate some of the underlying assumptions made in the literature by stating:

> An underlying assumption of this literature is that more open, accepting and uncensored attitudes toward sexuality will enhance quality of life for elderly individuals, especially those who reside in institutions. This assumption reflects at least in part, cohort-specific cultural values. Attitudes toward sexual expression and recognition of sexual 'rights' have become increasingly liberalised in the past century. (p. 31)

It is timely to repeat that the literature cautions against drawing conclusions that generalise older people and sexuality as people in RCFs may choose different ways to consider sexuality in their lives, or not to consider it at all (Gott, 2005). It also cannot be assumed that the resident population of RCFs are more tolerant of sexuality and intimacy than staff are. Several studies showed that residents and their spouses were less tolerant than staff about any enactment of sexual behaviour (Gilmer et al., 2010). Staff have also been shown to differ in their views, depending on the professional group they belonged to. Several studies point to differences between professional staff groups, with senior staff (regardless of professional background) and nursing staff having the most permissive views, followed by allied health staff. Caregivers are considered the most restrictive in their views when compared with other groups, and it is suggested that this is due to access to education and training (Gibson et al., 1999; Gilmer et al., 2010; Horden & Currow, 2003).

It is important to identify what the circumstances would be where sexuality and intimacy could be seen as appropriate within a RCF. Gibson et al.'s (1999) study identifies that residents, resident's spouses and care staff all share the same view that people need to have a private environment. Residents and their spouses were less tolerant of solo sexual behaviour, such as masturbation or use of sexual materials but the study did not investigate differences of opinion within couples. When considering 'inappropriate sexual behaviour' such as a resident

who is cognitively compromised making sexual approaches to staff, other residents were the least tolerant of this behaviour. The authors suggest that this may be because they have to live in the environment all of the time, rather than staff or spouses who can come and go. This study focused on a male (96%) War Veteran population, which weakens the ability to generalise the results as the authors suggest that participants may be less tolerant of breaches of decorum. Most RCFs designed for a more general elderly population tend to be populated by a high number of women. Statistics in the USA would place 76% of RCF residents as women (Naylor, 2013). It is of interest then that many of the studies based in RCF focus on the sexuality of male residents. This leads Miles and Parker (1999) to posit that there might be a double taboo of older women and sexuality to explain this phenomenon.

A review of the literature (Bauer et al., 2007) establishes that there are similar findings across different sectors of health care. Patients and residents in rehabilitation settings have similar experiences to people in RCFs (Ali, 2004). In a similar manner, the review confirms that sexuality in these settings was not seen in a positive or beneficial light (Archibald, 2003) and that staff and families frequently shared the same view that sexuality was an activity to be curtailed and controlled (Hajjar & Kamel, 2004). There is also an acknowledgment in the literature that building and facility design adds to the difficulties of providing privacy and opportunity for intimacy (Edwards, 2003; Hubbard, Tester, & Downs, 2003), further compounding the attitudinal barriers that exist.

Healthcare staff attitudes towards later life sexuality, and sexuality and intimacy in RCFs

The literature describes a tendency of health professionals to focus on functional sexuality issues such as fertility, libido, erectile function or menopause rather than on intimacy focussed sexuality. This focus is then assumed by staff to be the perspective of patients/residents and their partners (Nay & Gorman, 1999; Tarzia et al., 2012). There is increasing recognition by health professionals that sexuality and intimacy needs for residents are important (Jones, 1994), but there is little evidence to suggest that a liberalising of attitudes amongst staff has translated into permissive communication, policies or behaviour amongst staff (Bauer et al., 2007; Gott, 2006). There is a lack of research aimed at how the culture of residential care (and other care settings) needs to change in order that residents' intimacy focussed sexuality needs are considered routinely and are included as a standard consideration of care.

At least 11 articles over the last 10 years have focussed on staff attitudes and behaviour towards the sexuality needs of residents within RCFs. A further 12 articles were found that

compared the views of residents and the views of staff. RCF staff attitudes have been shown through repeated studies (Eddy, 1986, Hajjar & Kamel, 2004, Luketich, 1991; Roach, 2004), to be primarily negative towards older people's sexuality, and are therefore barriers to resident sexual expression. Moreover, sexuality and intimacy needs are often a component of care plans, but the literature suggests that this is an area that care staff find hard to consider. Tarzia, Fetherstonhaugh, and Bauer (2012) state that:

> Existing literature strongly indicates that RCFs do not tend to be environments that are conducive to or supportive of the freedom of sexual expression. Furthermore sexuality tends to be ignored or poorly addressed by RCFs in terms of their policies and institutional frameworks (p. 609).

Whilst this quote relates to residents with dementia, it could be argued that this view encompasses all intimate relationships for residents, regardless of diagnosis. The literature repeatedly reinforces that society in general is uneasy about the notion of older people and sexuality (as previously discussed in this review), so staff who work in care facilities are unlikely to be exempt from this societal discomfort, or youth orientated perspective. As previously stated, this may make the sexuality and intimacy needs of residents either invisible, ignored or considered distasteful (Hajjar & Kamel, 2004; Heath, 2011).

The literature has a strong focus on staff concerns when considering sexuality for residents with dementia (Frankowski & Clark, 2009; Roach, 2004; Tarzia et al., 2012). The central concept contrasts the right of a person with dementia to express their sexuality, against whether the person has the cognitive capacity to give or withhold consent for sexual contact with another person. Tarzia et al. (2012) sums this up by stating that staff 'have apprehensions about the abrogation of their duty of care and concerns about unlawful activity, anxiety about potential risks to the resident and fear of negative repercussions from a resident's family' (p. 609). Unfortunately, the research finds that the legislation around mental capacity and decision making does not assist staff, as it focusses on legal, financial and medical decisions (rather than sexual decisions), or the worst case scenario of unlawful sexual contact with a person with diminished mental capacity (Heath, 2011). This contrasts with the ethical and legal premise that mental capacity should be assumed unless proven otherwise (Miles & Parker, 1999). The literature posits that staff are likely to respond conservatively as they hold responsibility for care and may feel disinclined to encourage sexuality, intimacy (or indeed privacy) in case they are held to account or criticised for a lack of oversight (Mollica, Sims-Kastelein, & O'Keefe, 2007). A contrary finding suggests that a single approach to sexuality and dementia is not appropriate as dementia is an illness which exists along a continuum from mild to severe impairment (Tarzia et al., 2012). The literature also finds that a high number of

people with dementia (from mild to severe) recognise their spouses or partners. The researchers conclude that dementia does not stop people from making and continuously assessing choices around intimacy and sexuality and that these choices are reliable, especially with long standing partners (Carpenter, Kissel, & Lee, 2007).

Empirical evidence shows that RCF staff find aspects of intimacy and sexuality difficult to consider either personally or as a practitioner, and also difficult to discuss with residents and colleagues (Horden & Currow, 2003; Reynolds & Magnan, 2005). This is compounded by the finding that very few RCFs have policies and procedures for assessing sexuality and intimacy needs (Bauer et al., 2007; Shuttleworth, Russell, Weerakoon, & Dune, 2010; Tarzia et al., 2012).

The concept of privacy is repeatedly discussed in the literature. There are two perspectives that are presented. Firstly, the need to provide oversight for residents and therefore, inhibit privacy, and secondly, the need to provide privacy because this seems to be a key feature in the acceptability of sexuality expression for staff, residents and partners alike (Gibson et al., 1999; R. Morgan, 2009). One study examines the views of residents who do not have dementia, and staff within a RCF. This qualitative study interviewed 110 staff and residents, in roughly equal numbers to ascertain the views of both groups. Most of the staff participants were women (which compares to staffing in New Zealand), and unusually for studies in this field, the participants were randomly selected (with the ability to refuse to participate), and were evenly balanced between male and female residents. The main barriers that participants identified were lack of physical privacy such as private lockable space (which is recognised elsewhere in the literature by Morgan (2009)) and relational privacy. Participants identified that the gossip that can occur in facilities (either between staff or residents) was a significant barrier to their privacy. The authors conclude that residents are subject to an informal surveillance network, quoting one participant as saying:

> Every new thing becomes a public affair and sexuality also becomes public. There are no secrets and sex needs secrecy, so people hold themselves back, because nobody likes to be the subject of gossip (p. 5.)

 In addition, they reported on the residents' experience of carer/staff reporting, either in written format (in care logs or case notes) or verbal reports to families. This practice of reporting back to families has been noted with concern elsewhere in the literature (Gilmer et al., 2010; Tzeng et al., 2009). Residents also disliked the 'symbolic' knock as the door is opened to a resident's room, concluding that this did not provide privacy (Villar, Celdrán, Fabà, & Serrat, 2014). This is noted elsewhere in the literature where it is concluded that most

RCF environments run counter to the cultural prescription that sex is a private act that occurs between consenting adults. They state that almost nothing in RCFs is private or seen as consensual (Frankowski & Clark, 2009).

Many studies find that sexual behaviours are relatively infrequent in RCFs (Spector & Femeth, 1996; Villar et al., 2014; Walz, 2002) and this is likely to be for reasons outlined previously. Relationships are re-shaped and sexuality is shaped by intimacy rather than sexual behaviour (Kaplan & Ade-Ridder, 1991). However, for the couples that do wish to continue to be sexual, Villar, Celdrán, Fabà, and Serrat (2014) conclude that 'for many residents, maintaining sexual interests and expressing them in a RCF may be simply out of the question' (p. 6).

Summary

When we consider the literature that examines the experience of later-life couples who are contending with health changes, the evidence suggests that older people describe clear changes in their relationships in later life and with ill-health. These changes both draw the couple together and create a stressful situation. If the couple are separated by the requirement for residential care, this alleviates some of the care tasks but further alters the relationship. A developing theme in the literature highlights the differing experiences of the person who is a resident, to the experience of their home-based partner. For partners, there is the need to grieve the relationship as it was, and life as it was, to acknowledge that the move to residential care can represent the position of 'widowhood or widower hood' without experiencing the finality of a death. For some partners, there is a process of repositioning that occurs in the way they see their partner. In addition, the community-based spouse is adjusting to life on their own, and having to develop effective relationships with RCF staff at a time of emotional change.

Several studies suggest that health professionals may under-estimate the importance of these concerns. RCF staff may misunderstand the intimacy and sexuality needs of residents, seeing them as function focussed and therefore focussed on the ability to maintain intercourse. Many studies identify training needs for health professionals in raising awareness, developing reflexive practice and learning specific communication skills to talk about sexuality issues. However, it is pertinent to ask whether these programmes are delivering the desired change as continued studies over the last two decades have failed to identify much in the way of organisational change or shifts in practice. It is of particular note that some of the earlier studies carried out in the 1980s describe some of the broader misunderstandings that can

occur between staff and partners of residents, and the impact of this on relationships and communication. Whilst the more recent literature discusses the adjustment process for couples that occurs with a move to RCFs, and the need for staff to understand this, it is not represented either as comprehensively, or with a theoretical underpinning to explain it, in the same way as these earlier studies. This seems crucial or otherwise the behaviour and reactions of partners (and the reactions that staff might experience in response) do not consider the assumptions and communication processes at play. The combined evidence from the older studies and more recent work is needed in order to consider this complex and elusive issue.

The literature review reveals the possible sexuality and intimacy concerns that couples may experience, suggesting that a focus on intimacy and connectedness is appropriate. It describes how the focus may be different for the home-based partner and RCF based partner because they are contending with different issues. The importance of sexuality and intimacy as a component of an individual and a couple's quality of life is confirmed within the literature. The next three chapters take up this discussion from the point of view of the participants in the study, and utilise the theories that have been outlined in this chapter. These three chapters examine firstly, the experience of grief and loss, secondly, coping with practical aspects of life and lastly, examining privacy and surveillance within RCFs.

CHAPTER THREE
METHODOLOGY AND METHODS

Introduction

The main objective of my research was to gain insight into intimacy and sexuality concerns for couples when they are separated by a move (by one in the relationship) into a RCF. I wanted to understand the views of the partners who remain at home as there seemed to be a scarcity of information from their perspective. It also seemed important to establish the views of staff who work in these facilities because the literature suggested that their perspectives may differ to residents or their partners. I wanted to see what the differences were in more detail and also to see what commonalities existed between their perceptions. Ultimately I hoped that the insights gleaned from both of these groups might assist residential staff and possibly the community more broadly, to better understand the experience of couples in this position.

Methodological Approach

It was clear that there would be many stories rather than a single perspective or 'true story' to tell, so my aim was to critically examine the topic using qualitative methods. It made sense to use a qualitative approach because it asks participants to explain their thinking and behaviour (Pope   & Mays, 2000), throwing light on to their 'lived experience' (Morse & Field, 1995; Seymour & Clark, 1998). This seemed important for both partner and staff participants because this topic relates to an individual's personal views, attitudes and experience. The data was collected through a series of individual stories from partners and the shared story of several groups of staff, with a broader aim to highlight and examine some of the underlying beliefs of partners and RCF workers about intimacy and sexuality. It was important to carry out a thorough analysis and comparison of the various accounts and my hope was that this analysis would add to or develop a greater understanding of the issues.

Partners are potentially in an isolated position, and therefore, they may not perceive that others appreciate the situation they find themselves in. The participants were older people, and some needed to place their partner into residential care because of their own health needs. They talked about their own relationships, rather than making observations about other people's relationships. Staff participants were in a less vulnerable position, but still had to be

open to voicing their own views, which could differ to their colleagues or the policies of their employing organisation.

An important aspect of qualitative research lies in the acknowledgment and examination of the role of the researcher. Adopting a reflexive position means taking into account how the analysis of the data will be impacted by the researcher's own background and life experiences (Rice & Ezzy, 1999, p. 25). It is crucial that the researcher considers their ontological and epistemological position when they are collecting and analysing data. Davidson and Tolich (2003, p. 25) describe this as being central to all social research: "These ontological and epistemological questions cannot be answered 'scientifically' or with 'evidence' because they are precisely about what it means to be scientific and what is allowed to be classed as evidence."

Further to this, they quote Hughes (1990) in stating: "… research tools operate only within a given set of assumptions about the nature of society, the nature of human beings, and the relationships between the two and how they may be known" (p. 25).

Green and Thorogood (2009, p. 18) describe a continuum that ranges from positivism at one end - seeing reality as being more scientifically orientated and externally measureable, through to constructivism and interpretative approaches at the opposite end, which recognise that an individual formulates their own view and perspective. The task for the researcher is to consider where they might place themselves on this spectrum. When I was at the start of this project, my knowledge of this topic was from my experience of working as a psychotherapist in palliative care and previously in cancer care and in hearing the concerns of couples who were considering the need for residential care and navigating changes in their relationship. I had worked in an inpatient and outpatient cancer service and in a hospice, and felt that my psychotherapeutic background would encourage me towards an interpretive approach (Neuman, 1997). I had not worked in a residential care facility and I thought it was an advantage as I would not be carrying out the research with pre-conceived assumptions developed through work experience. Adopting an interpretive approach was further clarified to a phenomenological position, finally arriving at a hermeneutic phenomenological position. There are a number of methodological approaches in qualitative research, and phenomenology is one of the mostly commonly used in health research (Holloway & Wheeler, 2010). The word phenomenology comes from two Greek words: *phaenesthai*, which means appearance, and *logos* which means knowledge (Holloway & Wheeler, 2010: Liamputtong, 2009). It is principally a philosophical approach, and focuses on the theory of knowledge, how we have a sense of knowing and how we experience things as individuals

(Liamputtong, 2009). There is a focus on personal knowledge and experience – the lived experience - rather than experience gleaned from others. (Patton, 2002). The philosophical underpinnings to phenomenology are drawn from the work of Edmund Husserl (1859-1938), a German philosopher who wrote about consciousness, and how we, as humans, experience consciousness in our lives. Husserl introduced the concept of life-world (*lebensweld*) or the lived experience and this has shaped twentieth century phenomenology as we understand it. Phenomenology has been further developed and can be considered as falling into three major groups: descriptive phenomenology; hermeneutic phenomenology and existentialist phenomenology. Hermeneutic phenomenology draws on the work of Martin Heidegger (1889-1976) who was a pupil of Husserl. He further developed his thoughts and writings to move from descriptions to interpretations of human experience. The word hermeneutics comes from the Greek mythological god Hermes, who acted as a messenger/translator between the mortal and divine world, and Hermeneutics is the theory of the interpretation of meaning (Holloway & Wheeler, 2010; O'Brien, 2003).

When hermeneutics is linked with phenomenology, Koch (1995) states:

> Heidegger (1962) declares nothing can be encountered without reference to the person's background, and every encounter entails an interpretation based on the person's background, in its 'historicality'. The framework of interpretation that we use is fore conception in which we grasp something in advance (p. 831).

Koch's statement encapsulates the core principles in hermeneutic phenomenology - the notion that individuals make sense of (interpret) and reflect on their experiences in life, and these experiences are holistic (Bailey, 1997; O'Brien, 2003). Seymour and Clark (1998) also posit that it is a particularly suitable methodology to highlight taken-for-granted assumptions that exist in health-care settings. This combination of a holistic approach and the possibility of examining assumptions seemed important when considering the topic area and the characteristics of both partners and staff in this study.

The understanding that I brought to the project also relates to my own life experience, having lived with the changes in a partner relationship that serious and life-limiting health concerns create, albeit many years ago, and at a younger stage of life. I also have had several close family members navigate a couple relationship where one partner had been living in a RCF. It seemed important to me to acknowledge this, in order to be able to clearly identify my experience and then to concentrate on both what the interviewee was saying and how they said it. As part of a process of reflexivity, the research practices and views of the researcher require critical analysis in the same manner as the topic area (Green & Thorogood, 2009, p.

23). It was important to identify any underlying or taken-for granted assumptions I had about the research topic (Green & Thorogood, 2009, p. 24). My assumption was that individual participants would hold a range of opinions ranging from sexuality and intimacy being an important aspect of their relationship, through to it being irrelevant. I imagined that it might be difficult for people to discuss openly, partly because this is a difficult topic to 'put into words' and partly because I thought people may say what they thought was an acceptable answer. I expected that staff would have a range of opinions and views about resident intimacy and sexuality needs and I was curious whether social and peer norms would have a part to play too. I speculated that it might be difficult for staff to express misgivings, or reservations in case this was seen as unacceptable by their peers, or conversely, if they were permissive about sexuality and intimacy needs within the facility, whether this might feel risky and be considered unacceptable too. I was interested in whether power relationships between carers and registered staff would impact on the focus groups and possibly 'silence' junior or unregistered staff. I wondered what perceptions staff would have about me asking questions about this topic area when I was not from either a nursing or carer background, but from a less familiar professional background.

I was also interested in how the participants in the study would view me, a stranger to them, asking about a very personal and sensitive topic. It was important to establish rapport and trust both in the individual interviews and in focus groups, and that I would need to communicate my willingness to listen to their view, without assumptions of a right or wrong answer. Interviewees in qualitative research are active participants, and naturally evaluate and consider the interviewer in terms of social and cultural characteristics, such as age, gender, ethnicity, class and education (Green & Thorogood, 2009, p. 109). I have an accent that identifies my country and region of origin so was likely to be seen as a foreigner, and wondered whether any or all of these factors could either be inhibiting or conversely, helpful. For the partner interviews, I was aware that I might be the approximate age of some of the participant's adult children, and that male participants would experience a cross –gender conversation. I was very clear that the relationship was not part of a clinical or therapeutic encounter (Koenig, Back, & Crawley, 2003), and was mindful of Kovach's (2005) warning that a failure to recognise the nature of the relationship between researcher and interviewee could result in an undue influence on responses or interpretations. I decided upon a brief 'preamble' before an interview with the intention to create mutuality and connection. I told participants that I was not employed in a residential care facility and therefore was not aligned to any provider, but that I was from a health professional background. I also acknowledged that several of my family members had been cared for in RCFs in other parts of New Zealand

and overseas. Where the interviews were carried out in Southland, I said that I had lived in Southland in the past, but this seemed less necessary to say before the Otago-based interviews because of my University of Otago student status. When facilitating the staff discussions, I repeated this preamble to set the scene and also added in a sentence or two about my background and training in sexuality related concerns.

Green and Thorogood (2009) identify that the interview provides access to what the person has said rather than what they do or think or feel (p. 106). I expected that people would be relatively guarded because of the sensitive nature of the topic and that they might speak generally rather than specifically. Three potential participants declined to be interviewed after initially agreeing, because of the personal nature of the topic. I was interested in not only what people said but also what they did not say, and in their non-verbal communication. I noticed that most individual participants were very open about the emotional experience of their situation and their acknowledgement and expression of grief, loss and loneliness. Despite asking no direct questions about this it did not surprise me, on reflection, that a discussion of this nature would elicit an emotional response. The experience of hearing people's accounts has been a powerful privilege and I have taken the responsibility of this very seriously.

Methods

Data for the study were sought in two ways: in-depth interviews with partners of RCF residents, and focus groups with RCF staff. Individual in-depth qualitative interviews are considered suitable for topics where new and unknown information is being sought (Rice & Ezzy, 1999). They allow for an inductive approach, utilizing the knowledge and insights gained from earlier interviews to help clarify new issues in subsequent interviews. They also provide an opportunity to focus more specifically on the perspective of the participant than a group interview would allow. The personal and sensitive nature of the topic also suggested this medium would be most appropriate, as people were discussing their own relationship experiences. Most partner participants were older, and some did not have good health, mobility or transport options. Therefore, interviewees were offered the option of carrying out the interview in their own home or at an appropriate room in the RCF. Most chose to be interviewed at home and one participant chose to be interviewed at the RCF where their partner lived. One partner participant did not wish to be interviewed either in the RCF or at home, so after consultation, the interview was carried out in my psychotherapy practice room.

A focus group format was chosen for gaining the perspectives of RCF staff. Focus groups have gained popularity in health care research particularly when addressing sensitive issues (Fossey, Harvey, McDermott, & Davidson, 2002). This is because participants may feel more relaxed about talking when they see that others hold similar perspectives and the group format may assist to 'reduce the imbalance in power relationships between the researcher and participants that gives the researcher an authoritative voice" (Liamputtong, 2009, p. 305). Importantly, focus groups have been used before when investigating views on sex and sexuality (Frith, 2000), which was a consideration for this study. One of the defining features of a focus group is the reliance on interaction between participants, and that group interaction can yield a greater volume and richness of information than a participant's individual thoughts (Kitzinger, 1995). There is a theoretical underpinning of group process (Liamputtong, 2009) which holds that the group creates a conversation that yields more than individual conversations. Morgan (1988, p. 12) states that "the group interaction… produces data and insights that would be less accessible in an individual interview". One of the limitations of a focus group is that it only represents the views of the participants who are present, and therefore, can only infer the attitudes of a broader group. This replicates the situation within a RCF where it is possible to discern the perspectives of individual staff members and co-workers who are on a shift together. However it is more difficult to discern the consensus perspective of the whole staff group because shift work makes a meeting format difficult to achieve. Whilst focus groups are useful for accessing cultural or group norms and how these translate into everyday situations (Green & Thorogood, 2009), they are less useful to accessing opinions which do not fit within the cultural norm, or for accessing views of people who are lower in the status hierarchy (Green & Thorogood, 2009). This was a concern because RCFs, in common with other health environments, have a defined hierarchical structure. For that reason I wanted to ensure that one focus group would be held purely with care staff to ensure that it might be possible for these staff to speak freely. From the perspective of clinical practice, nursing and care work relies strongly on a team approach and standardised practice in a way that is less crucial in other health care professions and I hoped that the use of focus groups may highlight some of the issues that occur in practice. In order to establish these groups, I met with all facility managers initially to introduce myself and the research project. The first focus group was with four care staff and no registered staff. The second focus group was with a mixed group of eight staff, comprised of four carers, one Enrolled Nurse (EN) and three Registered Nurses (RNs). The third focus group was held with four senior nursing staff: including facility management, quality co-ordination, unit management, and a senior practitioner. The facilitation style aimed to be unobtrusive and

facilitative rather than directive or intrusive (Morgan, 1997), and the aim was for participants to discuss the issues between themselves rather than directing comments to the interviewer.

The purposive sample

Tarzia, Bauer, Fetherstonhaugh, and Nay (2013) identify that recruitment is very difficult when attempting research about sexuality and residential care. This was certainly the case in this study and it is doubtful that sufficient participants - either staff or partner participants - would have been obtained without finding a 'reliable insider' to approach potential participants at an initial stage. Tarzia et al. (2013) state that:

> having a reliable and enthusiastic 'insider' at a facility management level who was prepared to provide residents (*in the case of this study, resident's partners, or staff participants*) with information about the project, gauge their interest, and with their permission, give us their names (p. 363).

Partner participants were also identified by other health care professionals such as GPs, Hospice staff members and Age Concern fieldworkers. There were two considerations for the study that were amended through discussion. The first consideration was to focus on partner interviews where residents were thought to be in the last year of life. However, it was decided that this would exclude participants with perspectives that would offer insights about the topic. Therefore, the decision was made to interview partners regardless of whether the resident was thought to be in the last year of life. The second consideration was to exclude partners where the need for residential care had been triggered by their spouse/partner having a dementia diagnosis. There were queries over whether this may add complicating factors to the study, such as resident consent, and fears of negative family repercussions to expressions of sexuality (Tarzia et al., 2012). However, it became clear that to exclude partners of people with dementia would be more complex than initially envisioned. Some partners related that the reason for their partner requiring care was due to another health factor, such as a series of strokes or a brain tumour, but a further diagnosis of dementia often emerged. Both pragmatically and philosophically this seemed to be a perspective that needed to be heard, and therefore the decision was revised. It was clear that there were sufficient ethical safeguards through the ethical consent process as the interviewees were not people with a dementia diagnosis themselves. Partners were all home-based (although two participants who were based in supported flats adjacent to the facility where their spouses lived), and their partners were being cared for by a range of non-government organisations and private providers in the region. It was not possible to look at the potential differences amongst different RCFs in the study. The staff who participated in the focus groups were employed by either Presbyterian

Support Otago (PSO) or Presbyterian Support Southland (PSS) which are the biggest providers of residential care in Otago and Southland.

Ethical approval

It was very important to ensure that potential participants were fully informed about the study, and that their participation was confidential. Two partners were concerned that their participation would be viewed by staff as a complaint about the facility and it was important to reassure them that no-one (other than the overall service manager who had discussed the project with them) would know of their participation. I told them that their comments would not be communicated back to facility staff, instead being used to develop collective themes which would not be attributed to an individual or a facility. The University of Otago Ethics Committee gave consent for the study in March 2014, and information and consent processes were carried out prior to the start of each interview.

Data collection

Two partner interviews and one focus group were held in April 2014, the second focus group and four partner interviews were held in mid-June 2014, and the remaining partner interviews and focus group were held in July 2014. As the interviews and focus groups were both semi-structured, I drew up interview and focus group guides to ensure that all the relevant areas were covered. All interviews and focus groups were carried out face to face. All except for one individual interview were recorded (with the participants' consent) on to a digital voice recorder and the recording was then transcribed verbatim. Handwritten notes were taken during the individual interview that was not recorded and the notes typed after the interview. Adherence to hermeneutic principles was maintained through my maintenance of an open minded attitude, and noticing any conclusions that I was tempted to draw about participant content and meaning. A reflective process was useful in this process and is described shortly.

Before each interview, I discussed the consent form, and then introduced myself through the 'personal preamble' described before, and gave the reasons for doing the study. I invited the partners to complete the consent form and gave them each a $20 grocery voucher. I reiterated that we could turn off the recorder at any time, and stop the interview if they wished to. The interviews ranged from 43 minutes to 78 minutes. I started the interview by asking the participant to describe the process of their partner going into residential care and what had led to this decision. This allowed partners to approach the topic sequentially. To conclude the interview, I asked them whether they would have any advice for other people who might be

placed in their position or any advice for staff who were working in RCFs. My final question was an invitation to mention anything that they thought I might have asked, or to add anything else that they wanted to say.

The focus groups took place either in a residential care facility or in the main office of the residential organisation. The groups were held in the early afternoon to enable staff from both the morning and afternoon shifts to attend. There were four participants, in the first group, eight in the second group and four in the third group. Each group lasted for an hour because of the shift work time constraints. At the beginning of each focus group, I discussed the consent form, asked participants to complete it and offered a grocery voucher to each participant. I introduced myself in the manner described previously and invited people to introduce themselves and to say how long they had worked in the area of residential care. I added up the number of the years and stated the total number to the group at the end of this introduction process as I wanted to acknowledge the work experience that was held amongst the group. I concluded focus groups by asking them whether they had any thoughts about how things may change in the future as far as sexuality and intimacy in residential care was concerned. In the same way as the individual interviews, my final question was an invitation to mention anything that they thought I might have asked or to add anything else that they wanted to say. In the same manner as the individual interviews, I adhered to hermeneutic principles by maintaining an open minded attitude, utilising a reflective approach and being aware of any conclusions that I was tempted to draw about participant content and meaning.

The decision to utilise a semi-structured approach appeared to be a 'good fit' after the first partner interview and focus group as it was clear at that stage that there were aspects of the discussion that I would not have envisaged in the interview guide. This meant that I was able to incorporate this awareness into subsequent interviews. I reviewed each recording after completion in order to review my interview style. My sense was that I would need to approach the subject by asking about their situation more generally before asking about intimacy and sexuality, so I asked the interviewee firstly to describe the circumstances that had led to the decision for residential care. Whilst all of the interviews had different elements, the differences between interviews were more marked in the partner interviews. It felt important to be respectful of the need for participants to discuss matters that touched on the topic, but also had elements exclusive of it. For the focus group staff, it was important to ensure that discussion occurred about consensual intimacy between existing partners rather than behaviour management for individual residents who were approaching other residents non-consensually.

There were elements, that in hindsight, I would have improved. Each partner interview had digressions or 'side stories' that occurred and this was an aspect I had imagined could occur in the interviews, both because of the possible intensity of the topic and my experience of the conversational style of this population group. I was, and remain, curious about the functions of 'side stories' and their purpose in a project of this type. It has been difficult to find any reference to this within the scientific literature but I have wondered whether it was a way to regulate emotional reactions by switching the topic to another area for a period of time, either consciously or unconsciously. Whatever the underlying reasons, it seemed to be very important to respect the need to move towards and away from the topic and to respect the individual's autonomy. At the end of each interview and focus group, I utilized a reflective process, and asked myself what had surprised me about each interview, what material had appeared to be newly expressed and what I had heard expressed before. I also acknowledged my own emotional reaction to the interview, as this seemed an important factor to be conscious of before proceeding to the next one. I was aware of the high intensity of grief and loss expressed by partners and whilst I am familiar to working with this as part of my work role, there seemed to be a difference when experiencing this as a researcher. I concluded that the structures of the therapeutic frame - such as the regularity of time and place and the consistency of therapist behaviour - help provide a containing environment for emotional intensity and make it possible to explore issues in depth (Symington & Symington, 1996, Holmes, 2006). In comparison as a researcher, the frame is not present in the same way and there is no mandate to explore issues as deeply. So, whilst the interviews may have involved discussion at less depth, the intensity of the feelings were expressed very powerfully. This left me with a renewed appreciation for the aims of the research and the generosity of participants as well as the necessity of the therapeutic frame in clinical work.

 There were natural gaps in the timetable of interviews that allowed a transcription to be completed before the next set of interviews. Once the interview was completed, I aimed to transcribe it as soon as possible. Any aspects of conversational hesitation or lengthy asides were not transcribed or were truncated. When developing the study proposal, it was planned that interviews would be returned to participants to allow for respondent validation. However, after consultation, it was decided that the interview would encapsulate the participants view at that moment in time, and therefore would not be necessary. It is important to acknowledge that people's views may differ at different times, as we may all hold many realities within ourselves (Green & Thorogood, 2009).

Data analysis

The data were analysed through a thematic approach and an iterative process, drawing on recommendations by Pope and Mays (2000), Green and Thorogood (2009), and Braun and Clarke (2006). The interviews were transcribed, and read through several times in order to carry out an initial analysis following the principles of hermeneutic phenomenology (Colaizzi, 1978; Todres & Holloway, 2006; Van Manen, 1998). This approach considers that the data are not merely a description of participant's experience but also an interpretation of it. The data gleaned in the interviews 'throws light' onto the experience of partners, and health professionals, in an area where there may be many assumptions. The use of hermeneutic principles attempts to focus on the lived experience of the individual partner and the collective experience of staff and to use the data to establish an interpretation that clarifies both the similarities and differences in these experiences. It encourages the researcher to look beyond descriptive content, and explore ways that participants make sense or interpret their situation, particularly when considering convergent and divergent themes (Morse & Field, 1995; Seymour & Clark, 1998).

I then re-examined each interview, identifying and highlighting phrases or sentences which directly related to the area under investigation. As this process was repeated with successive interviews, my task was then to identify and group together data with similar meanings which formed a consistent theme or thread. It was important to pay attention to discordant themes that emerged, as they would also throw light on important factors at play (Pope & Mays, 2006). The identified themes were then used to shape further data collection and analysis.

At the end of the data collection period, all of the data was organised into themes. Themes were developed from the data by reading and re-reading the transcripts and highlighting significant features of the text. These texts were then collated into potential themes (Braun & Clark, 2006), and then reviewed again into a thematic map (Braun & Clark, 2006, Pope & Mays, 2006). Appropriate and significant quotations were recorded alongside the identified themes after ensuring that any details that would identify the participant were removed (O'Brien, 2003). To ensure participant confidentiality, pseudonyms have been used at all times. Following the thematic analysis, a synthesis of findings was developed which utilised theoretical comparison with appropriate psychological concepts. Finally, the three identified themes are discussed together and overall conclusions from the study are drawn. These conclusions are then translated into recommendations for policy and practice, staff development and care planning where possible. Any further research recommendations are also identified where appropriate. The following three chapters provide an analysis of the

significant findings that emerged from the twelve individual interviews completed with partners and the three focus groups completed with staff (these are referred to partner interviews and staff interviews throughout the thesis). The first chapter explores partners' experiences of grief loss and transition, and ways that the relationship is re-shaped through the experience of ill-health and placement into residential care. This chapter also explores the ways that staff recognised and understood this process. The second chapter examines what the concerns were for partners as they managed these changes and what assisted them to cope. Again, the understanding and recognition of this process by staff is also explored. The third chapter explores the concerns from the perspectives of partners and staff around privacy and surveillance within RCFs and explores issues around autonomy and protection for residents.

CHAPTER FOUR

THE EXPERIENCE OF GRIEF, LOSS AND TRANSITION - WHEN ILLNESS MEANS SEPARATION

The following three chapters examine the findings of the study and combine this with a discussion of these results. This chapter seeks to consider the individual participants' experiences of grief loss and transition, which was a major theme that emerged from the data. Whilst the staff focus groups did acknowledge grief and loss for residents and their partners, the experience of partner participants who are describing their story is very powerful. Three perspectives are considered in this chapter: firstly, the individual experience of grief loss and transition, secondly the re-shaping and transition within the relationship, and thirdly, the experiences of loss of broader life roles, including identity and sense of self. The research into grief and loss tends to divide into two broad groups: the sociological constructions that inform understanding of grief, loss and transition, or psychological constructions and theories of these areas. When examining the themes identified from the interviews, it seemed important to recognise that both theoretical perspectives had a part to play in understanding the rich and complex experiences of individual participants, and then to examine these experiences within the broader social context of older men and women contending with these significant changes in their relationship and their lives. From a sociological perspective, Kaplan and Ade-Ridder (1993), Howarth (2000), and Charmaz and Milligan's (2006) work on the social implications of caregiving and loss of a partner relationship within the context of contemporary society helps broaden the individual view. Within the analysis in this chapter I have drawn on the psychologically-based work of attachment theorists such as Parkes (1996). Attachment perspectives help shape understanding of the bonds that exist between people, and why separation or loss is so emotionally painful. Rando's (1986) work on anticipating grief and loss has helped frame how fore-knowledge of ill-health and deterioration impacts on partners. Stroebe and Schut (1999) formulated the notion of the Dual Process model (DPM) which drew from previous coping models in bereavement research, and considered individual reactions to grief and loss. The dual process model invites people to consider the experience of grief to be considered as a two- sided process which requires the individual to balance two positions. On one side lies the experience of what has been lost and is considered as a 'loss orientation'. On the other side of the scales is sited in the need to acknowledge practical problems and adjust to the current situation and is considered as a 'restoration orientation'. The model posits that both sides of the process are important, and many individuals 'balance

out' the ways that they focus their thoughts and actions over a period of time to include both sides of this process. They also suggest that some individuals may focus on one side more than the other, possibly due to personality, social expectations or environmental factors, but importantly this isn't presumed to be problematic. As this chapter focuses on the experience of loss and therefore is considered within the loss orientation in the DPM.

Living with the feelings –
'It's up and down like a bloody radio, I don't know where I am'

All the individual participants in this study spoke about their experience of grief and loss, as they navigated the changes and transitions in their lives. Grief and loss are 'everyday' words used interchangeably within society, and has been defined in chapter two. Whilst it is acknowledged that grief is experienced in situations other than death, there has been less attention paid to this in the literature. The participants' descriptions of grief were very individual, alongside their differing situations. For some participants, the move to residential care had been very recent. Keith, a 66-year-old Southland participant had been living alone for two months since his wife had gone into residential care:

> *For me, it's been hell…I know I've got to get over it…it's just losing her… your whole life is tipped upside down, and all I can do is think about her…so that's why it's a rollercoaster for me, it's up and down like a bloody radio, I don't know where I am. (Keith, Southland)*

Charmaz and Milligan (2006) state that intense grief 'elicits considerable mental and physical distress, it… not only inundates the bereaved person's emotions but also destabilises his or her life and self" (p. 519). Participants in the study described, as Keith did, a common experience that life was destabilised around the time their partner had moved into a RCF.

The amount of time that participants had lived alone since their partners had moved into a RCF varied. Out of 12 participants, six had been living alone for under a year, four participants had lived alone for between one and three years and two had lived alone for between seven and 10 years. Their perspectives varied with these differing time periods. Howarth (2000) describes the need for people to construct a biographical narrative as part of restabilising, allowing a restored sense of meaning and continuity. She states that 'each individual must have a clear sense of who they are in the present and of how the past has lead them to this present' in order to create a clear and structured narrative of events that has led to the current situation (p. 131). Raewyn, a 68-year-old Otago woman whose husband had been in care for two years, described her reactions across this time period:

There were days when I hated him, I hated him for what he'd done. It was all his fault. And our money was disappearing - not that money is important, but I feel deprived that all my options for the future have gone because we have had to spend all of our savings.

She goes on to describe how her views have changed over the last couple of years, but also that some of her original feelings remain:

The social worker said that there would be a time when I would feel like his wife again, and you will feel differently again. And she was right, after 2 or 3 months, I started remembering the good times. I remembered the good things – although it wasn't a perfect marriage, no marriage is… (Raewyn, Otago)

As part of the process of thinking through reactions and responses, it was clear that most participants had given careful thought and reflected on the development of health problems for their partner in order to gain a sense of 'where this all started'. All participants described a period where they knew that their partner's health was changing, even if identifying the health problem was unclear. Elizabeth's husband was found to have an inoperable brain tumour and she described her sense that he was becoming unwell, which contradicted the hospital staff's description of a 'sudden event':

I noticed deterioration prior to him going into hospital; probably a year, two years before. I did mention it to the doctor, but he said "oh leave him alone, he's alright". So there was nothing more I could do when I was told that. And then he collapsed in the corridor one night…. I know that there will never be improvement, only deterioration. (Elizabeth, Southland)

Parkes (1996) describes the human need to make sense of the situations we are placed in and that this often requires re-thinking the 'rules' or assumptions that we hold about life – a change to the 'assumptive world'. Some participants described a period in retrospect when they 'saw something, but didn't see it' which occurred simultaneously. Raewyn's husband was diagnosed with dementia at 59, and she describes her struggle to see this despite her work-related knowledge:

When I look back…. I think I can see a pattern, he was probably 57 or 58 when it started: pulling himself away. Retreating inside himself. I didn't notice but my son did. I was working full-time in a rest home and the thing is, his mother had Alzheimer's but it never occurred to me that he could have it, in a million years. (Raewyn, Otago)

Bill, who was one of the older participants, described being shocked when both he and his wife developed health problems in their late-70s:

You don't really expect this sort of thing when you retire. But that's what happens. (Bill, Southland)

It seems that whilst all of the participants indicated that grief and loss are inevitable especially in later life, this did not mean people thought about this until it was forced upon them. The study focused on older people's experiences – with an age range of nearly 20 years, with the youngest participant aged 66 and the oldest aged 85. This 20-year period is likely to be a time when people's health alters, and this alters the relationship between couples. Kahana and Young (1990) and Kelley (1981) acknowledge this is partly because external activities become harder to maintain. Even couples who have experienced much conflict in earlier stages of their relationship can find they are drawn together by the problems that ill-health can create. Ade-Ridder and Kaplan (1993) discuss the changes in later life marriages which brings about an increased inter-dependence between the couple. They argue that a heightened focus on communication and companionability develops as the couple increasingly rely on each other. Johnson's (1985) work notes that irrespective of possible marital problems at earlier ages, when individuals are old, being married provides a significant dyadic relationship for which there are no adequate substitutes. Judith, who at 71 was one of the younger participants, had got married later in life (her husband was 15 years older than her). She described how they had always had to contend with health worries within the marriage:

It was a sad marriage in a way because T got cancer as well, early on and so he got the treatment…. And then he was, that word orchiectomy is a terrible word because it sounds so beautiful, and I was appalled… (Judith, Otago)

The literature suggests that older adults generally experience less intense and less enduring patterns of grief (Lichtenstein, Gatz, Pederson, Berg, & McClean, 1996). However the experiences of grieving prior to a partner's death are more difficult to ascertain, and are particularly relevant to this study. With the exception of Bonanno, Wortman, and Nesse's (2004) study which seeks the perspectives of couples for a three year period prior to a bereavement, there is a gap in the literature which examines experiences prior to a partner's death. Ade-Ridder and Kaplan (1993) state that this gap is due to an assumption that one of the reasons that people move into a RCF is because they live on their own. This assumption is of interest at a time when overall life expectancy is increasing and the burden of health is switching from acute care to chronic conditions. Current estimates in Australia, for example, show that at least 55% of deaths are associated with complex symptoms and gradual deterioration, rather than a sudden death (McNamara & Rosenwax, 2007).

The participants in this study talked about the inevitability of their lives changing, coming to terms with living alone and facing the deterioration and death of their partners. Those participants whose partners required residential care because of their physical health had a clearer sense of the challenges of the future, but the participants whose partners had required care due to dementia, were more uncertain about the life expectancy they foresaw for their partners. Schoenberg, Carr, Kutscher, Peretz, and Goldberg (1974) and Rando (1986) describe the process of anticipatory grief, where reactions to loss start before the person has died. They posit that this foreknowledge lessens the impact of bereavement once death has happened because the person has already embarked on this process. Parkes (1975) states his belief that grieving may take a different course for couples when it is forewarned. He argues that the couple can share grief between them. He also contends that the surviving spouse can gradually take their leave from the partner after an 'opportunity to make restitution for any deficiencies in relationship with the deceased person' (p. 129). This is likely to be more difficult for couples who are facing a dementing process, where awareness is compromised. Maureen's husband has been in care for six months and she described her sense of the future in this way:

> *I knew that when he went in there (to RCF) I had to accept that it was the beginning of the end. It marked the end of the marriage, of us, really… but I wouldn't leave him to get on with it. I am still here…*

When a diagnosis is clear and the prognosis is clear, participants stated that this assisted them to be able to come to terms with what lay ahead. However, when the situation holds uncertainty or doubts, this was described differently. For one participant, there were questions over his wife's diagnosis which had significant implications. If she had severe depression then she could recover; if she had dementia, then she would not.

> *She was her old self again for a few hours. She sat down and looked at photos… and the doctors there they couldn't shut up about it….As much as you don't want to play on the fact that there is a bit of hope, it's in the back of your mind….. I've always thought she was aware of what was going on. You mention the word 'dementia' and she would withdraw into herself. (Keith, Southland)*

Keith described his attempts to predict and respond to both possible scenarios because it was not clear what the situation was for his wife. For other participants, the situation seemed more certain, which allowed them to envisage what was ahead. Bill, a participant from Southland who was in his mid-80s, had lived alone for seven years since his wife had gone into residential care. He described his wife's recent deterioration and his views on this:

The thoughts in the back of my mind all this time that this could be it. Not that I dwell on it but every now and then I think of it. When all's said and done, she's outlived her mother and father and her brother. (Bill, Southland)

Some participants had lived with a care situation for many years and John, a 73-year-old participant, had lived with this for longest. His wife has lived in residential care for nearly 10 years and has required substantial care both at home and residential care for 45 years of their 47-year marriage. For several years, both his wife and his mother were placed in the same facility. He described his life over a prolonged period as a balance between the needs of his wife's care, the raising of their children and maintaining his full-time work role (until he retired). However, he described a sense that he received additional help because of being a man:

The sad part is in life, if it had of been the other way round, I think if it had been me, M would have been expected to look after me a lot longer than I looked after her… almost slightly sexist, the woman can look after the man but the man can't look after the woman. (John, Southland)

This concept is recognised by Shanas (1979) as the principle of substitution within society, where husbands are looked after by their wives, and wives are cared for by their adult children, often their daughters. Men who are placed in the role that a wife would usually occupy may be offered additional support, or to draw on Keith's perspective, be seen as being less capable of providing care. He goes on to add:

I've seen it so often where the female has ended up going into care where she could still have been at home. I think that I was lucky because I worked at the freezing works and we used to have all those smells and things anyway… and if the husband would look astounded and I'd say come on, grow up, it's not that bad, and they can't do it for themselves. (Keith, Southland)

This is an aspect acknowledged in the literature: men who are informal caregivers for a partner are more likely to receive assistance both paid and unpaid than women (Boylstein & Hayes, 2011).

A perspective that was found across all interviews matched Howarth's (2000) description of the development of a biographical narrative. This was particularly clear in the narratives of the process leading to the decision for RCF care. All participants described three stages to this: firstly, a period where the decision was made and enacted, secondly, a period of time immediately after the partner moved to RCF, which allowed the carer to recover physically from the tasks of providing care: and lastly, there was an emerging awareness of the need to adjust or come to terms with the new situation in which they were placed. One common

feeling amongst participants, especially in the initial period when their partner had gone into care, was a sense of relief:

> *I got so stressed up, I crashed the car into the back of the garage, and that's when I realised that I couldn't cope. My friend said, he must go somewhere, you don't look like you used to… I realised that it was visible to others then. (Ngaire, Otago)*

Another participant Raewyn, described the sense of freedom she experienced after a period of two years of providing care at home:

> *He wouldn't let me out of his sight…even if I went to the toilet, he was waiting right outside…yes, he was totally reliant on me, and in total denial that there was anything wrong with him…so it was wonderful at first (when he went into care). Loved it! I could sit and watch TV… but a year on, I miss him. (Raewyn, Otago)*

For another participant, it was a relief when the decision was made by health staff, as it took this burden away from her:

> *I really didn't want it to be my decision, I didn't want to live with that, but it was the doctors who said that. (Peg, Otago)*

Four participants stated that the decision for residential care had been made because health professionals had witnessed behaviour that caused concern. The participants described that they had already reported this behaviour to staff. Ian, an 85-year-old participant talked about his wife's aggressive behaviour:

> *So I communicated this to some of the staff the state of play, but she just came home on the bus as normal…but the next week, it turned out that she had had an episode of paranoia…. So she got admitted and it was all because of a sudden episode that they hadn't seen before…. In some ways it was shattering, in some ways a relief that other people had seen the sorts of things I had been living with for quite some time…I had communicated that things were happening, but well, I don't know what they thought about them, but having seen an episode, the wheels were set in motion. (Ian, Otago)*

After this initial period where participants described a sense of relief, this was often followed with a period where the decision was questioned:

> *But I do feel guilty – I do think I could have looked after him a bit better - but maybe you always feel that… (Raewyn, Otago)*

> *When I still had him (at home) I used to bawl every night because he'd get me upset. But then you get over that and oh, it's hard. (Maureen, Southland)*

Some participants, particularly those whose partners had significant mobility problems, were more reconciled to the need for RCF than those partners who had dementia. Elizabeth described her realisation that she could not look after her husband at home:

> *I was told by the doctor that there was no way I could have him home because he had an inoperable brain tumour and it was only going to get worse… and this home is not built for wheelchairs or high gutter frames, not even a little Zimmer frame. So, I knew that there was no way I could take care of him, and give him the 24 care that he needs. (Elizabeth, Southland)*

Most of the participants described a sense that they had at least partially, if not wholly, reconciled the decision within themselves about residential care. As an observation, the women participants expressed this more directly:

> *I would sit and cry a lot but I've got over that now. I've had to go through the whole lot…. all of the decisions, putting him in here, I've had to get power of attorney. All sorts of things that I would never have thought would have to be done. (Maureen, Southland)*

> *I don't feel that he gets the care that he would get at home, but I can't help that because I can't have him home. (Elizabeth, Southland)*

This compares with comments from participants who were men:

> *It was her decision to go into a home. For respite. And whilst she was in there, she just said that she was going to stay there and that was it. Well, it took a bit of adjusting to, but I took it in my stride... I was surprised, don't know if it was my cooking or what…. (Bill, Southland)*

> *I was just told that she was booked in facility X, and that was it. (James, Otago)*

These observations suggest that there are differences between partners in the ways that they view their relationship once health changes have occurred.

Reframing the relationship – '*I'm neither wife nor widow*'

Ade-Ridder and Kaplan (1993) describe that each partner in the couple are on a different trajectory when they are separated in these circumstances. The home-based partner is adjusting to living separately, grieving and coping with living alone. Rollins, Waterman, and Esmay (1985) use the term 'married widowhood' to describe this experience of grief, but without the clear, delineated demarcation that death brings. The position of the home-based partner has changed and can be seen as "dangling in the grief experience……they are in an

emotional limbo that goes on and on" (p. 70). This was an experience that every participant described in a variety of ways. Ian described it as follows:

> *You are still married and you have a partner and the emotional ties that you need to cultivate, but it is living alone… it is difficult to move on or see how you could move on. (Ian, Otago)*

Gladstone (1995) described four ways that people may start to position themselves and view their situation – seeing the marriage as a memory, seeing the marriage as illusory, a perception that the marriage has changed, and conversely, a perception that the marriage had not changed. Elizabeth described seeing her marriage in ways that echo the concept of seeing their marriage as a memory:

> *He sort of knew me right until the end, well, he didn't know that I was his wife, but he knew that I was an important person in his life, and he an important person in mine - but I can't pretend that the dementia didn't utterly change him and utterly change us. (Elizabeth, Otago)*

Maureen also felt that her husband did not recognise her. This was a significant aspect in Gladstone's (1995) findings – that people had the view that their marriage was a memory because their spouse was not able to be companionable or responsive to them. This was usually because of cognitive decline. She described that she was not sure if her husband recognised her and that there was no relationship between them that she could feel sure of now:

> *He can say clear words but it's no conversation, I used to ask him 'what's my name?' and he'd just laugh. And have you seen your wife. 'No' – and so serious…. He spends his time fiddling with the curtains rather than be with me. (Maureen, Southland)*

Raewyn described her marriage in these terms, possibly drawing on the notion of the marriage as illusory, being neither married nor widowed and finding this ambiguity a challenge:

> *I moved here and started to go to (community organisation) and a gentleman was interested in me. I was terrified. I pulled out of going. He didn't mean any harm, but I couldn't deal with it, being married. Yet, my daughter has said if you ever meet anyone, she said you are not being disloyal. There's a widows club in town, but I can't join it because I am not technically a widow. Some of those people could be looking for a wife. But not me! (Raewyn, Otago)*

Gladstone (1995) described a group of spouses who emphasized their view of a changed marriage and often saw this in parent-child terms, or as a very dear friend. Peg used the following words to describe her view of her marriage:

It has changed things, it had changed a long time before he went up there (to the RCF), you've learned to live in a different way…… what it is now is a great friendship. (Peg, Otago)

It seems relevant that for Maureen and Raewyn, their partners had a diagnosis of dementia, whereas Peg's husband had a number of health conditions but no cognitive changes, which allows for the continuation of shared connection, conversation and shared memory.

The last category that Gladstone (1995) described was the concept of an unchanged or continuing marriage encompassing a sense that nothing had changed, or that the current circumstances were just another stage in their marriages. John, the participant whose wife had lived with changed health circumstances for the longest period (and had been in residential care for 10 years) was very clear in describing his view of the marriage as unchanged, despite his wife's multiple health conditions including dementia:

We are still very much a couple, even after all of this… sometimes when I walk in the door I get this great big smile. And that's worth a million words. Some days I'll get 'it's nice that you're here'.

John's situation is particularly striking. He and his wife had only a two-year period at the beginning of their marriage before serious health problems developed for his wife. This may contribute towards an explanation of why he does not see further deterioration in health as affecting or diminishing the marriage as this was a long-standing situation in their relationship anyway.

Overall, the participants varied in their views of the relationship across the time of the interview – which would suggest multiple realities, not easily categorised clearly into one view of a relationship. Boylstein and Hayes (2011) describe this process evocatively, stating that "men and women express feelings and emotions that oscillate regularly between love and despair, undying commitment and fatalism or living with the spouse that they love, to living with an empty shell of a person who once was" (p. 3). Raewyn described the variability she experienced in relation to her husband:

…… so then I am really excited about seeing him (in the RCF) and then when I am there, he pisses me off. (Raewyn, Otago)

The themes in this study support the literature which suggests that women are more likely to see their relationships as having changed, whereas men were more likely to see the relationship as unchanged (Boylstein & Hayes, 2011; Gladstone, 1995; Miller, 1987; Pruchno & Resch, 1989). The literature suggests that men frame the caregiver role and the changes in

the relationship as a job or work role, seeing themselves as a helper to their partners. Studies suggest that women frame caregiving as an extension of childcare or other caregiving roles and are more likely to see themselves in a parental role to their partner rather than a helper (Boylstein & Hayes, 2011; Calasanti & King, 2007; Russell, 2001).

This study asked about partners' views of sexuality and intimacy and whilst all participants discussed intimacy, most participants were more reticent to speak directly about sexuality. However, where sexuality was discussed it was to acknowledge that the sexual side of the relationship had become less important over time, and with changes in their partner's health. Importantly, this pre-dated the relocation to a RCF. Intimacy was seen as very important by both men and women in the study. Peg stated this very specifically in her interview:

> *People shouldn't be worried about the sexual side of things because in reality, by the time one partner gets up there (in a RCF), you've learned to live in a different way because you've aged. You have contentment and satisfaction if you like, from just seeing each other, or just being together – just a touch on the cheek… (Peg, Otago)*

Judith described how her relationship had changed with her husband's prostate cancer diagnosis some years before he developed dementia. She described her anger that her husband would not be affectionate with her at all after his prostate surgery:

> *He didn't see how important it was to me, that's why I couldn't sleep with him anymore…. I was really agitated and angry. But then we learned…. and did other wonderful things together, like going to shows. (Judith, Otago)*

The themes in the interviews affirm the literature in acknowledging that relationships change over time and that intimacy between couples in long term relationships may be less reliant on sexual acts and more focussed on touch and emotional connection (Weeks, 2002). Shaw (1997) talks of the importance of understanding the relationship rather than through the presence or absence of physical acts. James described his sense of loss of intimacy that had occurred when his wife went into care:

> *I miss cuddling her at night… it does feel like those days have passed now. But I have got great memories – that's something I will never lose. (James, Otago)*

Ian talked of the sadness he experienced because his wife did not recognise him due to her dementia, but talked about how he maintained a connection with her:

> *She's not up for a conversation, but if we are going walking, I only have to put my hand down and she will take my hand, and that's so important for me. (Ian, Otago)*

Raewyn talked about a change that had occurred between herself and her husband: having to ask for affection because her husband no longer initiates these gestures without a prompt:

I have to say, give me a hug, give me a kiss goodbye. And he is quite happy to do it, but doesn't voluntarily do it… what I miss is being hugged. And having a cup of coffee together – those intimate things, I miss that. (Raewyn, Otago)

Peg talked about the ways that she keeps her connection with her husband and acknowledged that she felt that this was easier for them because his health problems did not affect his cognition and recognition:

You must stay in touch. In more ways than one, because when I go up there, the first thing I do is go and give him a kiss on the forehead, you know what I mean? And a cuddle sometimes if he needs it, if he's getting down a bit…. We hold hands and touch each other. (Peg, Otago)

Judith talked at length about her husband's wish to lie in bed next to her when he was in the last weeks of life and her struggle to achieve this within the facility:

One day we there holding hands…. and he suddenly turned to me and said, "I want to lie with you again". And it really hurt me, it knifed me, but it was wonderful that he'd thought of it, he'd obviously been thinking of it for a while. So I asked (senior staff member) if we could do it there, and she talked to the other staff, and they couldn't see any way that we could do it…

She then told a support person outside of the facility, and they approached another facility to arrange this:

We got picked up in the wheelchair taxi, and they had put another single bed next to the other one in the room, and gave us this wonderful fish meal; beautiful meal, beautifully set up. And when we were ready, we called them… and they hoisted him into the bed beside me…. So we had a couple of hours together talking and dozing and things. It was fabulous, it was wonderful. See, almost like a normal thing….

She reflected on this process as part of the interview, concluding with the following comment:

The staff were lovely …., but they didn't really see us as human, with human needs for closeness, affection and comfort. So, it wouldn't have crossed their minds… it was very difficult when they said no, I did feel like I'd asked for something a bit sordid. (Judith, Otago)

It seems important to consider Judith's situation carefully, hence the decision to include several excerpts from her interview. She acknowledged that it had taken her considerable courage to ask facility staff to be able to share a bed with her husband and then have the courage and persistence to ask another facility when her request was declined. Kaplan and

Ade-Ridder (1991) argue that even if RCFs work hard to support couples in their intimacy and sexuality needs then the couple may still not take advantage of this. If the home-based partners were women then they rarely took this up. This corresponds with the earlier discussion on re-positioning relationships and the possible ways that men and women may differ in their responses. They suggest that staff have a role in recognising this and by communicating that sexuality and intimacy needs can continue or be substituted by emotional focused intimacy such as holding hands or touch. The research suggests that RCF staff are more likely to respond in the way that Judith first experienced (Eddy, 1986; Hajjar & Kamel, 2004; Luketich, 1991; Roach, 2004). Judith's experience suggests that it takes courage and persistence to carry these changes into facilities, but when this happens the outcome for Judith and her husband was '*fabulous, it was wonderful. See, almost like a normal thing….*'

Losing life-roles – *'It's so small here, it's like someone took away my life and gave me someone else's'*

All individual participants discussed the loss of their shared life with their partner, and this was a significant and powerful theme. They described being lonely and that this loneliness shaped their current life. This is well recognised in the literature (Lopata, 1996; Moss, Moss, & Hansson, 2001). Elizabeth thought that her husband's previous activities outside of the house helped her to prepare:

> *He got picked up at night time and taken to bowls 3 or 4 times a week during the winter, that broke me in for the loneliness, I've felt lonely but not at night time. (Elizabeth, Southland)*

Bill, one of the older participants, talked about his experience of loneliness and of other losses intertwining with each other:

> *On occasions I feel a wee bit lonely, but I try and get up and do something… but then I have had a stroke too, and can no longer drive…. so that's a big loss as well…. I've lost my independence too. (Bill, Southland)*

Maureen had decided to move to an independent living unit adjacent to her husband, so she was able to visit each day. She continued a night-time 'habit' from her previous shared life as a way to combat her sense of being alone:

> *I just think, I look out of the window and that's where he is right over there where the light is. I can think, he's in bed now. Just a habit I always had at home too. I'd look out of the sitting room window and say, well our neighbours are in bed now too. No, I know he's not far away. (Maureen, Southland)*

A dominant theme that emerged in the interviews was the changes in how people fundamentally saw themselves – considerably more wide-reaching than a straightforward change in the relationship between themselves and their partner, but also a change in the place they occupy in the world. These changes were also described as losses: the loss of identity, changes in social and work roles and the losses of their own health as well. Charmaz, Howarth, and Kellehear (1997) describe loss as a "crisis of the self" (p. 233). Lofland (1982) expands on this idea, describing that the 'lost part' is mirrored in the relationship – therefore, how can we still be a mother or a father without a child, or a husband without a wife? This theme was particularly evident in the younger participants where the changes placed them out of step with their contemporaries. Keith, as the youngest participant, and whose partner had very recently gone into care, described his sense of being alone in this position:

> *None of my friends are in this situation, nobody's had illness, and no-one else has lost a wife or a partner. It's quite amazing really, I can reel off 20 maybe 30 people.* (*Keith, Southland*)

He saw one friend (who had separated from a partner because of a relationship breakdown) as having similar feelings to him. Whilst the situation was different, they shared a similar sense of bitterness about their situation:

> *And she's on her own she's never with anybody, he remarried, so…So she obviously went through the same as what I am going through, she's very bitter, too.*

Keith struggled with strong feelings of being out of place and out of time, Howarth (2000) draws on Van Gennep's work (1909) to convey the idea of liminality, which describes the experience of time and place between status in life, such as the place that exists in between being married and widowed, alive and dead. This term was originally used to describe clear transition times such as the period of time immediately after the death of a spouse and before a funeral had taken place, which would usually be a matter of days or weeks. This concept is useful when considering the 'limbo-land' that people in this study described inhabiting; a prolonged period with no clear beginning or end. Raewyn put this succinctly: '*I am neither a wife nor widow'*.

Some participants may see their partner as also occupying a similar place 'in limbo' too. Raewyn spoke directly about this:

> *God, yes, someone said to me 'how long has your husband been dead'. I said 'He's not dead', and then they asked 'Oh are you divorced' …. Well, I didn't*

*want to say he is in facility X... sometimes I think it would be easier if he was
dead, but you don't want that either. (Raewyn, Otago)*

The participants in this study are people without partners but without the finality of death.
Many of the participants echoed a comment from John, which describes the loss of a
companionship in shared their activities:

*Like when you would go to do something, you would go as a pair, and nowadays
you haven't got a mate to go with you .And it is very different from what I
imagined we might do, we both had our little plans about what we would do in the
future. (John, Southland)*

Some described how their feelings were experienced in response to their partner, sometimes
leading to a decision to change one area of life which resulted in a loss for another area. Judith
talked about her experience of her husband being in care and her attempts to continue to
work:

*He was saying for about six months,' I am so lonely when you aren't here, it's so
lonely without you', and this broke my heart (Judith, Otago).*

This eventuated in a decision to finish work, move to a significantly smaller house and to give
up driving – decisions she felt were advantageous to support him, but that were difficult for
her later, as she attempted to re-establish her life after her husband's death.

*It's been hard for me as well, I am still coming to terms with it, we had such a big
life, and now, oh yes, everything's small. It was really sad... It's so small here,
it's like someone took away my life and gave me someone elses. (Judith, Otago)*

One of the ways that participants seemed to reconcile the 'smallness' of their current
situation, was to go back to their memories of the beginning of the relationship and this
provided comfort and resilience for the current situation. It was a theme for many of the male
participants in particular, and James described it in this way:

*We've been married 57 years and I would marry her again tomorrow. We've had
a marvellous life. It's a horrible thing (dementia) but you have to make the best of
it, I go down and I get a big smile and she comes to give me a hug (James,
Otago).*

Keith offered a similar perspective:

*If you are early in your relationship, look at your partner's family history. If they
have got anything stay away! Prevent all of this then, wouldn't it? No, I don't
know, it wouldn't change anything (Keith, Southland)*

Howarth (2000) says that people manage the liminal space by "constructing their own worlds, with their own meanings for these worlds, and their own self-identity within those worlds" (p.130), and they do this through the creation of a narrative. This makes sense of the wish to go back to the beginning of the relationship, in order to 'hold' the story together. The psychological notion of containment proposes that a painful situation is more bearable for us as an individual, if it is held together or contained inside ourselves in one of a number of ways (Holmes, 1996). Creating a coherent narrative provides an important holding function, and provides a thread that binds the past and present with continuity. This is, ultimately the overall theme that links everything in the study- the individual's need to develop and convey a clear narrative of their situation and to use it to support and make sense of the situation that the person now finds themselves in. The participants in this study also needed to find ways to manage their day to day lives now that these changes had occurred. The following chapter examines the ways that participants found ways to continue their lives now that they were living separately from the partner.

CHAPTER FIVE
MANAGING THE PRACTICAL ASPECTS

This chapter examines the ways that partners described how they coped with the changes in life once the decision had been made for residential care. It also examines staff perceptions and recognition of these changes. The chapter examines the perceptions that partners described in balancing the need to develop aspects of a separate life from their partner, contrasted with the ways that they maintained and supported their relationship with the RCF-based partner. As acknowledged in the previous chapter, Stroebe and Schut's (1999) formulation of the Dual Process model (DPM) provides an overall framework to consider this process. The DPM envisages coping with grief and loss as a two-sided process and is envisaged as a set of balance scales. The previous chapter examined the orientation of loss, and this chapter examines the restoration orientation, including the participants' descriptions of their practical experiences, the difficulties that they faced and the ways they found to continue their lives and relationships. As this chapter focuses on perceptions around coping, then the Stress and Coping model (Lazarus & Folkman, 1984) has been utilised to examine participant findings. Whilst this model has been further modified to the Dementia Caregiver framework (Pearlin et al., 1990), it excludes partners whose spouses have conditions other than dementia. For that reason, the decision was made to utilise the original model. This chapter examines participant perceptions of the ways partners describe coping when living alone and findings that relate to gender differences are explored where appropriate. The findings that explore how home-based partners maintain carer roles and relationships with their partner are also examined.

Managing practical aspects of life – *'if he was sick, how would we manage?'*

Most of the individual participants acknowledged that there had been difficult times for them in both running their home and providing care for their partner until the decision had been made about residential care. Some of these practical struggles around decisions and responsibilities were brought into sharper focus after their partner had gone into care, as this allowed the opportunity to reflect on decisions and processes. Of course, many problems continued after the partner had gone into care, albeit in a changed form.

Most studies on caring and coping utilise the Stress and Coping (SCM) developed by Lazarus and Folkman (1984), which examines responses to care situations either in the home or other

settings. As previously described, in this model stress is identified as being comprised of four components: the context or situation in which care in provided, primary stressors (which are directly related to the diagnosis or health situation), secondary stressors (which arise from the position of providing care) and potential mediators. There are three potential mediators that assist with coping: managing the situation, managing the symptoms, and managing meaning. Managing meaning requires the carer to change their expectations of the situation which then changes the meaning that is attached to the experience. The caregiver burden model (Macleod, Skinner, and Low, 2012; Van den Hoonaard, 2010) examines caregiver burden and what support assists carers. They describe that individuals may have a need for instrumental support (such as home care) emotional support (e.g., a supportive person to talk to) and informational support (e.g., educational resources). When considering the responses of participants in this chapter, comparisons will be made against the stress and coping model and will relate to perspectives of caregiver burden, where appropriate.

Several participants commented about the lack of help that was offered from people who knew them, such as friends and family. Their perceptions varied about the reasons behind this. The literature has tended to take the view that social support is helpful to family caregivers and has a buffering effect against the stress of caregiving (Cohen & Wills, 1985) and therefore in an incremental manner, more support is more helpful for the partner/carer (Goldsmith, 2004). However, there is an emerging appreciation that social support may create tensions and difficulties and lead to negative effects from seeking, receiving and maintaining social support (Lincoln, 2000). These difficulties may differ depending on the situation and relationships involved. Anne chose to move herself and her husband from the North Island to be closer to one of their adult children and then made the decision to seek placement for her husband in residential care:

> *I was just, I didn't have any help even from people that I thought were friends….*
> *when we decided he was going in…. his family, his ex-boss kept saying bring him*
> *home, we'll do this, we'll do that. But they didn't do it before, so they wouldn't*
> *have done it when I went back. (Anne, Southland)*

Anne thought that offers of help could not be trusted or maintained and this confirmed her decision that residential care was her best option. Angelo and Egan (2014) suggest that carers may not ask for help as a way to avoid acknowledging the additional stress they are experiencing, or to avoid additional stress between family members who may have differing views about the situation. They also point out that it may be easier to say no to offers of help which protects the partner who would have considered the task to have been 'their job' to complete.

Wittenberg-Lyles, Washington, Demeris, Oliver, and Shaunfield (2014) posit that family caregivers can feel fraught about asking for help as it can complicate relationships with friends and family members. When asking for help from friends, the boundaries of a friendship are tested, creating a relational 'turning point', which the caregiver may not wish to seek. The research also suggests that asking for help from family can be the hardest task as the request for help acknowledges a lack of support. This can be perceived by family members as an attempt to induce guilt. Therefore, Wittenberg et al. (2014) suggest that carer/partners may take great effort to provide explanations for the lack of offers, and reasons not to ask for help. Raewyn talked about the difficulties in asking family members for help, and finding it difficult when help was not offered:

> *I knew that people cared but they never came near us – I always thought that I could rely on my family. I guess looking back, I can see that they just couldn't cope with him. I think that they were frightened about what he might do. (Raewyn, Otago)*

If we consider the stress and coping model, she manages the meaning that she places on her experience by attempting to understand why her family did not offer to help and creates some understanding for them in this way.

Several participants corroborated the research findings which recognise the stress of decision-making once a partner has been placed in residential care. Partners in this study perceived the loss of support from the partner as a major change which then left them holding sole responsibility for decisions (Wittenberg-Lyles, Washington, Demeris, Oliver, & Shaunfield, 2014). This was a strong theme and was described as a significant struggle at times for participants to face decisions alone when they would have been shared previously in their lives. Some of the decisions that participants faced were major, as the decision for residential care often initiated a succession of subsequent life changes. Ian described the decisions that he felt he was facing:

> *All the decisions, things like buying a car or selling something and even wondering whether to continue with the holiday house. (Ian, Otago)*

From a stress and coping perspective (Lazarus & Folkman, 1984), Ian was attempting to manage the situation. Judith also described a number of decisions that she faced simultaneously: a recognition that she could not stay in their shared home on one pension, her worry about RCF funding, deciding to stop driving and therefore, save on the expense of running a car, and the decision to move away from a small supportive community. Most important to her was telling her husband, and coping with his reaction:

> *I put the house on the market, and he was furious with me. And he didn't say anything the day I told him, but two days later he suddenly turned to me and said, 'and you're not selling my house: it's my house and you're not selling it'. (Judith, Otago)*

Wittenberg-Lyles et al. (2014) recognise this as an issue, particularly as most partners are like Judith and are sensitive to the views of their partner. They describe that the approval of the partner was instrumental in influencing whether or not caregivers sought additional support. They state that it is not unusual for caregivers to avoid difficult subject and omit to discuss these dilemmas with their partner, thus avoiding an argument. This was not a strategy that any of the participants described using in this study. For Peg, it was the opposite response: once her husband was placed in residential care and there were others in a position to offer him support as well as her, it emboldened her to be more open and honest with him about decisions:

> *With his depression and that, he was quite an emotional person and I wouldn't want to upset him. ....He didn't think he was depressed, did he? Oh no. So you didn't touch certain subjects, but last year, his mother passed away, and I made sure that he was involved. In the facility, the staff handle him really well, they won't let him get away with it, like I did at home. (Peg, Otago)*

Peg described her reactions in a way that fitted with Lazarus and Folkman's (1984) notion of a primary stressor (part of the condition or diagnosis) within the stress and coping model, and she sought a potential way of mediating this through managing the symptoms of the situation, assisted by the RCF staff.

One of the most compelling experiences from the participants was the need to simultaneously hold together a number of difficult changes. Judith encapsulates this in the following excerpt:

> *When I couldn't drive anymore, I had to catch a bus into town, and then it was another bus ride to the gate (of the RCF). I had to think of all those things at the same time, but I didn't want to think about them at all. I got rid of about 99% of what was in the house, and I don't know how I did it, to be honest, without going barmy. (Judith, Otago)*

Again, it is useful to use the stress and coping model to examine Judith's situation. Whilst the move to residential care assisted her to manage some of the primary stressors associated with her husband's ill- health, she had a number of secondary stressors (resulting from the demands of a carer role) and potential mediators to consider at the same time and it was only at the end of the practical process of moving home that she was able to attend to meaning making aspects of the situation.

Gender based roles –

'I didn't realise how much a wife puts into running a house'

The literature suggests that there are gender differences between the coping strategies employed by men and women partners in caregiver situations (Baker et al., 2010; O'Rouke & Wenaus, 1998; Papastravrou et al., 2011). However, it is also important to note the breadth of individual differences to this experience, regardless of gender that are also found in the literature (Gottlieb & Wolfe, 2002).

Some studies suggest that women more commonly use support seeking (finding someone to talk to about the problem) and emotion focused coping (such as wishful thinking- 'hoping it will all go away') as well as problem focused coping (finding possible solutions to the problem). Men more commonly use reappraisal ('trying to see the positive side') and problem focused coping (Ade-Ridder & Kaplan, 1993; Borden & Berlin, 1990; Johnson, 1985; Lutzky & Knight, 1994; O'Rourke & Wenaus, 1998; Papastavrou et al., 2011; Stone, 1987). However Baker, Robertson, and Connelly (2010) caution against concluding differences on a gender basis, suggesting instead that individual differences are more relevant. The categories of coping identified above have comparisons with both the stress and coping model (Lazarus & Folkman, 1984), and caregiver burden models (Macleod et al., 2012; Van den Hoonaard, 2010). Problem focussed coping correlates to managing the situation and may involve the need for instrumental support. Emotionally focussed coping and support seeking correlates to managing the symptoms and seeking emotional and informational support. Reappraisal correlates to managing meaning. The literature strongly suggests that the use of strategies such as reappraisal and problem-solving relieves a sense of burden in caregivers, who then feel more confident to tackle the problems that may occur when providing care (Dockendorff, 2014; McNamara & Rosenwax, 2010; Wittenberg-Lyles et al., 2014).

Several participants reflected on their need to develop skills that their partner had held responsibility for, often without the benefit of time to learn these skills. This was a recurring theme for several men in the study with household management tasks. Bill's wife had a severe stroke which changed their relationship instantly. He described a 'traditional marriage' (Stefani, 2004) where he held responsibility for the garden, car and house maintenance, whereas household tasks and bill payments were her domain:

> *I have to admit I didn't realise how much a wife puts into running a house until I had to do it all by myself. And she used to do all of the accounts, pay all the bills, and then when she couldn't do it, I had to learn – where do I start? …. and she couldn't tell me. No handover, I had to learn fast. (Bill, Southland)*

Bill utilised an approach of managing the situation, in line with Lazarus and Folkman (1984) and problem focused coping (O'Rourke & Wenaus, 1998) to develop solutions for his situation. As well as the practical skills component, several male participants talked about meal preparation and acknowledged that this was an aspect of daily life that they missed sharing with their partner. This suggests that this issue evokes a number of difficulties, rather than purely a matter of unlearned skills. Ian states that he was very unsettled when his wife went into care:

> *In the first year, I found it very difficult to settle… I didn't make many meals and only did the washing occasionally, a lot of the things that we did together didn't seem particularly attractive. (Ian, Otago)*

If we use the stress and coping model to consider this situation, Ian is describing a secondary stressor (Lazarus & Folkman, 1984) in the context of his situation - his experience of living alone and possibly utilising the management of meaning as a way of rationalising his response to this difficult period in his life.

John, who had a long experience of providing care for his wife at home prior to her going into a RCF, described other men in similar positions to him who he felt lacked these skills. He felt that it was important to look after himself properly:

> *When you are at home on your own, you have to cook, not just be using KFC. I wasn't really lazy in the kitchen, but M did do most of the cooking… I do know some guys who, and I am not being silly, don't know how to boil a jug properly. (John, Southland)*

John clearly identifies the ways that he has coped by managing the situation (Lazarus & Folkman, 1984), and developing ways to cope through problem focused coping (O'Rourke & Wenaus, 1998) in a similar manner to Bill as solutions to his situation. His experience and expertise is extensive, as he has coped with the stress of caregiving over several decades.

Most of the literature that addresses these issues describes the perceptions of men and women who are living alone because of the death of their partner, rather than the circumstances of this group. However, the difficulties that they describe correlate with the experience of men and women in this study.

Prochaska and Prochaska (1978) and Cancian and Oliker (2000) acknowledge that given the traditional division of labour amongst older couples, this can leave men with a greater need for a helpmate - instrumental support as described by Macleod et al. (2012) and Van den Hoonaard (2010). Instrumental support assists partners with the tasks that their wives had

previously provided, such as meals, homemaking and maintaining health regimens. In contrast, women may expect to find themselves living alone in later life (because of women's longer life expectancy), and may experience less concern about the familiar tasks of managing a house (Prochaska and Proschaska, 1978). There were areas that women in the study found difficult and they too correlated with traditional divisions of labour. For example, whilst women may have carried out day-to-day financial tasks, they may not have held responsibility for overall financial management, which may align with a 'breadwinner role' more commonly held by men in these generations. Many of the women in the study described their concerns about financial management and navigating financial systems. Raewyn, who had moved from her home town to Otago, cited financial pressures as being very significant to her decision:

> *If he was sick, how were we going to manage? We'd have to go on a benefit and it sounds mercenary, but when you get older, you get more fearful. (Raewyn, Otago)*

Maureen, a Southland participant who moved from their shared home to a retirement village unit, also described her concerns about money:

> *One pension instead of two, and now I am paying rent as well as paying for the insurance on what had been our house together. (Maureen, Southland)*

Raewyn had hoped to be able to transfer her husband to a facility in Otago after her relocation south, but this had not been possible. Her financial concerns had been exacerbated by the travelling that she was required to do to see her husband.

> *I didn't realise how hard it would be to get him transferred down here. I used to fly up until the money ran out, but now I have to get the bus up. (Raewyn, Otago)*

The concerns about financial matters that women participants described, involves a mixture of factors within Lazarus and Folkman's (1984) stress and coping model. They were secondary stressors within the context of caring in the current social and health climate and required the participants to be very resourceful, managing the situation as a potential mediator in order to seek the support that they required. Some of the financial concerns that women participants had in navigating the benefits system, aligns with the caregiver burden model, through the difficulties of gaining informational support (Macleod et al., 2012), and the lack of professional assistance that was available to them. Peg described her struggle to complete the required paperwork for her husband's care funding:

> *I applied for assistance for him to be up there (in the RCF). And that was a real performance, they (Ministry of Social Development) are not very good at this you know – they tell you that you have got assets that you don't even know you've*

got….I've sent another application away and there were 90 pages in it. And I think that this is getting a bit over the edge when they've already had two previous ones. (Peg, Otago)

Participants spoke very positively about their contact with professionals who provided and organised instrumental, emotional and informational support (Macleod et al., 2012) at the time that the care decisions were being made. In particular, Needs Assessment services came in for particular recognition and several people felt that there was a gap in the provision of ongoing support. As Peg described, these needs did not end when their partner went into care. Raewyn, who was one of two participants to have a geographical comparison between District Health Boards (DHBs), felt that the services she experienced in Otago were not well structured in comparison with her previous DHB:

Whilst it's lovely here, the services are not well planned. I was part of a Board review for the DHB here, and they said nothing about Alzheimer's at all… I don't think that there are enough Social Workers…. I did lots of courses in (city) but there is nothing like that here. This area has an ageing population – what does the Board think is going to happen in the future? I think it's terrible….. I feel sorry for people that are first diagnosed… (Raewyn, Otago)

Raewyn's experience suggests that in other parts of the country, there may be arrangements to assist carers to develop some of the skills that they might need for the times ahead and therefore to be better equipped for this rigorous challenge.

Living alone – *'the worst time is late afternoon, just when I'd be thinking, now what shall we have for tea?*

All of the participants acknowledged that they had to get used to living alone, and that created some practical challenges. This was echoed by all three RCF staff focus groups who were very appreciative of the change in the partner's life:

They are losing the person who been there for their lives, they need to come in (to the facility). It's such a change and a split from their old life. (R.N. Southland)

One of the difficulties that participants described was in trying to balance the need to maintain or develop activities that they did on their own, against the wish to visit their partners. This could be viewed within the stress and coping model as a way of addressing secondary stressors through managing the situation and managing symptoms (Lazarus & Folkman, 1984). This placed participants in a dilemma as they had carried out many of these tasks and may have an explicit knowledge of the residents' idiosyncratic needs. Schmidt (1987) posits that the juggle for partners about visiting is likely to be part of the partner redefining their

role, and could be an indirect request by the partner to continue with some care tasks. Most of the participants had started off by visiting their partner every day – sometimes more than once a day – but this tended to change and reduce over a period of time with nearly all of the participants. Brubaker (1985) concludes that the care-giving role does not end with the move to residential care but instead changes. The partner or spouse is now a visitor from the external world, has a role as an advocate for the spouse and acts as a purchaser of items to bring in to the facility. The need to visit daily may then be reduced as the role changes.

Only two participants had not reduced the frequency of their visits: John, whose wife had been in care for the longest period of time, and Keith, whose wife had been in care for the shortest period of time. However their reasons for daily visiting were different; Keith was adjusting to a recent significant change, and John had visited daily for many years and for a period of time had visited both his wife and his mother together in the same facility. He saw his social life as being intrinsically 'tied in' with the facility, which ties to the stress and coping model (Lazarus and Folkman, 1984), through managing meaning as a potential mediator of his situation:

> *The staff are my friends and my social life – who else have I had chance to get to know as well as these people? I've been coming here so long now…they rib at me and I rib at them, it's a good thing, we have a good laugh. (John, Southland)*

Keith had been visiting two or three times a day but recognised that he was becoming very tired. He had no idea when his wife would be asleep or awake and described his experience of this:

> *I've started to prune it back to once a day – which doesn't help… Yesterday I went down there and she was asleep the whole time. (Keith, Southland)*

The two participants whose partners had died prior to the study (Judith and Elizabeth) stated that they had increased their visiting when their partner was in the last weeks and days of life, when they wanted to spend as much time as possible with them. Most participants described a reduction in the frequency of visits over a period of time and there were a number of different reasons for this. Bill's wife has been in care for seven years, and moved into a different facility three years previously. He initially visited every day, reduced this to visiting two or three times per week, and now visits once a week. Part of the reason his visits reduced was due to his own deteriorating health, combined with the loss of his driving licence. However, he also acknowledged that an important reason for him not visiting was due to his dislike of the current facility:

It's something about the atmosphere, I don't spend a long duration. I spent ages in the other place. This one, it's institutionalised, it's not friendly, not a homely home. Size has got a lot to do with it, and it's governed by the routines, what time you get out of bed, have breakfast, and get in the shower….. You go up to the desk to ask for information and they hum and haw and look at you as if you're not there. (Bill, Southland)

When participants described the process of reducing their visits, family members or facility staff were often instrumental in encouraging them to do this. Buckwalter and Hall (1987) also acknowledge the difficult positions that partners may find themselves in by stating that they can be "criticised if their visits are too frequent, too long or otherwise conflict with nursing home routines" (p. 178). Three participants expressed concerns in line with this. Peg avoided visiting at meal times in case she was seen either as a nuisance or perceived to be wanting a free meal. She described how she was encouraged to visit less in order to preserve her own health:

Well to start with I went up every day. And I got told (by family and staff) 'cut that out, you're not to do it. (Peg, Otago)

Elizabeth's family similarly encouraged her to reduce her visits and reinforced the message that this was important in order to protect her own health and well-being:

I've got to plan my day so I can visit X. I used to go every day, but I don't go every day now. That was one thing my daughter said…. 'Now mum, you look after yourself and feed yourself properly'. (Elizabeth, Southland).

Most of the participants experienced these comments as helpful and supportive, and acknowledged that it was difficult trying to stay connected to their partner as well as care for themselves. The staff in the focus groups also recognised this dilemma:

They're so tired…. They might want them to go, but once they're out of that door, it's very hard….they think their duty is to look after that person and they have failed. (E.N, Southland)

That's why we say that they are still the main carer. (Carer, Southland)

Some of the context of caring had changed for these participants with the move of their spouses to residential care (stress and coping model) (Lazarus & Folkman, 1984) but there are still primary and secondary stressors that require thought for partners on a continued basis The literature is contradictory about whether placement into residential care does relieve caregiver burden. Tornatore and Grant (2002) suggest that the emotional bond remains and therefore the burden is not reduced, and Yaffe et al. (2002) found that caregivers were

relieved when their partners were placed in care. Both opinions were reflected in the data from this study. One of the carers in Southland describes the dilemma that she sees for couples and families in this situation:

> *Just because their partner has come into care, we don't own them, they're still connected to their families… the people that are home alone, there's something missing for them. (Carer, Southland)*

All of the participants described the practical transitions that they were required to do in order to live alone and develop or maintain a sense of continuing interests. Cornachione (2006) acknowledges that many social changes and the loss of social integration are associated with changes in later life. Being in an older age group themselves meant that participants were experiencing ill-health or changing health in a number of ways- their partner's health, their own health and the health of their friends and associates. Dockendorff (2014) acknowledges that one of the most important ways that individuals manage this is through accommodation - employing emotional adaptation and acceptance in order to adjust to a situation (Folkman, Lazarus, Pimley, & Novecek, 1987; Stefani, 2004). This aligns with the stress and coping model (Lazarus & Folkman, 1984) through managing the meaning. Elizabeth described how her network of friends and their activities was affected by health concerns:

> *In this weather I can't get out and walk, unless I go with the walking group at church, and we walk around the top of the cycling velodrome. I used to walk with my neighbour, but she had a heart attack at Christmas so I have to walk on my own now. (Elizabeth, Southland)*

Peg described being very lonely because of injuries related to two recent falls. This meant she was house-bound and not able to play bowls or take her dog out. She said that she had never liked being on her own in the house, but was trying to come to terms with it:

> *I am an only child and I like people about me you see. Never mind, I've adjusted now I think. (Peg, Otago)*

The interviews were carried out during the winter time, which nearly all participants felt as being a particularly difficult time for maintaining connections or outside activities. The exceptions to this were Keith and Bill, who said that their workshop-based interests can be carried out at any time. They both saw their longstanding hobbies as having been very sustaining and helped them to manage the situation and manage the symptoms (Lazarus & Folkman, 1984) created by their situation:

I have good friends, and I rattle around in the garage with my cars…. Evenings are funny times for me. I get on the computer and listen to music. (Keith, Southland)

Bill's house had many pieces of turned and polished wood in numerous display cabinets. This is a hobby he has had for many years, and which he believes has assisted him through some difficult and lonely times:

I've got to keep busy, I might not get much done… but I just potter around, and keep a project on the go. I am a member of the wood workers guild, and they have a workshop one night a week… but I also have most of the machinery myself at home, too. (Bill, Southland)

Managing life alone was a common experience that all participants had faced, or were continuing to face. Ian made a comment that encapsulated a number of participants' views by acknowledging and making meaning of the situation (Lazarus & Folkman, 1984). He maintained that whilst it was difficult to live alone, he could not envisage continuing in the position he had been in:

When I listen to others at the Alzheimer's group who have their partner at home, I feel relatively fortunate of being relieved of that now…… it helps me understand that there are plusses. I don't think we could have continued in the way they were. It would have got to be a total nightmare – well it was…. (Ian, Otago)

Maintaining the connection – '*I did try my level best to make life … well you do because I loved him to bits….to make life easier for him there*'

All of the participants talked about the importance of maintaining links and maintaining the relationship in practical ways once their partner had moved into residential care. The majority of participants described this through assisting their partners in aspects of care, their knowledge about their partners' wishes and preferences in their daily lives. Schmidt (1987) talks about the difficulties that this can create in the RCF setting through linking to the concept of Institutional totality. In this model, a RCF is a benign totality, with an overriding principle to maintain smooth running of the facility and a need to provide the base level of care for all residents. By necessity, she argues, this requires routines to be institution- centred in order to provide care efficiently, and therefore, treats people in a similar way.

However, Schmidt (1987) warns that RCF care workers can perceive comments from partners as a criticism of their care and this was an aspect that participants in this study were very sensitive to. John said that he knew the carers could not help his wife stand up out of her

chair in the way that he could, and as he felt that she appreciated him being able to do this, he would try and help her:

> *She has no ability for walking, and I can't get her into the car anymore. I can hold M up, and she seems to enjoy the wee stretch – it about half kills me but that is beside the point. (John, Southland)*

This theme was echoed with a number of the participants. They saw their role being to add to the care that was provided by carrying out aspects of care they knew their partner would appreciate. They saw themselves being able to 'turn around' the caregiver burden model (Macleod et al., 2012) in order to assist the professional carers by offering instrumental and informational knowledge of their spouse and their needs. Raewyn summed it up in this way:

> *Because with a child, I'm his mother and I know best and with A, I'm his wife and I know best. (Raewyn, Otago)*

This recognition was also shared by some of the staff participants. They recognised the unique role that partners could have and one of the Southland carers described a situation in the facility where she worked:

> *We have a new resident…. her husband comes in and still showers her, they still have that contact. He was quite awkward about it at the beginning (because he had looked after her and could no longer do it) but its ok now. How cool is that? That's fine, that a nice thing. (Carer, Southland)*

Whilst this was one of the views within the staff groups, there was an opposing theme that expressed a hesitancy about family members providing or requesting care tasks. This arose when staff members saw family requests as putting additional demands on their time or when partners' requests interfered with the smooth running of the facility. One of the Otago-based RCF carers described it in this way:

> *For husbands and wives who are separated because ones in here – well, there's got to be a give and a take, but at the same time the facility needs to accept that and they also need to put us into their situation too. (Carer, Otago)*

The individual participants all recognised how difficult a task it is for carers and nursing staff in facilities, providing care to people with differing and complex needs and they wanted to assist wherever possible in offering support to the professional staff. They recognised that this could allow staff to attend to others who did not have a visitor with them:

> *The girls are so busy, there's usually only two of them, and there's ten people. If he needs to go to the toilet, I will take him, saves them a job… I bring him his afternoon tea and then stay until his meal time…. I had to feed that to him*

yesterday afternoon, he'd open his mouth but he wasn't really with it. (Anne, Southland).

It was also difficult for individual participants to see the standard of care as being less than ideal. Two participants specifically mentioned this in relation to their partner's incontinence and Ngaire saw it as being due to time pressures for staff:

It was hard for the facility staff to give him the time he needed, you know, to have his bowels open properly… so then you have the need for incontinence pants, don't you? …. Lots of people in those places miss out, but we were the 'standard keepers'. (Ngaire, Otago)

Keith's perceptions were that staff did not always pick up on the cues that would suggest that his wife wanted to go to the toilet:

When she's agitated and starting to pace, she just needs to go to the toilet. But she doesn't tell you that. I never had accidents here, it was never an issue. (Keith, Southland)

Keith and Ngaire raise an important issue about the time pressures on RCF carers. Brubaker (1985) describes the home-based partner as an advocate and case manager for his or her partner, and the following chapter looks at this in more detail. However, all of the participants felt that they had a role to ensure that their partner was being cared for appropriately. This was harder for some participants than others. Some were not always able to visit the facility because of their own health problems, and therefore they may not have been able to act as an advocate, or to assist with care themselves. However, the need to maintain contact was still there. Peg was in this situation and her husband was able to ring her from the facility. She described this as a crucial way of managing the situation and managing symptoms through the stress and coping model (Lazarus & Folkman, 1984). As he was able to speak to her on the telephone, they could maintain a connection when she wasn't able to visit:

Finally, I got him to ring me. And it does make a difference, and I think it makes a difference for him too… we don't talk for very long but it just means that we've been in touch. So that's good. (Peg, Otago)

Keeping up appearances – *'He was a meticulous and fastidious man'*

All of the participants described that one of the most important ways they could maintain the connection with their partner and maintain a sense of their spouse as they had always been was by maintaining their partners' appearance and dress. This was described by several participants as being a way to maintain the person's dignity, maintain them as an individual and maintain a connection between the two of them as partners. Boylstein and Hayes (2011)

describe this as one way that "caregivers can maintain a sense of love for their spouse as a spouse, rather than as a child, or as a memory of what they once were". Kaplan (1996) has a similar perspective in acknowledging that the changes in relationship can be conflicting and challenging for home-based partners. Focussing on maintaining the appearance of their spouse is one way that their pre-existing identity as a couple can be maintained alongside the process of realisation and recognition of change through illness. The process of balancing two perspectives has some similarities to Stroebe and Schut's Dual Process Model (1999) described at the beginning of this chapter. Kaplan (1996) states that the spouse recognises the changes and losses in the relationship, but nevertheless wishes to maintain and restore aspects of self and self-care that are intrinsic to their partner. However, it may raise the need for some instrumental skills through the caregiver burden model (Macleod et al., 2012) that the partner either has to acquire themselves or ask for assistance. Ian described his struggle to get someone to help him with this:

> *It's quite distressing that she, her general attire and the state of her clothes. At the moment she is distressed about some long hairs on her chin… the hairdresser wouldn't attend to this, so a friend is going to attend to it with wax strips. (Ian, Otago)*

Hajjar and Kamel (2004) conclude that the wish of partners to assist their spouse to help maintain their appearance is important and is a significant way for many RCF residents to express sexuality and intimacy. Gott (2005) also concludes that maintaining appearance is an important aspect of sexuality for older women in RCFs. Kass (1978) acknowledges that assisting one's partner in a RCF is a way to maintain an emotional connection with them. Ngaire talked about the importance of ensuring that her husband continued to dress in the way he would usually have done in his life, even though she thought that staff misunderstood her need to do this:

> *He was a meticulous and fastidious man, so I brought his clothes in. I bought two of everything and brought them in in zip lock bags. Some of the staff made sarcastic comments like 'oh he's always got something new on', but the care staff from the Philippines and India understood, I think that they understood culturally. The management though – well it was all about the look of the facility, but no worries about residents having un-brushed teeth. (Ngaire, Otago)*

If we look at her comments through the stress and coping model, Ngaire described her need to manage the symptoms and manage the situation, even though she was no longer coping with the primary stressor (coping with her husband's dementia) on her own (Lazarus & Folkman, 1984). Raewyn expressed a similar wish for her husband to look 'like the man he always

had', and described her difficulties trying to help her husband maintain his appearance from a geographical distance:

> *I do have to ask …haircuts, my husband looks like a werewolf, I have to say, 'here are some clippers, can you please clip his hair and his ears? (Raewyn, Otago)*

Raewyn also described her concern about the financial implications of maintaining her husband's clothing, teeth and glasses when she was very short of money. This again placed her in a position of coping with both the primary and secondary stressors of his illness, and attempting to manage the symptoms within her financial means (Lazarus & Folkman, 1984):

> *He loses everything, all his clothes, he's only got half his top teeth, even his glasses. I frequently have to buy new underwear and socks for him… and it all costs. I have to pay for it because they take all his money for the facility subsidy. I go to the op-shop for his clothes now, I find it hard, so I save what I can, putting $40 a month into a jar to cover all of those things (Raewyn, Otago)*

Summary

The participants' accounts outlined in this chapter discuss the practical worries that people face when a decision about residential care is made. It has been relevant to consider the position of participants through the lens of the stress and coping model (Lazarus & Folkman, 1984) and possibly to a lesser degree, the caregiver model (Macleod et al., 2012). The decision about residential care often triggered a cascade of further decisions that intertwined around each other. This means that participants are managing situations, symptoms and attempting to make meaning of the situation simultaneously, making it difficult to see where one potential moderator starts and finishes. This raises the question of whether it is more appropriate to explore the movement between potential moderators. Similarly, in a 'role reversal' of the caregiver burden model (Macleod et al., 2012), it was important to recognise that participants saw a role in providing staff caregivers with instrumental and informational support – and possibly emotional support too in their roles, particularly in offering individualised care for their partners.

This suggests that expertise and skills are held by both partners and by staff in care situations and knowledge is a dual process between partners and professional carers. Each may offer useful and pertinent resources and sources of support to the other individual or group. Partners were aware of the responsibilities and skills that they then needed to develop in order to live in their changed circumstances, and most staff recognised this too. This required participants to balance the need to look after themselves and maintain a connections with their

partner. This last quote summarises the efforts that participants made in keeping the interests of their partners foremost:

> *I did try my level best to make life … well you do because I loved him to bits….to make life easier for him there. (Judith, Otago).*

The importance of maintaining physical appearance leads us to the final theme in this study. This theme examines privacy and surveillance from partner and staff perspectives within the RCF environment and explores the concerns and conflicts with this situation.

CHAPTER SIX
PRIVACY AND SURVEILLANCE

This chapter explores the issues that both partners and staff raised about privacy and surveillance. A discussion about privacy and surveillance in RCFs also requires a discussion of the reasons that residents may require privacy and the understandings that staff may have about these needs. The understanding of intimacy and sexuality needs for people in RCFs are perceived as major dilemmas in the residential care sector. These dilemmas relate to residents' choices and decision making, and include staff concerns about keeping everyone in the facility safe and holding overall responsibility for the environment. Morgan (2009) in describing this dilemma stated: "Those in the setting, including residents their relatives, and the direct care staff and managers are charged with making choices daily about balancing safety and autonomy, individual rights to privacy and the facility responsibility to provide oversight and protection" (p. 200). This chapter starts with discussion from both partner and staff participants on the reasons and requirements for privacy in RCFs and then explores staff participants views about resident sexuality (as this was the reason that they presumed that residents might require privacy). The chapter then continues with an exploration of staff perceptions about sexuality for women and men living within a facility. Aspects of surveillance that occur within a facility are then discussed, which includes the surveillance of staff within different levels of the hierarchy, between staff and residents, staff and family/whānau, and between residents themselves. The chapter concludes by considering some of the problems perceived by staff in documenting and discussing intimacy and sexuality needs. This is contrasted with partner views about staff discussions and their fears of gossip.

Having a little bit of privacy – *'You have to wonder if it's our place to have any comment about what they're up to'*.

Maintaining a high quality of life when becoming increasingly frail is a significant challenge for many older people, and if you also live communally in a shared residential facility, there are additional challenges to autonomy and privacy. The topic of privacy was discussed by both staff and partners, and is found in the literature on RCFs (Morgan, 2009). There are two conflicting perspectives that co-exist when considering privacy, firstly, the need to provide oversight for residents and therefore, inhibit residents' privacy and secondly, the need to

provide privacy to ensure that residential care replicates aspects of 'normal' life (Mollica et al., 2007). Furthermore, Villar et al. (2014) refine the concept of privacy further by categorising it as both physical privacy and relational privacy. When we consider the environment within RCFs, many residents are likely to spend much of their day in larger public spaces such as dayrooms, TV rooms or dining rooms. Residents may share a bedroom as well and if assistance is required for personal care, such as showering and toileting, an individual may have little or no physical privacy at all. If the RCF holds a medical model or hospital-orientated ideology where the priority is on monitoring residents, then this further erodes physical privacy through the requirement for oversight (Eckert, Carder, Morgan, Frankowski, & Roth, 2009; Morgan, 2009).

The expectation that the facility will provide monitoring and oversight of residents means that it can be rare for residents to close their bedroom doors, unless it is for a specific reasons (Bauer et al., 2013). Residents may be reluctant to request their door to be shut, or to have access to a lock because they do not wish to arouse the curiosity or disapproval of staff (Bauer et al., 2013; Morgan, 2009). This occurs despite it being a symbol and aspect of adulthood that is easy to take for granted. Having the 'key to the door' is a common cultural marker of adulthood (Morgan, 2009). All of the individual participants said that their partners were in a private bedroom in the facility that they resided in and most of them talked about the importance for their partner (and themselves) to close the door on occasion and to be able to invite people in. Similarly, the focus group participants did recognise the difficulties for residents and their partners in finding space to be physically private and to be removed from oversight. One of the registered nurses (RNs) described the difficulties of this in the sense that it may leave people 'on show':

> *Normal stuff within couples where people are grumpy with each other, you (as staff) should step back and make sure that we don't favour 'you over you'. And we don't know what they used to be like, and people shouldn't always feel like they should be good and on show. (RN Southland)*

It is common in RCFs – as well as in hospitals and other care facilities - for there to be a 'symbolic' knock as the door is opened to a resident's room. Several individual participants described this as being the practice at the facility where their partner was living, but some participants like Peg talked about the need to be able to close the door and that staff respected this at the facility where her husband lived:

> *If we do close the door, and generally we close the door when we might be discussing things, or if X wants to go to the toilet. And if the door is shut, the girls knock and wait before coming in. (Peg, Otago)*

Peg was clear that they did not always require privacy in order to maintain the intimacy and connection between them as a couple, but did require this in order to discuss financial or family matters. She felt that they were able to maintain a connection as a couple with gestures of affection which she could offer whatever the environment was:

> *It sort of doesn't matter….the first thing I go and do is go and give him a kiss on the forehead, you know what I mean? And a cuddle if he needs it… I will go and sit on the bed next to him and give him a cuddle. If he's feeling alright he might give me a peck on the cheek. (Peg, Otago)*

Peg described how she felt that her marriage had changed in terms of intimacy and sexuality over the previous years. This is in line with Gladstone's (1995) conceptualisations of a changed relationship. Where some partners saw the marriage as a memory because their partner was a changed person, some saw the marriage as illusory and therefore did not see themselves as either married or widowed. Some spouses perceived the marriage as changed either to a parent-child relationship or a close friendship. The remaining view from partners was that their marriage was unchanged or continuing, perceiving the current situation as another stage in their marriages. Peg described her perception that her husband was a very dear friend. Many participants such as Judith described the importance of gestures of affection:

> *We would sit there holding hands, sometimes we didn't talk much. He would just love it. I had books on tape so we would sit quietly holding hands and listening to the stories. (Judith, Otago)*

Gott and Hinchliff (2003) affirm Gladstone's (1995) findings on the changing concepts of sexuality and intimacy for older couples especially when facing ill health. Peg and Judith's comments encapsulated the comments of all individual participants - both men and women - where couple intimacy and connection was focussed on non-sexual expression, meaning that gestures of affection were able to be carried out within the sight of other family, residents and staff. Whilst Peg's and Judith's perceptions were very similar, their husbands had very different health conditions. Peg's husband did not have dementia and Judith's husband did. This is important when the needs of people with dementia are often differentiated within the literature (Tarzia et al., 2012) by staff groups. In the comments made by individual participants, partners were guided by their spouse and their relationship, rather than by the diagnosis. Two participants Judith and Ngaire, wanted to be able to stay overnight at the RCF during the last days of their partner's lives and wanted to be able to share their bed for periods of time. This would have been a situation where they would have wished for a greater degree of privacy.

For partners, their perspective on their privacy needs encompassed both physical privacy requirements (such as the need for physical privacy related to personal care requirements) and the need for relational privacy when discussing personal matters. This is an important consideration, highlighting that the need for privacy comprises both physical and relational privacy requirements rather than either component in isolation.

The focus on affection, intimacy and connection by partners was in clear contrast to the staff discussions which focussed more specifically on specific sexual behaviour and in particular, sexual behaviour that staff considered a problem. This finding strongly correlates with the literature in this area (Eddy, 1986; Hajjar & Kamel, 2004; Luketich, 1991; Roach, 2004) which suggests that staff groups focus less on the intimacy and relational needs of residents but instead frames privacy issues around sexual behaviour, problem sexual behaviour, and consent issues. One staff member framed it in the following way:

> *We are seeing and logging a lot more than we realise, to advocate for our people… we get honed into us about appropriate and inappropriate touch. (Registered Nurse, Southland)*

This area seems to link directly into Morgan's (2009) concept of the dilemmas that exist for RCFs and in particular, balancing the need for residents' rights to privacy against the need to provide oversight for residents. This is a significant dilemma for staff who are exposed to criticism if they are either conservative or permissive towards sexual and intimate behaviour. If they have a permissive and encompassing attitude toward resident sexuality then they can be criticised for exposing elderly and vulnerable people to risk, particularly if dementia or other cognitive changes bring consent into question. Similarly they can be criticised if resident sexuality is monitored and scrutinised which can be perceived as controlling. This issue has parallels with other sectors of social and health care such as child protection work, where there are similar dilemmas in balancing autonomy, risk taking, responsibility and monitoring (*Children's Action Plan*, 2014). In the focus groups, the starting point of considering privacy needs then broadened into a more comprehensive discussion about intimacy and sexuality in its broadest sense– a topic which was described as being difficult for staff to consider. One of the Registered Nurses (RNs) described it in this way:

> *And I guess we don't really know, because it isn't discussed. Until it is all brought out in the open as such, then we are all surmising here…. People don't raise it with us and we don't raise it with them, well I haven't raised it with anybody. I don't think anyone else has raised it with any resident as well. (RN, Southland)*

A carer also talked about how it was something she had not previously thought about and surmised what she thought people may want privacy for:

> *I mean they might just want to sit there and hold hands. Have a kiss. Who knows, they might want to have intercourse, I don't know....it's not something that happens too much, we don't get a lot of it, so we don't normally think about it. We haven't got time. (Carer, Otago)*

However, some of the focus group participants did notice when residents needed privacy. One of the carers described a married couple who lived together within the facility where she worked, where a lot of thought was given to their need to be together as a couple:

> *There's an older couple who share the same room, the dementia is advanced but they are still together. I think it's wonderful... all the care staff, they sort of huddle around and go 'aaah'. (Carer, Southland)*

It is important to recognise that staff did not necessarily think that all privacy or intimacy needs were to be discouraged, but it was difficult for staff to maintain a broader focus. One of the RNs described some thoughts she had during the focus group:

> *I am just thinking of the residents who have never married or had children, I have one woman in mind, and I have never thought what sexuality and intimacy might mean for her – this (focus group) has brought it up for me. I don't even know whether she has ever had a boyfriend or anything. She has girly things in her room and dresses up nicely so I guess that is an expression of her sexuality. (RN, Southland)*

This was the only comment within the focus groups that considered sexuality in terms of an individuals' core sense of self (Gott, 2005). Whilst the definition of sexuality has a number of broad components when considered from an academic perspective, this is not reflected within society and within the practice settings of health professionals (Horden & Currow, 2003; Teifer, 2004).

Forming attitudes and opinions about sexuality – *'A lot of staff around this table haven't addressed their own thoughts and feelings about this'*

A striking feature from all of the staff groups was a pattern where participants found it very difficult to say why they found it difficult to consider intimacy concerns for residents and their partners. Initially, participants speculated about why their colleagues might find it a difficult consideration and it seemed difficult for people to acknowledge their own views. This may have been a disadvantage of using a focus group methodology, which does not afford the same privacy for discussion and reflection as individual interviews. However, the

reasons that participants offered for their colleagues' actions was important, because it suggested reasons for the discomfort:

> *There's younger ones (staff) coming on all of the time and a lot of the younger ones wouldn't handle it. (Carer, Otago).*

There was speculation that younger staff would struggle to think about these issues, or that it might be difficult for some staff to consider because of their cultural background:

> *The other thing is, we have a lot of nationalities, and it might be their culture. (Carer, Otago)*

However, in all of the focus groups, the discussion deepened and participants were then able to look at their own views to a degree. The discussion moved from general comments about the possible views of staff from various nationalities to a reflective discussion of the culture that exists within one's own family/whānau. Participants perceived that these cultural influences originated either from their family of origin or from experience in life which shaped their attitudes. One of the registered nurses described her recognition that her views about relationships were based on what she had witnessed and experienced in her own life:

> *You can try and be non-biased, but you're always going to have an opinion from whatever happens at your house, I guess. (RN, Southland)*

There was a similar comment from one of the carers in a different focus group which acknowledged the differing views between people in a staff group:

> *Even if they or we are from the same cultural background, we might have different views, families are different. (Carer, Otago)*

One of the RNs talked about the varied views that had formed within a staff team when two residents started a relationship with each other. She described how they discussed it together as a team:

> *We just talked about it and allowed people to vent a bit. There were always people who thought it was disgraceful….but some of the staff were experienced caregivers who had worked in the industry for ages and had insight. (R.N Southland)*

A carer in one of the focus groups described herself as an 'old hand' having worked in the sector for many years and acknowledged that she had changed her views over her working life, describing it as her 'evolution as a person'. She acknowledged that her starting point had

been the attitudes held within her family of origin, which she saw as being typical for families when she was growing up:

I came from a (pākehā) culture where you (as a woman) were seen and not heard… I never saw any intimacy at home. (Carer, Otago)

One of her colleagues also described herself as pākehā and said that her experience was similar to her colleagues:

Well, it was the same for me too, and I am in my 30s. (Carer, Otago)

In contrast one of her carer colleagues from the Philippines described her family influences in the following way:

My parents were always very affectionate but as my parents have grown older, they show more PDA (public displays of affection) I see them walking down the street holding hands, it's kind of cute. (Carer, Otago)

An aspect that was discussed in two of the three focus groups was the recognition of generational aspects and how this made it harder for people to consider the sexual perspectives of people older than ourselves. The RN who had talked about the staff struggles previously then speculated about why she and her colleagues found this a difficult situation:

These two residents were in a really sexual relationship for a while and the only thing that was abnormal was that they were living in residential care. So…. like the rest of us we don't like to think of our parents having any sex life at all. (RN Southland)

The literature would strongly support her speculation. There is clear recognition that it is difficult to think about people who are older than ourselves, or of our parents' age having needs for love, affection and physical closeness. As previously described, Bouman et al. (2006) state that this has three components to it. The first aspect is a societal expectation of discreet silence about older people and sexuality, creating an invisibility for older people. The second aspect places sexuality in heterosexual, intercourse-focussed ways. The third aspect maintains that younger people see older people and sexuality as a distasteful subject. Hajjar and Kamal (2004) posit that the societal position of older peoples' sexuality (seen as grotesque and incongruous) is likely to influence staff attitudes and practice within RCFs. One focus group participant talked of her personal experience with her grandmother and how this had influenced her understanding of the struggles that family members may face:

> *My nana was in residential care, and as my grandfather had passed away 30 years before, she was alone for 30 years. And she started a relationship with another gentleman in the facility (who had a wife). For our family to see Nana with another man, it was really hard… (RN Southland)*

This staff member drew on her own experience to identify her views and to offer an explanation for the attitudes and beliefs of her colleagues. This raises an important point in considering how attitudes are formed and changed, and how attitudes are shaped within staff groups.

Men and women: problematic sexuality and invisible sexuality – *'sometimes mum has put up with a lot over the years'*

A notable feature of all of the focus groups was that much of the discussion around sexuality focussed on men, either male residents or male partners visiting the facilities, whereas this was not part of the individual participant discussions at all. The behaviour of men was framed as problematic and a cause for concern within the staff discussions. One RN described her concerns in this way:

> *We are dealing with a generation that are a little more reticent, more stoical…elderly women don't have the understanding that sometimes male behaviour is inappropriate. (RN, Southland)*

Again, initially this was described in very general terms initially, and then explored more comprehensively through the group discussion. Another RN who has worked in aged care facilities for a number of years described this in the following way:

> *I think that we've all had men in our areas who have been sexually inappropriate, not because they are deviant but it is part of the aging process. (RN Southland)*

Staff concerns were initially attributed generally to men, either residing in the facility or visiting. However, after some care to clarify this, it transpired that all of the concerns lay with men who were living in the facility with only one example of concern from a male partner who was visiting his wife which had occurred five years previously. Staff in all of the focus groups acknowledged that any examples they had of sexual behaviour with residents were relatively infrequent, and had tended to involve male residents. This conclusion affirms the literature which finds that sexual behaviours are relatively infrequent in RCFs (Spector & Femeth, 1996; Villar et al., 2014; Walz, 2002). Villar et al. (2014) state that "for many residents, maintaining sexual interests and expressing them in a RCF may be simply out of the question" (p. 6). Interestingly, the focus group participants felt that their recall of these

situations was clear and memorable because it was a situation which prompted different views within the staff group. One staff member posited a reason for men's sexuality being more conspicuous for staff: she felt that it was possible for male residents to express aspects of their sexuality directly when compared to women:

> *Its most often the men that show the physical signs, a lot of older women don't show the signs that they need a bit of loving, I guess. So they're a bit harder to read the older ladies, whereas the cheekier older guys would say 'oh yes, I'd be up for a bit of that'…. The women might just want to cover up a bit this area when they're getting dressed. (RN, Southland)*

There is a similar focus in the literature that emphasises the sexuality of men within RCFs rather than women residents. Miles and Parker (1999) speculate whether there is a double taboo of older women and sexuality at play in this situation particularly when we consider that the number of women exceed the number of men in RCFs. Current New Zealand estimates suggest 76% of RCF residents are women (Naylor, 2013).

When staff discussed specific concerns, they reverted to talking about the concerns of their colleagues, rather than for themselves. One of the RNs talked about the difficulties for some staff with a situation that she did not identify as problematic herself:

> *One of the residents was reasonably young to be in care, and he would like to partake in a bit of masturbation, and I think for the younger care workers, this was a difficult thing… he wouldn't mind so it was really about educating them. It happens because people still have those feelings – it's just about how you deal with it. (RN Southland)*

This participant felt able to acknowledge her own position, stating that she did not object to residents being able to masturbate as long as the person was doing this in private in their room. It is however, important to acknowledge that as a registered staff member, she would hold authority within the facility hierarchy which may facilitate her stating her perspective. Her stance is supported by the literature which suggests that registered nursing staff are likely to hold the most liberal attitudes of staff groups within a facility (Gibson, Bol, Woodbury, Beaton, & Janke 1999).

This participant noted the importance of privacy to allow for sexuality needs to be expressed, and others in the focus group agreed with her that this was crucial. This leads us back to the beginning of the discussion - a RCF environment is not conducive to privacy, which means that these conditions cannot easily be met. Frankowski and Clark (2009) comment that most RCF environments run counter to the cultural prescription that sex is a private act that occurs

between consenting adults. They state that almost nothing in RCFs is private or seen as consensual (Frankowski & Clark, 2009).

Another issue that staff identified was residents' use of internet pornography. It is pertinent that this arose from the discussion on masturbation as it is common for these to occur together (Klein, 2012). Staff within the focus group felt that the use of internet pornography was likely to increase alongside the rising use of the internet in RCFs:

> *We had a resident that had a computer, and it came to our attention that he was looking at inappropriate material – some of the girls got offended. (RN Southland)*

It was important to identify what was meant by the term 'inappropriate' as the material was not illegal and was being viewed by the resident in his own room in private. It transpired that the use of the word 'inappropriate' was because some staff were offended and did not approve of internet pornography. One of the other participants talked about how they approached this issue as a team:

> *With internet porn, we have had to talk about it as a staff group – it's his room, his house. (EN Southland)*

The term its 'their room, their house' or a variation of it was used in two of the three focus groups on several occasions. It warrants closer examination and will be discussed further in the chapter. The comments about internet pornography then led to a discussion about the attitudes of some male resident's towards women staff members in one of the staff groups. One participant described her views, and this was widely agreed with by her colleagues:

> *I notice sometimes (with male residents) that their disrespect for the opposite sex comes in, it shows up when you are working in a predominantly female environment…. You have to understand where they're coming from, but they have to adjust as well if they are going to survive in this environment…. (EN Southland)*

The perspectives of this staff member were not found in the literature, but she raised an aspect of her work experience that seemed to be shared strongly by other female staff. This comment arose as part of the discussion about internet pornography and whilst this was not explicitly stated, there was an inference that linked the depiction of women in pornography and the attitudes held by men that use it (within facilities) towards women staff. It warrants further exploration as it may signal that female workers may experience male residents' sexuality as an expression of prejudice or power towards them as staff members.

Whose home is it anyway? Surveillance and oversight –
'it's their room, their home"

This phrase was used in two of the staff focus groups, suggesting a willingness to consider that residents were entitled to feel at home in their own room. It appears to draw from concepts in the literature on assisted living (Mollica et al., 2007) and resident-centred care (Brooker, 2004; Kitwood, 1997). Assisted living philosophies recognise that resident privacy is supported wherever possible, and that there are inevitable risks present in health conditions and when residents determine their choices. The key characteristics of assisted living stipulate small numbers of individual lockable rooms grouped together with a kitchen and living room where older people are supported to 'age in place', even when their needs change (Eckert et al., 2009). Assisted living aligns to a social framework rather than a medical model of care. Resident-centred care encourages residents' rights and perspectives, with the aim of enhancing their ability to make decisions in all areas of life, which includes their sexual life (Brooker, 2004; Kitwood, 1997). It is recognised that the systems within most RCFs are structured and hierarchical (Tarzia et al., 2012). Many RCFs have an established management structure and mandatory profession-based systems of staff oversight and responsibility. Registered nurses have supervisory responsibilities for the work of enrolled nurses and care staff (NZ Nursing Council, competencies for registered nurses, 2012). It is important to consider the culture of RCFs when evaluating whether the resident is able to stipulate the conditions in their own room. The literature suggests that RCFs function as a benign institutional totality (Goffman, 1961), standardising residents' lives in order to facilitate surveillance and the smooth running of the institution (Schmidt, 1987).

The concept of 'their room their home' was discussed by several RCF staff as a way to suggest that residents can be autonomous within that room. This recognition of decision-making and autonomy can work well for non-controversial choices within traditional RCFs, such as residents choosing whether to have breakfast in the dining room or in their room, but is less easy to determine when the options may meet with staff uncertainty. Surveillance and scrutiny extends not only to the resident but to the staff member if you are working under supervision. Horden and Street (2007) state that there is an underlying assumption within the health hierarchies which suggests if a health professional is told to communicate with patients, clients or residents, they will just get on and do that, regardless of the individual's competence, comfort levels or topic area. Horden and Street (2007) argue that this assumption ignores the dominant structures within healthcare environments which dictate who, how and when to speak to a patient, and what is taboo to discuss. From a practice perspective,

healthcare professionals recognise dominant structures and avoid transgressions within the structure. One of the focus groups was composed purely of carers with no enrolled or registered nursing staff. In this group there was an allusion to the hierarchy when discussing the steps that were required in order for 'sensitive' decisions to be made, usually through several levels of management. One example was when the resident's health was deteriorating and the 'usual rules may need to change' within the facility:

> *If the partner wants to stay overnight – say when their partner is dying, we have to make a note of it, tell the RN and then they have to ask the management as well. (Carer, Otago)*

It was clear that within this focus group, the carer staff perceived that there was a dilemma in conveying a private and intimate request to a number of people. In the other staff groups, it was also noted how difficult it was to make a record of personal and private requests from residents and their partners.

Documentation, discussion and gossip

Both partners and staff discussed the content of residents' records and the content and format of handover meetings, and other methods of discussion between staff. Staff had a strong sense of their legal and organisational responsibilities in this area. One of the carers described it in this way:

> *If it isn't documented, it didn't happen, it's very important -don't know how that works for couple stuff though. (Carer, Otago)*

It was clear that staff saw that they needed to balance documentation and reporting requirements whilst also maintaining residents' privacy and dignity. One of the RNs stated that intimacy and sexuality needs were not assessed or documented and she felt that staff ignored the issue. She felt that the best way to highlight this issue was to approach it through formal RCF systems that would ensure there was a discussion about it:

> *Documenting, you have to be objective….. I would probably leave an incident form. (RN, Southland)*

Her perspective was that this would encourage the development of policies and procedures and therefore lessen the need for individuals to ask as staff would know what the options were. This practical solution puts the impetus onto staff to communicate these options to partners and families/whānau. Ngaire expressed her annoyance that she had not been told by facility staff that she could have stayed overnight during her husband's last days of life:

> *It turns out that I could have stayed overnight during his last few days – but no-one told me that! (Ngaire, Otago)*

If ways to meet intimacy needs are a standard part of policies and procedures, this may reduce the uncertainties for junior staff in particular, who might otherwise respond conservatively. It would convey to residents and partners that there were 'routine' considerations that residents may choose. This would enable discussions with residents and partners to specify a regular time in the day where no staff member will disturb them (unless they are asked to come in), so they can rely on privacy during this period. Other possibilities may be the offer of a companion bed, or a reclining chair for partners if the resident's health deteriorates or they are perceived to be at the end of their life.

However, it is important to note that individuals make different choices and James had a different view about whether staff needed to inform him about choices and options in the facility:

> *The staff have got a job to do and I don't see it extending to have too much concern about me, but I know that I am always welcome there. (James, Otago)*

James and Bill both felt that the facility had a job to do and that it was not their place to question any aspect of care. This was conveyed in subtle ways and through inference as much as the content of what they said and could be described as a sense of them 'knowing their place'. This would align with Goffman's (1961) theory of institutional totality as residents and families are required to adhere to the needs of the institution. Bill and James indicated that they were circumspect about what they said or did within facilities. Bill was the most direct about this and spoke about this at several times during his interview. He did not pose this in any way as being a problem for him, but more in the manner that 'this is the way that things are':

> *I would never attempt to tell someone how to do their own job. You don't know anything about it yourself so why stick your nose in… well I wouldn't like anyone to try and tell me how to do my job, and you wouldn't either. (Bill, Southland)*

Other participant's described a sense of 'knowing their place' but concluded that this was a less comfortable position for them to be in. Peg thought that staff might discuss their opinions of her and their family between themselves and described her decision to avoid visiting at mealtimes in case staff complained about her:

...sometimes I will go about three. But I don't like doing that too often because it looks like I've come with the intention that I want afternoon tea up there. Well, if you did it too often, I know how the staff would disapprove. (Peg, Otago)

Elizabeth felt that she and her husband had been the topic of discussion at the facility where he lived. When she agreed to be interviewed, this was a factor in where she chose to have the conversation:

I don't want you to interview me at the facility, I don't want them to know that I am talking to you. I know that the staff gossip about residents and their families – I've heard them. If they saw me talking to you they would just think that I am complaining. (Elizabeth, Southland).

Elizabeth described her reasons for believing that staff gossiped about the residents through her concerns about staff handover:

When they have hand-over it's at half-past three in the foyer where the reception is. It does annoy me, they are laughing and giggling and carrying on…. I don't think that's a changeover. It should be saying 'keep an eye on Mrs So-&-So in room X'. (Elizabeth, Southland)

Staff in the focus groups acknowledged the need for staff to discuss situations between themselves and that this sometimes involved laughter which could be misconstrued. One of the registered nurses described a situation where two residents developed a relationship within the facility:

We just had to talk about it, and allow people to vent a bit. Because there were always people who thought it was disgraceful….but some had worked in the industry for ages and had insight. They laughed about the (male resident using) aftershave. And I laughed. It wasn't unkind laughter, more like kids… (RN. Southland)

Villar et al. (2014) conclude that gossip occurs between staff within RCFs and that this constitutes a significant barrier to privacy, even if it does assist the staff team to work together and acknowledge differing reactions to situations. The research also recognises a system of resident oversight which is distinct from staff oversight (Eckert et al., 2009; Morgan, 2009). It has been described as a system of resident-to-resident surveillance, which has an all-encompassing effect on a resident's life, including a strong impact on sexuality and intimacy for residents. They quote a participant from their study as saying:

Every new thing becomes a public affair and sexuality also becomes public. There are no secrets and sex needs secrecy, so people hold themselves back, because nobody likes to be the subject of gossip (p.5).

This quote would certainly affirm the views of individual participants in this study. Whilst the term 'surveillance' was not used by either individual participants or staff participants, it was recognisable as a concept in their comments and discussions. It is also important to acknowledge that oversight or surveillance has been described as a three-way process – directed by staff to residents and families, directed by residents to other residents, and lastly directed to staff by residents, partners and families (Eckert et al., 2009; Morgan, 2009; Villar et al., 2014). It is interesting to note that individual participants commented on how surveillance could occur in the number of ways described above, but staff participants only described the surveillance role that they occupied. Several individual participants discussed their role as providing oversight about the standards of care that their partner received, and as described in the previous chapter, Ngaire saw herself as the standard keeper of her husband's care. Before her retirement she had spent her working life as a registered nurse, and she had a clear sense of what she considered to be acceptable care. She described that some staff did not listen to her if she spoke directly to them, so she developed another strategy which she knew was effective from her work experience:

> *I found myself making comments to my daughter in a very loud voice, I knew they would listen to that. Otherwise the staff didn't want to hear if you had any complaints. (Ngaire, Otago)*

Elizabeth was another individual participant (who was not from a health background) and described similar concerns to Ngaire. She had raised these concerns with the facility staff and felt that the facility managers did take her concerns seriously. However, she did not believe that had influenced the care that her husband received:

> *My complaints are about hygiene – don't you wash his hands after using the toilet? They say they don't have to because he's not touching anything, but he has his hands on the handlebars of the standing hoist – how do you know who touched those handlebars before him? If he has to go to the toilet when I am there, I wash his hands for him. (Elizabeth, Southland)*

A significant worry for her was a concern that staff covered up inadequate care, or documented that care tasks had been carried out when they had not:

> *There was some suspicious brown stuff on the tallboy in his room and on the wardrobe – now he can't get out of the chair, so he couldn't have put it there! The cleaner came in and I said 'what's that' and she said 'chocolate', but it was faeces. He had a big brown mark on his back in between his shoulder blades…… it was dried faeces… in the resident's file supposedly he had just had a shower…. (Elizabeth, Southland)*

Elizabeth's fears about her husband's care highlights a possible concern for staff that they will be criticised if care is found to be inadequate and whilst some individual participants were critical, they were also extremely conscious of the workload pressures for RCF staff. They actively worked to support staff in their roles by offering care to their partners where possible, and observed the difficulties that staff had in providing care to all residents at busy times.

Summary

This chapter has explored a number of interconnected aspects of the realities of RCFs. It is clear that residents' partners understand their privacy needs and that they include a combination of relational and physical privacy (Villar et al., 2014). Partners did not perceive a requirement for high levels of physical privacy to maintain an intimate connection with their RCF based spouse, as intimacy was not seen to be dependent on sexual behaviour. Staff views affirm the literature in perceiving that privacy needs were related to specific sexual behaviour (Bouman et al., 2006) and it was difficult for staff to consider sexuality broadly. The views of RCF staff towards male sexuality appears to focus on problematic sexual behaviour despite the recognition that this was relatively uncommon within facilities. There was an absence in the visibility of sexuality for women residents which is borne out by the existing research in this area (Miles & Parker, 2009).

There is also a complex system of oversight, hierarchy and surveillance that operates at many levels within facilities. This seems to be poorly understood by registered staff but is well recognised by carers and partners alike and is affirmed by the literature (Bauer et al., 2013; Mollica et al., 2007; Morgan, 2009; Villar et al., 2014). This system of surveillance can be seen to create an environment where staff, whānau and partners push against each other in endeavours to oversee and provide surveillance for each other's position (Eckert et al., 2009; Morgan, 2009; Villar et al., 2014). An environment which recognises these conflicts and utilises different approaches to care may allow a different approach. Staff attitudes towards older people and their intimacy and sexuality needs were also explored and there was recognition that staff's individual perspectives were shaped by their own family/whanau and relationship experience. This has been identified in the literature (Bouman et al., 2006) and may suggest that this recognition needs to be part of staff training in order for attitudinal change to occur. Otherwise the literature suggests that there is a reliance on educative approaches that do not seem to result in practice changes (Gibson et al., 1999) even if staff develop a more open and uncensorious attitude.

In terms of practice change, one staff participant suggested the development of policies and procedures to lessen the need for individual decision making and consultation through hierarchies of staff. The example of partners being able to stay overnight or bed-share for periods of time with their partner at the end of life is a potential option that could be addressed in this way.

The previous three chapters have examined the significant themes that arose from partner and staff participants. The following chapter further examines and reflects on the findings, leading to the development of recommendations.

CHAPTER SEVEN
FURTHER DISCUSSION, RECOMMENDATIONS
AND CONCLUSION

The aim of this study was to establish how partners of residents in RCFs perceive intimacy/sexuality needs in their relationship and how staff in RCFs perceive these needs. Whilst there were some differences in views between partners, there were many similarities in their perceptions. Similarly, staff had many common views and concerns as well as some individual differences. All participants, both partners and staff acknowledged that placement into a RCF was a significant event with far reaching effects for the resident, the partner and whānau. The differences between the two groups lay in the lack of recognition by some staff of how later life relationships may differ to relationships during younger years. There was also a lack of recognition by some staff about how sexuality and intimacy is positioned in relationships where ill-health is a feature and when the couple are separated through placement into a RCF. Partners identified that they wished to maintain intimacy based sexuality with their partner (hugging, touch, flirting, feeling masculine or feminine) whereas staff either did not consider sexuality needs or were more likely to focus on functional sexuality (libido, and intercourse issues) or cognitive capacity and consent concerns (Ade-Ridder & Kaplan, 1993; Nay & Gorman, 1999; Tarzia et al., 2012). These misunderstandings lead to staff concerns that do not match the wishes and needs of couples in this situation. Additionally, because this is a difficult topic for residents, partners or staff to consider, the situation is unlikely to change readily. This chapter outlines the significant findings of the study, identifies implications and challenges from the work and highlights recommendations for further study. Whilst recommendations are alluded to throughout this chapter, specific recommendations arising from the study are included as a separate list as an appendix.

A changing relationship and a changing life

Marriages undergo change in later life which tends to lead to an increased interdependence between the couple. Whilst relationships can be shaped in many ways, the formal and group contacts that are held outside of the relationship can lessen after retirement and as their same-age friends and family members contend with ill-health or die. Increasingly, the couple provide social companionship and reciprocity to each other (Kelley, 1981) and this can be heightened with ill-health and caregiver responsibilities (Horowitz, 1986). Even if a

relationship has experienced conflict at earlier stages, a couple may be drawn together in the process of aging and coping with ill-health (Ade-Ridder & Kaplan, 1993). Unless the decision for RCF placement arises suddenly, couples are likely to have been contending with changes for some time. When one partner in the relationship becomes a caregiver for the other, this changes the relationship in many ways, creating stress, an inequality of dependence and the need to continually adjust to the situation (Silverstone, 1989). Part of the adjustment process requires the construction and re-construction of a biographical narrative (Howarth, 2000) and the majority of partners in this study had reframed the relationship (Gladstone, 1995). This reframing process occurred before their partner moved to a RCF and included how intimacy and sexuality was perceived in the relationship, placing an emphasis on touch and emotional contact rather than sexual acts. These findings from the study are consistent with the literature (Gott & Hinchliff, 2003; Tarzia et al., 2012; Weeks, 2002). In a similar way to other studies, this study showed that some staff did not have an awareness of this process and the ways that relationships are altered in later life (Eddy, 1986; Hajjar & Kamel, 2004; Luketich, 1991; Roach, 2004). Intimacy and sexuality was framed narrowly by staff, seen specifically as sexual behaviour, and this was often perceived as a problem, necessitating questions about the resident's cognitive capacity for consent. This will be discussed more fully later in the chapter.

Partners saw the move to a RCF as momentous. For many, this was a landmark event in an ongoing process as age and ill-health changed their relationship. They described a process of coping and adjustment which ties with the Dual Process Model (DPM) (Stroebe & Schut, 1999). The DPM outlines the ways that an individual copes with loss (rather than a generic model that describes bereavement more broadly). Stroebe and Schut (2010) define coping as "processes strategies or styles of managing (reducing, mastering, tolerating) the situation in which bereavement places the individual" (p. 274). There are two stressors that the individual has to accommodate: the recognition of the losses that have occurred (loss orientation) and the recognition and re-orientation of oneself within a changed world (restoration orientation). The individual oscillates or moves between the two orientations, having times when each orientation is confronted and avoided. The DPM posits that these times of confrontation and avoidance are necessary and importantly, the individual also has times when they are not involved in either orientation thus gaining 'time out' from the process (Stroebe & Schut, 2010).

Staff showed some understanding of the loss-orientated reactions that partners may experience. They most readily recognised expressions of sadness, loneliness and guilt,

whereas partners also described feelings of anger and frustration. Anger and frustration were less recognised by staff and this can lead to a poorer appreciation of the breadth of experience for partners and residents. It also increases the possibility that emotional reactions may be misunderstood. In the study, some staff alluded to partners and whānau as being 'difficult' if they were perceived as angry, frustrated or critical towards staff or the facility. The restoration orientated responses of partners were less acknowledged overall and many staff did not appreciate that partners may continue to offer care as a way to cope practically with the situation. Providing care continues a life role for the partner and provides a way to maintain connection in the relationship (Ade-Ridder & Kaplan, 1993; Bauer & Nay, 2011). The staff members who did not recognise restoration responses tended to see the assistance of partners as inconvenient or disruptive to facility routine. However, other staff members did recognise this need and were able to describe the importance for residents and partners alike.

The dominance of facility routine for some staff ties with Goffman's (1961) descriptions of Total Institutions where staff consider residents as a 'block' of people to be showered, dressed, fed or otherwise cared for, rather than individuals with their own preferences, routines and wishes. Partners described having a strong awareness of staff attitudes over the matter of routines and other aspects of care. Mostly partners felt that staff were very supportive towards them, and that support was indicated verbally. In contrast, disapproval or critical attitudes were usually communicated non-verbally by staff. This is important as it suggests that many facility norms are communicated covertly rather than overtly, and these norms may vary between individual staff members. Partners were concerned about visiting too often or too little and of being too involved or not involved enough in care tasks, as they felt this had the capacity to 'annoy' staff. Several partners were directly encouraged to visit less often and whilst some experienced this advice as supportive, allowing them to consider ways of re-orientating their life, others experienced this advice as intrusive.

Being alone and being together

RCF placement precipitates many other life changes and decisions for partners. It requires an adjustment to living alone, maintaining a connection with their partner in the RCF and a need to develop relationships with staff in the facility. In adjusting to living alone, the findings of this study were similar to other studies: men tended to find difficulty in the practicalities of running a home and women tended to find difficulty with managing financial aspects and navigating the benefits systems (Baker, 2010; Papastravrou et al., 2011). Adjustment entails practical and emotional adjustments to the situation (Carr & Boerner, 2013; Lazarus &

Folkman, 1984; O'Rourke & Wenaus, 1998) and the Stress and Coping model (SCM) is one way to frame the inter-connected nature of stressors and the need to respond in a number of ways (Lazarus & Folkman, 1984). This interlinked process requires partners to solve practical problems, whilst also reacting and adjusting emotionally and finding a 'bigger sense' or meaning to the situation (Dockendorff, 2014). The lack of informal or formal support for partners to develop the skills required to be a caregiver was evident, including developing a sense of when RCF care might be warranted. Residential care decisions tended to be made at crisis points and led by health professionals rather than through shared decision making between couples, whānau and health professionals. Studies have documented the need for the development of a problem solving approach, learnt caregiving skills, self-care and advanced planning in these circumstances (Angelo & Egan, 2014; Macleod et al., 2012).

Continuing to offer some aspects of care to a partner within a RCF is a way to maintain connection and relationship (Brubaker, 1985). This is distinct from the process of re-orientation to relationship losses as discussed previously. Care tasks included providing special foods, helping at mealtimes and ensuring that their partner was well-groomed. Some staff acknowledged the importance of these tasks but others thought it intruded upon their work and work routines. Again, this ties with the model of Total Institutions where facility routine is paramount and individuality is minimised (Goffman, 1961). Partners perceived the different opinions of staff (communicated non-verbally) and would determine whether to offer help or information depending on the staff on duty. The experience of being observed and evaluated either as a resident, partner or family member is powerful if one's behaviour can be judged as an infraction of the rules. This is particularly powerful if the rules are not always overt or if they change with different staff (Owens & Meyer, 2012). Despite this, partners perceived themselves as an asset, adding to the care that was available to their partner and also lessening the workload for staff who they perceived as overworked and undervalued. This evidence supports Ade-Ridder and Kaplan's (1993) assertion for staff to allow partners to "set the tone for what their continued role will be… defining (the) marriage in a way that serves their needs at this transitory time" (p.21).

Intimacy and sexuality

Western society holds negative views towards the sexuality of older people and people with ill-health, associating sexual expression with youth, beauty and societal attractiveness (Bouman et al., 2006; Weeks, 2002; Yai & Hynie, 2011). If the sexuality of older or ill people creates societal discomfort then this will impact on both older people themselves and staff

who work in RCFs (Hajjar & Kamel, 2004; Heath, 2011). Partners were reluctant to speak directly about sexuality, but spoke very readily about intimacy. They responded to cues from their partner about ways to maintain intimacy and this occurred regardless of the resident's diagnosis. Staff discussed specific sexual behaviour more directly, but spoke less about intimacy and non-sexual touch. Concerns were defined through the resident's diagnosis rather than specific knowledge of the resident. This finding supports existing literature which suggests that diagnosis, cognitive capacity and consent are key concerns for staff contributing significantly to the culture of risk aversion within RCFs, particularly for residents who have dementia (Bartlett, 2010). Conversely, some staff in this study did not differentiate between residents with dementia and those without: all residents were considered as though they had a dementia. The literature has a strong focus on staff concerns when considering sexuality for residents with dementia (Frankowski & Clark, 2009; Roach, 2004; Tarzia et al., 2012). The central concept contrasts the right of a person with dementia to express their sexuality against the concern whether the person has the cognitive capacity to give or withhold consent for sexual contact with another person. It is very important to remember that whilst partners in this study did not want to enact sexual behaviour, some couples may wish to retain a sexual relationship and therefore it is important to consider the barriers that they face.

Staff concerns centred on whether RCF residents were fully aware of their actions and decisions about sexual behaviour. Tarzia et al. (2012) state that staff "have apprehensions about the abrogation of their duty of care and concerns about unlawful activity, anxiety about potential risks to the resident and fear of negative repercussions from a resident's family" (p. 609). Unfortunately, the legislation around mental capacity and decision making does not assist staff as it focusses on legal, financial and medical decisions (rather than sexual decisions), or the worst case scenario of unlawful sexual contact with a person with diminished mental capacity (Heath, 2011). This contrasts with the ethical and legal premise that mental capacity should be assumed unless proven otherwise (Miles & Parker, 1999). Dementia is an illness which exists along a continuum, with mild effects at one end through to severe impairment at the other end, which suggests that a single approach to sexuality and dementia is not appropriate (Tarzia et al., 2012). This study examined intimacy and sexuality within long-standing partner relationships and Carpenter, Kissel, and Lee (2007) found a high level of recognition for individuals with dementia in their marital relationships. They conclude that dementia does not stop people from making and continuously assessing choices around intimacy and sexuality and that these choices are reliable, especially with long standing partners. Staff in this study did not differentiate between long standing relationships

and more recent relationships (that were likely to have developed within the facility) when considering these issues.

Similar to previous studies, staff in this study found aspects of intimacy and sexuality difficult to consider personally and to discuss with residents and colleagues (Horden & Currow, 2003; Reynolds & Magnan, 2005). Senior and registered staff were more open to expressions of intimacy and sexuality when compared to care-worker staff and the literature suggests that the reasons for these differences is due to education and training (Gibson et al., 1999; Horden & Currow, 2003). However, the staff in this study alluded to the hierarchical structures and supervision within RCFs that could expose them to criticism by registered staff or management. It may feel risky if their decisions are judged as an infraction of the rules, especially if it is not clear what the rules are – and none of the staff interviewed had an awareness of sexuality and intimacy-related policies and procedures for the facility they worked in. Tarzia et al. (2012) acknowledge that it is common for there to be no policies and procedures about sexuality and intimacy in RCFs. Registered staff hold responsibility for overall care for specified residents (or at times for the whole facility) and too may feel disinclined to encourage privacy in case they are held to account or criticised for a lack of oversight (Mollica et al., 2007; NZ Nursing Council, 2012). These factors are likely to encourage a restrictive approach to matters of intimacy and sexuality. It is important to consider both staff education and hierarchical factors which perpetuate a risk-averse culture. It is noteworthy that there is less focus on hierarchical factors in the literature compared with educational factors.

The practice of offering partners and whānau the option to stay overnight and to be able to use a companion bed (even if nursing requirements mean this is limited to short periods) in the last days of a person's life is routine in some hospice services, but seems less common in RCFs. Staff perceptions were mixed and some stated that it would inconvenience the nursing and care staff in their tasks, which again prioritises organisational routines over personalised care for residents. Given the increasing role that RCFs are expected to play in providing care at the end of life (Naylor, 2013), this presents a challenge as older people are more likely to receive palliative care in a RCF (Naylor, 2013). The topic of privacy was brought up by both partners and staff participants in the study. Some partners did seek privacy, usually to discuss private family matters or to assist their partner with personal care. Importantly, it was not necessary for intimacy as this involved gestures of touch or communication that could be carried out in front of other people. Similar to previous studies, staff presumed that privacy would be sought in order to be sexual, which then generated concern (Eddy, 1986; Hajjar &

Kamel, 2004; Luketich, 1991; Roach, 2004). This has far-reaching implications on resident autonomy. Whilst staff report that they encourage residents to think of the facility as their home, this does not match with oversight and surveillance concerns, especially when the reasons for privacy are not understood.

Implications for future research

There were limitations to this study in exploring the impact of age, gender and ethnicity on the perspectives of partners and staff. These areas were touched upon but it was not possible to explore them further within the timeframes and scope of the study. Sexual orientation was absent in the discussions of both groups which is also noteworthy. The literature identifies that lesbian, gay, bisexual or transgender residents do not reveal their sexuality or their relationships because they perceive that their relationships will be ignored or stigmatised (Cahill, South, & Spade, 2000; Frankowski & Clark, 2009).

The evidence suggests that the health needs of RCF residents are likely to continue to change, with an increasing number of older residents who have complex medical needs, as well as residents with dementia (Naylor, 2013). The needs and wishes of older people with complex medical needs are less understood in RCF settings compared with residents who have dementia, and will require further examination. There is an ongoing need to review and modify care practices in order to provide care for this group of residents.

The culture of RCFs is also an area that requires further study, as it places resident needs for autonomy and oversight against autonomy and the 'dignity of risk' (Kane & Wilson, 1993; R. Morgan, 2009; Nay, 2002). This balance between conflicting needs is present in other areas of health care, such as residential services for people with learning difficulties and there may be merit in utilising the research and knowledge of services in this area in order to establish a direction for RCFs. Hierarchical structures and aspects of institutional totality (Goffman, 1961) are present within RCFs, and the impact that this places on residents, partners, whānau and staff is worthy of further examination.

Conclusions

Partners in this study provided a rich and multifaceted view of relationships in RCFs and the challenges they face. Their accounts included the challenges of aging, ill-health, change and loss and its impact in their life. Staff described the difficulties in balancing autonomy and privacy and in considering issues around sexuality within RCF culture, and the lack of

practical guidance through policies and procedures. The invisibility of older people's intimacy and sexuality in society in general compounds the invisibility of this issue, and may hinder the consideration of this aspect of care. Nevertheless, the link between relationships and quality of life for residents and partners is being recognised as important and is likely to become a consideration within audit and quality structures (Tolson et al., 2014). The view of relationships, sexuality and intimacy is continuing to change in contemporary Western society (Giddens, 1992) and future residents of RCFs may have very different views, wishes and needs to current residents and their partners. Future residents may be single, may have had a number of relationships across their lifetime or may be in a same-sex relationship. Staff attitudes, practices and systems will need to able to accommodate these differing configurations and embed ways of responding to intimacy and sexuality considerations as part of holistic care. Residents and partners, now and in the future deserve nothing less.

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APPENDIX A: Partner consent form

"Still a couple?" A case study of sexuality and intimacy concerns in Residential Care from the perspective of residents' partners and care staff.

CONSENT FORM

Residents' partners

I have read the information sheet concerning this project and I understand the nature of this research. All my questions have been answered to my satisfaction and I understand I am free to request further information at any stage.

Following signature and return to the research team this form will be stored in a secure place for ten years.

1. I agree to take part in this research, and that my participation is entirely voluntary

2. I understand that I will be asked my opinions through an open questioning technique, and that the precise questions have not been determined in advance, however, I understand that I can decline to answer any question(s) that I feel uncomfortable with or withdraw from the interview at any time, without giving a reason

3. I agree to be audiotaped

4. If I was to become uncomfortable or distressed by any aspects of the interview, I can stop the interview at any time. I can also ask for a referral to an appropriate counsellor.

5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time without disadvantage.

6. I understand that I will be able to review the transcript of the interview should I wish to

7. I understand that potential recipients of the research will include residential care providers, palliative care providers, policy makers and other researchers

8. I know that I will not be named or identified in any of this research

9. I know that when the study is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the study, and that these will be placed in secure storage and kept for at least ten years. After this time, they will be confidentially destroyed

10. I understand that I will receive a $20 voucher for my participation in the interview.

11. If you would like a summary of the findings, please provide an address to which this can be posted:

_____

Name: --

Signature: --- Date: ----------------------------

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (telephone: 03 479 8256). Any issues you raise will be treated in confidence and investigated and

Participant Information Sheet

For partners' of residents in Residential Care Facilities

Project title: **Still a couple? A case study of sexuality and intimacy concerns in Residential care from the residents' partners and care staff.**

Principal Supervisor: Associate Professor Gillian Abel, Department of Population Health, University of Otago. 03 364 3619, Gillian.Abel@otago.ac.nz

Secondary Supervisor: Dr Lee Thompson, Department of Population Health, University of Otago. 03 364 3644. Lee.Thompson@otago.ac.nz

Researcher: Clare Greensmith, Master of Health Science Degree Student, Department of Population Health, University of Otago. **021 042 5855** grecl820@student.otago.ac.nz

Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project?

Scientific research suggests that having time with your partner in the usual ways you have as a couple is very important. This continues to be important even if people are living separately because of their care needs, or if they are very ill.

The reason for interviewing you is to gain your perspective as a partner on the relevance of these issues. The insights gained will contribute to research which is part of a Masters' thesis. Ultimately this information will help to identify what Residential Care home staff might do to support couples in this way.

If you participate, what will you be asked to do?

I invite you to take part in my research by participating in an interview. This this audio-taped interview will likely take about an hour of your time. I will ask you to talk about your experience now as a partner of someone who is living in a Residential Care Facility, when previously you lived together as a couple. It is up to you what you say and you do not have to answer any questions that you don't want to. Before the interview, you will need to complete a Participant Consent Form. Your participation is entirely voluntary.

In acknowledgement of your time, you will receive a $20 supermarket voucher.

Should the interview raise past issues related to grief or sexuality, then you will be given information about counselling services that you can approach

Confidentiality

Your anonymity and confidentiality will be respected, and there will be nothing to identify you associated with the information we collect. Your identity will be protected by:

- Not using participant names. Instead of using names on an interview transcript, a number code will be assigned.

- The audio tape of the interviewer will be transcribed by the researcher.

- Any data, including that on paper and audio recordings will be stored securely for a period of ten years and then confidentially destroyed.

- When this research is published or reported, it will be done in a way that does not identify you or anyone else, or identify a residential care facility.

Who is funding this project?

This project is being funded by the Department of Population Health at the University of Otago.

Who are we seeking to participate in the project?

There will be approximately 12 to 15 partners recruited into this part of the study.

If you agree to participate, can you withdraw later?

You may withdraw from participation in the interview at any time and without any disadvantage to yourself, and you do not have to give a reason for doing so.

Any questions?

If you have any questions now or in the future, please feel free to contact any of the people listed at the top of the Information Sheet:

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

APPENDIX B: Focus group consent form

"Still a couple?" A case study of sexuality and intimacy concerns in Residential Care from the perspective of residents' partners and care staff.

CONSENT FORM

Focus Group participants

I have read the information sheet concerning this project and I understand the nature of this research. All my questions have been answered to my satisfaction and I understand I am free to request further information at any stage.

Following signature and return to the research team this form will be stored in a secure place for ten years.

1. I agree to take part in this research, and that my participation is entirely voluntary

2. I understand that the group will be asked to offer their opinions through an open questioning technique, and that the precise questions have not been determined in advance. However, I understand that I can decline to answer any question(s) that I feel uncomfortable with or withdraw from the Focus Group at any time, without giving a reason

3. I understand that it will not be possible for me to withdraw spoken data once it has been provided.

4. I agree to be audiotaped

5. If I was to become uncomfortable or distressed by any aspects of the focus group. I can also ask for a referral to an appropriate counsellor.

6. I know that my participation in the project is entirely voluntary,

7. I understand that I will be not be able to review the transcript of the focus group.

8. I understand that audiotapes of the group will not be made available in order to protect the privacy of all participants.

9. I agree not to disclose anything discussed in the focus group

10. I understand that potential recipients of the research will include residential care providers, palliative care providers, policy makers and other researchers

11. I know that I will not be named or identified in any of this research

12. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the study, and that these will be placed in secure storage and kept for at least ten years. After this time, they will be confidentially destroyed

13. I understand that I will receive a $20 voucher for my participation in the interview.

14. If you would like a summary of the findings, please provide an address to which this can be posted:

_____

Name: --

Signature: -- Date: ----------------------------

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (telephone: 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Participant Information Sheet

For partners' of residents in Residential Care Facilities

Project title: **Still a couple? A case study of sexuality and intimacy concerns in Residential care from the residents' partners and care staff.**

Principal Supervisor: Associate Professor Gillian Abel, Department of Population Health, University of Otago. 03 364 3619, Gillian.Abel@otago.ac.nz

Secondary Supervisor: Dr Lee Thompson, Department of Population Health, University of Otago. 03 364 3644. Lee.Thompson@otago.ac.nz

Researcher: Clare Greensmith, Master of Health Science Degree Student, Department of Population Health, University of Otago. **021 042 5855** grecl820@student.otago.ac.nz

Introduction Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project? Scientific research suggests that having time with your partner in the usual ways you have as a couple is very important. This continues to be important even if people are living separately because of their care needs, or if they are very ill. The reason for interviewing you is to gain your perspective as a partner on the relevance of these issues. The insights gained will contribute to research which is part of a Masters' thesis. Ultimately this information will help to identify what Residential Care home staff might do to support couples in this way.

If you participate, what will you be asked to do? I invite you to take part in my research by participating in an interview. This this audio-taped interview will likely take about an hour of your time. I will ask you to talk about your experience now as a partner of someone who is living in a Residential Care Facility, when previously you lived together as a couple. It is up to you what you say and you do not have to answer any questions that you don't want to. Before the interview, you will need to complete a Participant Consent Form. Your participation is entirely voluntary. In acknowledgement of your time, you will receive a $20 supermarket voucher. Should the interview raise past issues related to grief or sexuality, then you will be given information about counselling services that you can approach

Confidentiality Your anonymity and confidentiality will be respected, and there will be nothing to identify you associated with the information we collect. Your identity will be protected by: Not using participant names. Instead of using names on an interview transcript, a number code will be assigned. The audio tape of the interviewer will be transcribed by the researcher. Any data, including that on paper and audio recordings will be stored securely for a period of ten years and then confidentially destroyed. When this research is published or reported, it will be done in a way that does not identify you or anyone else, or identify a residential care facility.

Who is funding this project? This project is being funded by the Department of Population Health at the University of Otago.

Who are we seeking to participate in the project? There will be approximately 12 to 15 partners recruited into this part of the study.

If you agree to participate, can you withdraw later? You may withdraw from participation in the interview at any time and without any disadvantage to yourself, and you do not have to give a reason for doing so.

Any questions? If you have any questions now or in the future, please feel free to contact any of the people listed at the top of the Information Sheet:

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

APPENDIX C: Semi structured interview guide – partner participants

PARTNER INTERVIEW GUIDE

Introductions and opening comments, details of interviewee, date, time and place. Ask interviewee to confirm their consent to be interviewed and taped. Repeat and confirm conditions of the interview and purpose of study.

1. Establish the interviewee's situation in relation to their contact/ relationship to RCF.
2. Ask interviewee to tell their story about their partner's decision to go into Residential care, and their thoughts about this decision.
3. Ask interviewee how they have been able to maintain a sense of being a couple since the move. Explore specific intimacy/ sexuality needs, and if their sense of being a couple has been maintained, how this has occurred, and what has helped them to do so.
4. If they do not think this has been possible, explore how this has occurred and what has hindered them.
5. Explore their views of facility procedures which encourage or support privacy, intimacy and sexuality needs, and respect of the relationship.
6. Explore their views of staff attitudes and behaviour that encourage or support privacy, intimacy and sexuality needs, and respect of the relationship.
7. If not already covered explore what could assist them and their partner in the future.

Close interview with discussion of follow up supports that are available to them if the content/ process of this discussion has been distressing or upsetting. Thank interviewee for their participation and offer food voucher.

APPENDIX D: Semi-structured interview guide – staff participants

STAFF FOCUS GROUP

Introductions and opening comments, details of focus group process, date, time and place. Repeat and confirm conditions of the focus group, and that comments will not be attributed to either an individual or a facility. Offer food platters/refreshment in recognition of participants' time.

1. Ask group to introduce themselves. Introduce study topic area.
2. Ask group members if they can think of any situations where one person in a couple had moved into a RCF (and is thought to be in the last year of life) and then ask them to describe the situation, including their observations and perceptions of this situation for the resident and for the home-based partner.
3. Ask group members what this was like for them in their role.
4. Ask group to consider and explore how they would assess the sexuality and intimacy needs of residents and their partners in the facility, particularly those who are thought to be in the last year of life.
5. Explore their views of staff attitudes and behaviour that encourage or support these needs and respect of the relationship.
6. Explore the views of staff attitudes and behaviour that discourages or hinders these needs and respect for the relationship.
7. Explore their views of facility culture which encourage or support intimacy and sexuality needs and respect of the relationship.
8. Explore their views of facility culture which discourage or hinder intimacy needs and respect of the relationship
9. If not already covered explore what else could assist this area of care to be achieved.

Close group with discussion of transcription process Discuss follow up supports that are available to them if the content/ process of this discussion has been distressing or upsetting.

Thank group for their participation.

APPENDIX E: Full List of Recommendations

- The needs of different resident groups within RFCs should be further researched in order to ensure current facility practice meet the needs of these groups.

- RCF staff should recognise and take account of the full spectrum of emotional experience for residents and their partners when grieving, coping with loss and transition during and after placement. This recognition needs to influence the care that is offered.

- RCF staff should recognise and take account of relationship reframing which can occur when ill-health occurs within a couple. This recognition needs to influence the care that is offered.

- RCF staff should recognise and take account of the differences between intimacy, sexuality and sexual behaviour, and be able to apply this to resident relationships in their work environment

- RCF staff should recognise the impact of their own views and attitudes on intimacy, sexuality and sexual behaviour in their work with residents, and take appropriate steps to minimise any effects on their work with residents.

- RCF staff should recognise their own needs for self – care when considering intimacy and sexuality for residents and be able to identify and access appropriate sources of support and assistance when required.

- Develop referral pathways and access criteria that allows partners of RCF residents to access NASC (Needs Assessment and Service Co-ordination) services and community social work at periodic times when required.

- Encourage facility managers and senior staff to explore the impact of RCF hierarchy on staff decisions around resident sexuality and intimacy.

- Encourage facility managers and staff to develop standardised policies and procedures which support intimacy and sexuality considerations for residents. This needs to be underpinned with the appropriate skills training to enable staff to communicate with

residents and partners, establish needs and then translate this to goals of care within the care plan.

- Ensure that group supervision or case review opportunities are available to staff teams when there are difficulties or differences in approach towards resident intimacy and sexuality issues.

- Ensure that there are individual supervision opportunities available for staff when difficulties are identified that relate to intimacy or sexuality considerations for residents.