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"It's been a good move" - Transitions into care: Family caregivers', persons' with dementia, and formal staff members' experiences of specialist care unit placement

by

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Thesis submitted to the School of Social Work

and Social Policy

Trinity College Dublin

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Summary

Specialist care units (SCUs) are segregated purpose-built long-term care (LTC) settings specifically designed to cater for the complex needs of people with dementia (PwDs). Whilst beneficial outcomes of these units for PwDs, family caregivers (FCs) and staff have been demonstrated in quantitative research, qualitative research reporting in-depth on such experiences is largely neglected. This is particularly true in Ireland. Little is known about why and how the placement decision is made, how news of the transfer is communicated to PwDs, what PwDs' and FCs' experiences are of adapting to SCUs immediately after placement, what their more long-term adaptation experiences are, and what staff's experiences are of deciding about new admissions. This thesis set out to explore these issues in-depth.

Choosing a constructionist-phenomenological approach, an inductive multiple case follow-up research design was used for the thesis. Three different SCUs located outside Dublin were recruited to the research conducted for this thesis. Individual in-depth interviews were held with nine FCs and nine PwDs at one month post-admission and six months later. Focus groups (FGs) were conducted with 12 staff members. Data emerging from both interviews and FGs were analysed by using Interpretative Phenomenological Analysis (IPA).

Findings showed that immediately prior to placement FCs were very stressed and received few formal support services. The issues that caused them most distress were dementia-related challenging behaviours including aggression, dangerous behaviour, sleep disturbance, and incontinence. Several also had major concerns about their relatives' safety. The rich qualitative data show the way in which dementia care not only affected the lives of the FCs but also had an adverse effect on other members of the extended family network. The stress of caring was exacerbated by lengthy waiting times

for a permanent bed and patchy residential respite services. Data revealed that making the placement decision was complex; it was made for several interrelated reasons including PwDs' extensive care needs, challenging behaviours, lack of adequate support, safety concerns and the unsuitability of the home care environment. This thesis provides new insights into how FCs communicated news of the placement to their relative.

New insights were also provided into staff's experiences of new admissions. It was shown that their decision was guided by a complex set of admission criteria including wait-list status. Deciding about new admissions was a distressing experience for staff as it always meant the loss of long-known residents, coping with FCs' emotional reactions, and adapting to new residents' complex needs. Findings also showed a lack of psychosocial supports for staff.

Data revealed that PwDs adapted to their new environment both immediately after placement and more long term. Improvements noted included increased levels of socialising and physical activity, improved communication skills, fewer challenging behaviors, weight gain, and improved mobility. Some disimprovements noted included wanting-to-go-home behaviours, increased levels of withdrawal, depression, mobility problems, and eating problems. Data showed that FCs remained stressed after the transfer. They had to adapt to new roles and responsibilities including visiting, monitoring PwD's well-being and liaising with staff. They also had to deal with sometimes paradoxical emotions such as guilt yet relief, happiness yet sadness, security yet uncertainties about the future.

These findings point to a need for improved community supports for families. There is also a need for more realistic funding to be set aside for SCUs. These specialised care settings are obviously a very scarce resource in the Irish dementia care landscape and there is a need for further research on the effectiveness of these units and for more of these facilities to be developed.

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List of abbreviations

AD	Alzheimer's disease
ADL(s)/IADLs	Activity(ies) of daily living/Instrumental activity(ies) of daily living
ASI	The Alzheimer Society of Ireland
CI	Cognitive impairment
DoHC	Department of Health and Children
DSIDC	Dementia Service Information and Development Centre
FC(s)	Family caregiver(s)
FG(s)	Focus group(s)
GP(s)	General practitioner(s)
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
HSP(s)	Health service provider(s)
IPA	Interpretative Phenomenological Analysis
LTC	Long-term care
MMSE	Mini-Mental State Examination
OECD	Organisation for Economic Co-Operation and Development
OTA	Office of Technology Assessment
PHN(s)	Public health nurse(s)
PwD(s)	Person(s) with dementia
SCU(s)	Specialist care unit(s)
UN	United Nations
VD	Vascular dementia

Chapter 1: Introduction

1.1 Background

The scale of dementia is significant and has implications for the lives and the well-being of all those affected by the illness (Gillies, 2001; O'Shea & O'Reilly, 1999; Prince, 2009). Whilst most people with dementia (PwDs) live at home in the community, there comes a time when, due to increasing disability, challenging behaviours, caregiver burden and/or the absence of adequate family or service support, long-term care (LTC) will be required for many (Annerstedt et al., 2000; Cahill, O'Shea, & Pierce, 2012; O'Shea & O'Reilly, 2000). Specialist care units (SCUs) represent one type of dementia-specific LTC option and are designed to cater specifically for the complex needs of PwDs (Brawley, 2001; Calkins 2001; Day, Carreon, & Stump, 2000; Habell, 2012; Van Hoof et al., 2010). To date, knowledge on many aspects of the process of admitting PwDs into a SCU is limited as is information on how PwDs settle into SCUs in the short term and more long term. This is particularly the case in Ireland (Argyle, Downs, & Tasker, 2010; Myers et al., 2007). It is for this reason that I have chosen the subject matter for this thesis, namely, admitting PwDs to SCUs, investigating how caregivers cope with the transition and how PwDs adapt to and settle into the new facilities over time. The next section introduces the broad topic by first discussing the magnitude of dementia globally and in Ireland.

1.1.1 Scale of dementia

The world's population is ageing and several factors including increased life expectancy, advances in medical treatments, technology and the recent demographic transition (a shift from high fertility and mortality rates to declining birth rates and low mortality rates) explain this phenomenon (Prince, 2009; Timonen, 2008). There are currently about 760

million people aged 60 years and older in the world; this number is projected to increase to over two billion by 2050 (UN Department of Economic and Social Affairs, 2011). Alzheimer's disease (AD) is the most common form of dementia and age is a key risk factor for developing AD and indeed other dementia subtypes (Gorelick, 2004; Launer et al., 1999). Over the age of 65 the prevalence of dementia doubles every five years (Corrada et al., 2010, p. 114; Cummings & Cole, 2002, p. 2335). Population ageing therefore means increasing dementia prevalence rates globally. There are currently 36 million people living with dementia worldwide (Prince, 2009) and numbers are predicted to increase to over 81 million by 2040 (Ferri et al., 2005). In this context Ireland is no exception in witnessing population ageing and it is this cohort of people aged 65 years and over who have a heightened risk of developing a dementia. According to recently published dementia prevalence estimates based on EuroCoDe's age- and gender-specific prevalence rates, there are currently 41,740 PwDs in Ireland and their number will increase to 147,000 by 2041 (Cahill, O'Shea, & Pierce, 2012).

1.1.2 Meanings of dementia

"Dementia" is an umbrella term that is used to describe a group of disorders with similar symptoms but different causes i. e. diseases that contribute to the illness (World Health Organization, 2013). It is a general neurodegenerative syndrome characterised by progressive impairment of various memory and cognitive skills such as learning, communicating, understanding, and decision-making (World Health Organization, 2013). These cognitive changes are usually associated with changes in emotional status, behaviours, and social relationships (World Health Organization, 2013). Dementia thus presents an all-encompassing condition with life-changing implications for the health and well-being and quality of life of those affected by dementia (Harris, 2002, pp. xviii-xix).

Dementia is a progressive and generally terminal condition causing irreversible decline in the person's psychosocial and physical functioning (Jenkins & Price, 1996). The underlying pathology of AD and most dementia subtypes is neurological and most

dementias cannot be cured by any medical treatments (Boller & Forbes, 1998; Jenkins & Price, 1996; World Health Organization, 2013, p. 8). Not surprisingly, the traditional approach to understanding and treating dementia has predominantly been biomedical (Adams, 1996; Bond, 1999; Lyman, 1989). This biomedical approach means viewing those affected largely as "diseased" or "atrophied" brains and seeing everything about that person through their dementia. This approach has led to individuals being labelled as "sufferers" and "victims" of an incurable disease where nothing can be done (Iliffe, Wilcock & Haworth, 2006; Woods, 1995). This rather nihilistic approach has resulted in PwDs and their caregivers being marginalised. It has also led to dementia not getting the budgetary and political attention an illness of its magnitude deserves (Illiffe, Wilcock & Haworth, 2006; Woods, 1995). For example, Woods explains that traditionally:

> "caring for those with a dementia has been seen as an unrewarding, relentless round of basic physical care and menial tasks, carried out in large, decaying, under-resourced institutions, by poorly paid and poorly motivated staff (...) expectations were of further decline to death, almost as if bodies were being looked after until their time to depart arrived, the mind long since having gone." (Woods, 1995, p. 116).

Such negative attitudes towards dementia and dementia care, as perpetuated by the biomedical model, have for some decades been challenged largely by social and behavioural scientists who have sought to promote a less medicalised, more individualised and holistic culture of dementia care (Gilliard et al., 2005). Probably the most influential of these social and behavioural scientists was the psychologist Tom Kitwood who as far back as the late 1980s commenced challenging the medical model (Brooker, 2007, p. 15; Kitwood, 1987). Kitwood essentially revolutionised thinking on dementia by putting forward his own theory of dementia – a theory that was underpinned by a social/disability approach and which argued for the need to recognise personhood. He defined personhood as;

> "that standing or status that is bestowed upon one human being by others, in the context of social being. It implies recognition, respect and trust." (Kitwood, 1997, as cited in Buron, 2008, p. 324)

Kitwood's approach to understanding and theorising about dementia care sought to redirect attention away from the illness and towards the person experiencing the symptoms (Epp, 2003). Although not denying the fact that the underlying illness is neurological, Kitwood viewed dementia as being one facet of a person's life and not the person's entire life (Kitwood, 1997). Other researchers and experts have over the years advanced Kitwood's theory (Adams & Gardiner, 2005; Brooker, 2007; Kontos, 2005; Nolan et al., 2004).

Kitwood and later other experts both in the UK and internationally were successful in reconceptualising dementia to consider the illness not only as an organic health problem but also to regard dementia as a disability. These writers claim that people living with the disability of dementia may be supported or hindered depending on the type of service providers they meet and experiences they encounter in their journey through the illness. They argue that opportunities for having a social life, participating in society, achieving personal growth, and ultimately experiencing a high quality of life are strongly determined by the societal contexts (including place and institutional arrangements) in which these people with dementia live (Gilliard et al., 2005). Quality of life can be promoted or hindered depending on the attitudes of others, the physical and built environment, staff training and occupation including involvement in meaningful activities.

This view of dementia necessitates treating a person diagnosed as a human being whose personhood, dignity, and human rights remain untouched for as long as they live; as a skilled and gifted fellow person who continues to contribute to society in many different ways; and as people who can, and deserve to, have an optimum quality of life throughout the course of their dementia. This perspective has strongly influenced the thesis.

1.1.3 Reasons for LTC

As mentioned dementia is a chronic progressive and usually irreversible condition not generally responsive to drug treatments. Thus, having dementia has correctly been compared to being on a journey in the lives of those affected (Cayton, 2004; Peacock et al., 2010; Teel & Carson, 2003). As the dementia progresses, the person's care needs are likely to intensify over time. This places increasing levels of strain on FCs – thus rendering their 'care-giving journey' a challenge (Boland & Sims, 1996; Connell, Janevic, & Gallant, 2001; McFarland, 2010). However, caring for a relative with dementia can also have positive outcomes for FCs, such as personal growth, a sense of fulfilment, and increased resilience (Connell, Janevic, & Gallant, 2001; Netto, Jenny, & Philip, 2009; Peacock et al., 2010; Zarit et al., 2012).

In Ireland like in other countries, most PwDs live at home and both Irish and international research shows that most older people would prefer to stay at home for as long as possible (Cahill, 2010; Garavan et al., 2001, p. 23; World Health Organization, 2012). Research also shows that PwDs living in the community are usually cared for by family members, most of whom are women (Cahill, O'Shea, & Pierce, 2012, p. 81; World Health Organization, 2012, p. 69). These studies also indicated that most FCs are willing to continue caring for their relative with dementia at home but would like some recognition for the care work they carry out (Cahill, O'Shea, & Pierce, 2012; O'Shea, 2007; World Health Organization, 2012, p. 71).

Although care needs of a person diagnosed with dementia increase over time (ALZinfo, 2013), people with early-stage dementia are usually able to manage at home reasonably independently with some minor support from FCs and community support services such as meals-on-wheels, in-home day care, and home help (Gillespie et al., 2012). In some countries today, PwDs with a mild dementia are increasingly able to use a growing range of assistive technologies designed to maintain their safety, orientation and independent living at the early stages of their dementia (Van Hoof et al., 2010). As dementia

progresses, those with a more moderate to severe impairment however tend to experience various and more complex losses and changes in their everyday functioning and skills such as loss of activity of daily living (ADL) and instrumental activity of daily living (IADL) skills, verbal and non-verbal communication skills, and orientation (ALZinfo, 2013). ADLs are hygiene and personal care activities performed on a regular basis, such as washing, toileting, dressing, and eating; IADLs are activities performed by an individual in order to continue living autonomously, such as cooking, handling money, shopping, and laundering (Spector & Fleishman, 1998; Won et al., 2002).

PwDs with moderate to severe dementia may also develop complex and challenging behaviours which may be difficult to manage for caregivers. These challenging behaviours may include aggression, paranoia, delusions, repetitive questioning, apathy, agnosis, sleep disturbance, restlessness, and agitation (ALZinfo, 2013). Some may also neglect their own personal hygiene and have difficulties reading, writing, and communicating verbally (Dick, 2006; McKhann et al., 2011).

With severe dementia, intensifying care needs mean that care-giving responsibilities may become around-the-clock and all-consuming (Butcher, Holkup, & Coen Buckwalter, 2001, p. 44; Meuser & Marwit, 2001, p. 670). FCs may be required to assist their relatives with all activities of independent living (Spector & Fleishman, 1998) including dressing, feeding, mobilising, toileting, showering, assisting them to take medication and monitoring their safety inside and outside the house on an ongoing basis (Shaji et al., 2003). These increasing caring responsibilities can be physically demanding and emotionally draining, placing increasing levels of strain on FCs (Butcher et al., 2001, p. 475; Ryan & Scullion, 2000b; Samuelsson et al., 2001). Most families caring for a relative with advanced-stage dementia also need more extensive help from formal support services, such as respite day care, residential respite care, and information/ education services (Philp et al., 1997; Wenger, Scott, & Seddon, 2002, p. 34).

People make decisions about placing their relatives with dementia in LTC for a diverse range of reasons (Naleppa, 1997). It is not surprising that the severity of dementia and the carer's inability to continue care-giving figure among these reasons (Park, Butcher, & Maas, 2004, p. 350). Often when the demands of care-giving become so great that the carer's own health and welfare is compromised LTC for the PwD is considered (Butcher et al., 2001; Caron, Ducharme, & Griffith, 2006; Ryan & Scullion, 2000b). The exact timing and the specific reasons for deciding to place a loved one with dementia in LTC are complex, individual and apart from caregiver burden the individual's safety and heavy dependency needs are also important issues needing careful consideration (Argyle, Downs, & Tasker, 2010). The placement decision may also be influenced by the level and quality of community supports provided to the family. Unreliable and fragmented community support services may result in premature or unnecessary institutionalisation of PwDs (Argyle, Downs, & Tasker, 2010, p. 6; Davies & Nolan, 2003, p. 431; Park, Butcher, & Maas, 2004, p. 351). The decision to place a relative with dementia in permanent care may also be influenced by the family's prior experiences of using residential respite care. Whilst some quantitative studies have shown contradictory results as to the role residential respite care plays in accelerating or delaying the permanent placement (Jeon, Brodaty, & Chesterson 2005, p. 301), a few qualitative studies demonstrate that using residential respite might actually help to progress FCs' decision to place their relative in LTC due to increased levels of familiarity with the care environment (Argyle, Downs, & Tasker, 2010, p. 15; Ashworth & Baker, 2000, p. 55).

1.1.4 Specialist residential care in Ireland

Despite repeated calls for a wider range of LTC options in Ireland for older people with dementia (O'Shea, 2007; The Alzheimer Society of Ireland, 2007) there are few alternatives to the traditional nursing home model for those who require residential LTC (Cahill, O'Shea, & Pierce, 2012, p. 106). This is in direct contrast with some other countries around the world as for example the USA, Australia, Norway and the Netherlands where small-scale group living has been part of the LTC landscape for over

three decades (Verbeek, 2011). In the USA for example the "Eden" and "Green House" model has been in operation since the 1980s (Rabig et al., 2006).

Most people who have dementia and are in LTC in Ireland are in general nursing homes which have not been adapted to cater for the complex needs of PwDs (Cahill, O'Shea, & Pierce, 2012b, p. 25). In other European countries, the UK, the USA, the Netherlands, Scandinavia, and Australia a range of alternative care options such as sheltered housing, small-scale group housing, housing with care and SCUs are offered to those in need of dementia-specific permanent care (Cahill, O'Shea, & Pierce, 2012, p. 106).

SCUs are long-stay care settings specifically designed to meet the unique and complex needs of PwDs (Calkins, 2001; Fleming & Purandare, 2010). The advent of SCUs is a relatively recent development in the provision of institutional care to PwDs in Ireland and it is difficult to trace their exact origin, given there is no real definition in Ireland as to what a SCU is and no register or listing available as to where these units are located and how they are administered. Due to their recent establishment and because of the fact that the development of SCUs in Ireland has been "ad hoc" and has not officially been documented (for instance by a nationwide register) there is no data available on when and under which circumstances the first SCUs emerged in Ireland. For example, Moïse et al. (2004, p. 44) reviewed the status quo of dementia care in nine OECD countries and concluded that SCUs have recently been or are currently being developed in Ireland as well as in other European countries including France, Sweden, the Netherlands, and Germany. As stated in other countries, SCUs have been in existence for several decades. In fact, in the USA the first SCU was established as early as 1965 (Cahill, O'Shea, & Pierce, 2012, p. 109).

SCUs do not represent a uniform type of care setting but rather vary widely in their individual set-up and organisation (Moïse et al., 2004, p. 44). Despite this 'individual' element, however, an international consensus exists on universal principles of SCU

design and care (Fleming & Purandare, 2010; Judd, Marshall, & Phippen, 1997; Sloane & Matthews, 1991). According to this consensus, SCUs should aim to promote personhood; focus on the person and his/her needs; enhance the PwD's identity, self-confidence and self-esteem; maximise awareness and independence; be meaningful and understandable to the PwD; enable the PwD to optimally use his/her skills; compensate for disabilities; involve families and the community; care for staff; and offer orientation and appropriate stimulation (Van Hoof et al., 2010, p. 206). These universal design principles it is argued should be implemented in SCUs through combining a purpose-built small-scale physical environment with a person-centred holistic model of care (Schwarz, Chaudhury, & Brent Tofle, 2004, p. 176).

1.1.5 Implications of moving into specialist LTC

Because Ireland's population is ageing and age is the strongest risk factor for dementia, it is estimated that in the future larger numbers of Irish people will require LTC because of their dementia. This assumes that in the foreseeable future no cure will be found for dementia. It is not only that there will be more people diagnosed (higher dementia prevalence rates) but arguably other factors impacting on care-giving such as the unavailability of informal caregivers and the scarcity of community-based statutory and voluntary care-giving arrangements will place additional demands on long-term residential care services (Cahill, O'Shea, & Pierce, 2012, p. 41; Macdonald & Cooper, 2007). It is important to acknowledge, however, that changing family structures (more older people with dementia, fewer younger caregivers) are altering traditional family caregiving structures (Antonucci et al., 2011; Bengston, 2001; Kobayashi, 2005). The most prominent example of these changing structures is the so-called beanpole family where "more generations" are "surviving because there are fewer kin in each generation" (Johnson & Troll, 1996, p. 178). Such "verticalization of the family" (Johnson & Troll, 1996, p. 178) may for example result in FCs themselves being aged 65 years and over; increasing numbers of men caring for their wives/ partners with dementia; and social

networks (friends, neighbours) outside the family playing increasingly a role in dementia care (M. Pierce, personal communication, 25/04/2013).

These changes in family care-giving arrangements may therefore not linearly lead to increasing demands for SCU LTC (and LTC in general). Despite this debate we need to know a lot more about how people access SCUs; how they experience the transition from home into SCUs and how both PwDs and their FCs adapt to changing and changed circumstances.

SCUs are an important feature of the LTC provision system. As such, SCUs represent one type of LTC setting but are unique and distinct from other (generic) LTC settings (for example, nursing homes) because of their purpose-built environment and a holistic, person-centred approach to care. However, by virtue of their being a *LTC setting* (yet specialising in dementia) and because of the scarcity of literature on the topic of admitting PwDs into SCUs, I mostly drew on the literature about LTC admission in general and contrasted the latter with literature available on the topic of moving into SCU LTC.

Moving into a LTC facility in general represents a significant life event for PwDs and FCs alike (Aminzadeh et al., 2009; Butcher et al., 2001; Castle, 2001; Kellett, 1999; Nolan et al., 1996; Reed-Danahay, 2001). The relocation may well affect the well-being and quality of life of all those affected by dementia. The move itself is a highly complex process, which has often been considered to occur over a lengthy period of time. It involves several different stages and includes the involvement of several different people both prior to, during and after the move itself (Castle, 2001; Naleppa, 1997). It is associated with significant psychological and social challenges for those affected by the LTC placement (Schumacher & Meleis, 1994).

Regarding the move into LTC in general, the literature shows that FCs often have to cope with ongoing distressing and ambiguous emotions including guilt, sadness and relief about

their relative's placement while at the same time adapting to new care-giving roles – such as monitoring their relative's safety and welfare in the nursing home, liaising with staff, and visiting (Davies & Nolan, 2006; Ryan & Scullion, 2000a). Regarding the PwD, the move means that he/she has to adapt to a new environment – learn to recognize new faces, navigate unfamiliar surroundings, socialise with peers and staff, and adjust to the facility's care routines (Myers et al., 2007). The adaptation may require time and considerable emotional and cognitive reserve, and may even result in failing health and increased mortality among PwDs after placement (Aneshensel et al., 2000).

Research findings on the topic of *moving to* as well as *living in* LTC, however, are overall mixed for PwDs and FCs (Castle, 2001, p. 324; Thorson & Davies, 2000). The research literature tends to be heavily dominated by quantitative studies (Day, Carreon, & Stump, 2001; Doody et al., 2001; Lai et al., 2009; Sloane et al., 1995; Sloane et al., 1998; Swanson, Maas, & Buckwalter, 1994; Zeisel et al., 2003). There are few qualitative studies on the topic of moving into and adapting to SCUs (Bramble, Moyle, & McAllister, 2009; Butcher et al., 2001) and as far as I am aware none that in particular attempts to investigate the topic from a variety of different perspectives including the viewpoint of the PwD.

Regarding quantitative research the inconclusive findings arising from these studies suggest that the way people adapt to the transition into residential LTC is individual and always relates to the contexts within which the transition experience is embedded. These contexts are multifaceted and include the PwD's health and well-being status, his/her level of cognitive and functional impairment, FCs' level of resilience and caregiver distress, and the quality of environment and care provided by the long-stay facility (Castle, 2001, p. 296; Elmståhl, Ingvad, & Annerstedt, 1998, p. 134).

These studies have shown both positive and neutral effects of *living in* as well as *moving to SCUs* for PwDs, FCs and SCU staff members. Positive outcomes included improved

mood, increased physical health, and improved relationships with significant others (Cioffi et al., 2007; Day, Carreon, & Stump, 2000; Myers et al., 2007). However, other studies identified no such positive effects (Day, Carreon, & Stump, 2000). Most of these studies use pre-post or post-occupancy designs, and tend to focus on aspects of the specialised environment (Day, Carreon & Stump, 2000, pp. 399-405; Doody et al., 2001, p. 8; Fleming, Crookes, & Sum, 2008). Few studies use a follow-up or longitudinal design. Accordingly in most of the studies undertaken to date, data is collected generally immediately before the move and afterwards (Day, Carreon, & Stump, 2000; Lai et al., 2009).

Qualitative studies exploring the whole process of transferring PwDs to SCUs are extremely limited (Bramble, Moyle, & McAllister, 2009; Butcher et al., 2001; Park, 2001). Furthermore, other qualitative studies that exist have looked at the process of placing PwDs into LTC in general and not in SCUs (Karlin, Bell, & Noah, 2001; Kellett, 1999; Nolan & Dellasega, 2000; Park, Butcher, & Maas, 2004; Ryan & Scullion, 2000b; Strang et al., 2006; Tilse, 2000).

These studies have for the most part found that FCs viewed SCU placement of their relative as a last resort; that the placement decision was complex and emotionally challenging; and that adapting to the new living circumstances was not easy (Bramble, Moyle, & McAllister, 2009; Butcher et al., 2001). Despite FCs' and PwDs' noticing improvements in their quality of life and quality of care after placement (Myers et al., 2007), both had to cope with complex and ambiguous feelings (such as sadness, relief, and uncertainty about the future). FCs in addition had to adopt new roles of caring at a distance and new responsibilities including visiting, monitoring care, and cooperating with SCU staff (Butcher et al., 2001; Myers et al., 2007).

As far as I am aware and based on a carefully conducted literature review, only one (qualitative) study has been conducted in Ireland exploring the experiences of moving

PwDs to SCUs on a permanent-stay basis. In this study Myers et al. (2007) examined the experiences of six PwDs, six FCs and six SCU staff members of moving from a generic ward to a newly opened SCU. They found that for the PwD the move actually resulted in a reduction in challenging behaviours, improved activity levels, improved sleeping patterns, and weight gain. For FCs, the move resulted in their feeling less stressed, and they visited more. Staff had more time to familiarise themselves with each resident and felt better supported in providing person-centred care (Myers et al., 2007).

A second Irish study conducted in a nursing home with a SCU attached explored the experiences of 14 FCs of transferring their relative with dementia into this nursing home on a long-stay basis (Argyle, Downs, & Tasker, 2010). Participants were admitted from different settings (community, hospitals). Yet the authors did not explicitly state if and how many of these 14 participants actually accessed either the general part of the nursing home or the SCU attached to the nursing home where the study was conducted (Argyle, Downs, & Tasker, 2010, p. 2).

It was partly a result of having read these works and reflecting on them in the context of the international literature that I embarked upon this thesis as there was clearly a gap in the literature both in Ireland and internationally on the topic. The section to follow introduces other factors that motivated me to embark on this thesis.

1.2 Motivations for thesis

Another key motivation for choosing this topic - i. e. the admission and adaptation of PwDs to SCU environments - was my personal background and prior work experience. I am from Germany, my background is in psychology. I have an interest in environmental psychology. I have worked in two different dementia day care settings in Germany and in both settings I had an opportunity to observe and reflect on the day care practices and its

environment. My work experiences led me to consider this topic as an area for research and helped inform the direction of this thesis.

1.2.1 Personal background

After qualifying, I had worked as a day care group leader to PwDs. As a qualified psychologist I had undergone training in systemic therapy and had a marked interest in this form of therapy (Hess, 2003; Von Schlippe & Schweitzer, 2003). Systemic therapy shares some key principles with the person-centred model of care such as promoting a non-medical holistic understanding of the individual; viewing the individual as inextricably linked to, and shaped by, his/her environment; and viewing oneself as co-creator – rather than an aloof expert - of any meanings and relationships developed in interaction with significant others (Boston, 2000). I have worked as a formal caregiver in two different day care settings in Germany. The first was a stand-alone dementia-specific day care centre located in a rural area south of Trier (Western Germany). This facility was originally an abandoned primary school and in 2006 was refurbished and opened for the first time as a day centre. The philosophy of care was strictly person-centred and every effort was made to adapt the environment and to purposefully design the centre. For example, we provided age-appropriate furniture (such as vintage-style sofas, wooden cupboards from the early 1920s, and hand painted pictures), we mounted hand-crafted visual orientation aides on all doors, and established different rooms for different functions (rest room, activity room).

The group of day care participants who attended this facility consisted of 10 PwDs, most of who had mild to moderate dementia. They had become familiar with each other from regular day care attendance. The majority of PwDs had attended the old day care centre prior to its refurbishment. Being employed by the day care centre during the period when it was being refurbished meant that I witnessed directly the impact the move to a more customised environment had for these PwDs. I saw quite clearly the improvement that the changed environment brought about for several of these people.

Prior to the move, day care was located in a large apartment in the basement of a family house. The apartment had a flight of steps, dim lighting and poor room temperature. While working there, I became very aware of the importance of the built and social environment for PwDs and being employed during the transition of these PwDs to a more purpose-built environment I experienced first-hand the benefits of transferring PwDs to an enhanced physical environment.

I recall how most clients settled into the new day care environment smoothly and quickly; expressing their happiness with the bright airy space, its picturesque surroundings (forests, village), and its calmness. The day care team also benefited. My co-workers reported that they felt less restricted due to the more cheerful upbeat domestic household setting. They enjoyed improved levels and types of activities inside and outside – for instance, going for walks, dancing, and sitting outside on summer days. All these activities were now fully supported by the new physical setting. My colleagues and I also felt that the new setting was safer, enabling us to better manage challenging behaviours.

The move did not merely result in changes to the physical setting but it also brought about complex and unique organisational changes (such as the recruitment of new staff members) as well as adaptations to the care approach, in particular being considerate of the disruption this move brought about to PwDs' routines and helping PwDs emotionally cope with the transition. As part of my role as group leader, I at the time also had responsibility for the transfer from home in the mornings and the return to home in the evenings of a small group of PwDs attending the day care centre. This daily commuting where I spent much time travelling with these people gave me new insights and convinced me of the important contribution environmental change such as moving to a skilled care environment makes to the well-being and functioning of PwDs.

The second organization in which I worked and which also influenced the choice of thesis topic was a large-scale traditional nursing home for older people located in the south of

Trier in Germany. Here I was employed as a care assistant and my responsibilities were twofold: (i) to manage and deliver an activity and stimulation programme for a group of PwDs attending the nursing home's day care centre, and (ii) to deliver a social activity and stimulation programme for a different group of LTC residents living in the nursing home.

What was most memorable about this nursing home was the inappropriate location of day care which was situated on a floor accessible only by elevator or stairs and very close to the bedrooms of the residents. The day care room was situated beside two dining rooms which meant large groups of residents were regularly assembling at meal time and causing a disturbance. The day care group was large (N > 20) and had a mixed group of residents, some cognitively intact and others who had dementia.

Among those with a dementia were a few people who had significant challenging behaviours such as pacing, trying to unlock doors, and constantly attempting to remove clothes or hygiene pads. These behaviours were disruptive and difficult for me to manage during the activity programme. PwDs attending the day care centre also varied greatly in their physical fitness. Some were extremely fit and could manage their environment without any assistance whilst others had severe physical disabilities that required skilful management such as mobilising with a wheelchair, transferring from chairs to beds, feeding, and toileting.

Designing and delivering an activity programme for this group of clients with diverse needs meant that I was conscious of trying to bring out the best in these people and work with their retained abilities. The programme I developed lasted for about 45 minutes and included activities such as singing, light physical exercises, and cognitive stimulation (reading newspapers, doing quizzes, playing board games). Sessions were scheduled either in the late morning before lunch or in the early afternoon before tea time, and due to space restrictions were usually held in the hallway connecting the dining rooms with private bedrooms (see above). A few months after commencing my work in the day care

centre I was asked to develop and deliver a similar activity programme to a group of LTC residents housed in different wings of the nursing home. This group met once a week (for about one hour) in a different part of the nursing home (i. e. not in the day care centre). Group members varied in terms of level of cognitive impairment (CI) and disability, dementia diagnosis, and support needs. Due to the nature of the venue, which was located in a group activity area at ground level and included the use of a kitchenette as well as a spacious community room, other types of activities could be included into the programme, such as cooking light meals, performing sitting-dances, and playing party games.

Whilst working in that setting I became acutely aware of how quality of life can be compromised if the setting where the day care activity programme takes place is not dementia-friendly. I was struck by the inadequacies of this physical environment and how this influenced the mood and temperament of both staff and day care attendees. I also felt frustrated running this activity programme as the poor environment prevented me from establishing truly person-centred interactions and relationships with residents and other staff members alike.

While working in both these settings I also became acquainted with clients with dementia on a day to day basis and often witnessed their fears and anxieties. Some day care attendees who were still living at home but whose families had begun discussing LTC options with them talked to me about their fears and concerns either during day centre or commuting back and forth to it.

Many day care clients appeared distressed and worried by the prospect of losing the life they had known until now. Some also expressed a fear of death. In their anxieties they sought reassurance from me and my colleagues, who in most cases were familiar with the FC's situation. The key reason why families then were pursuing LTC placement was because of the extreme levels of stress and exhaustion – physical, mental, and financial –

they experienced. This strain of caring prevented them from being able to continue to care for their loved ones at home. Dealing with their anxieties and concerns placed me in a difficult position. I remember feeling rather helpless and saddened when confronted with PwDs some of whom were distressed and crying about the prospect of giving up their home. I also remember observing FCs being under acute distress from their care-giving and other work and family commitments. Whilst I was sympathetic and supportive of FCs' decisions to place their relative into LTC I felt an intense sense of loss and grief for their relatives with dementia who as a result of LTC placement subsequently stopped attending the day care group.

In both settings, residential day care and stand-alone day care, I also witnessed feelings of unease and discomfort experienced by new clients to day care. These people were often initially reluctant to socialise with other day care attendees and staff members. I remember a small minority being so uncomfortable with the day care that they became unsettled and repeatedly asked my colleagues and myself about going home. In a few cases, some made attempts to exit the day care unit.

As it was my responsibility to help adapt new clients into day care, I realised over time that easing people with a CI into a new setting and helping them to adapt was a complex process. This required a certain skill set and a holistic approach from all staff members since we had to both ease in the new person and ensure the other clients' well-being with him/her. Although these experiences were never formally written up or evaluated and took place in Germany they made me acutely aware of what PwDs, staff members, and FCs must go through making such adjustments. These prior work experiences with older people and PwDs and their families made me also aware of how these people because of dementia are acutely sensitive to their built and social environment (Marshall, 1997).

1.2.2 Making an original contribution to research

There is a paucity of information published in the international literature on the topic of the process of admitting PwDs into SCUs, the protocols used, the way decisions are made and how PwDs settle into and adapt to SCUs in the short term and more long term. There is also a distinct dearth of in-depth information collected from both formal and informal caregivers of their views of how the transition has been handled and their attitudes to the whole process of admitting PwDs into SCUs. Following an extensive review of the literature I realised that studies on the topic of transferring PwDs to SCU-type settings are in general limited.

As mentioned existing studies have focused on the admission of PwDs into LTC in general (Edwards, Courtney & Spencer, 2003; Wilkes, Jackson, & Vallido, 2008a; Wilkes, Jackson, & Vallido, 2008b) and not on admissions to SCUs. These studies whilst offering important insights about reasons for placement, decision-making and placement, and adapting to the new care environment, do not take into consideration the fact that admitting family members to SCUs may be distinct from placement in generic LTC settings since SCUs are unique and different to other care settings (Argyle, Downs, & Tasker, 2010; Myers et al., 2007).

Reviewing the literature also revealed that most existing studies on admitting PwDs into LTC have also failed to investigate important aspects of the placement process, such as how news of the transfer is communicated to PwDs, what staff's roles are in managing new admissions, how staff prioritise people on waiting lists and how staff feel during this particular point in time as often admitting new residents means discharging others well known to them (Day, Carreon & Stump, 2000). Existing studies have been particularly limited with regard to following up residents' immediate adaptation and their more long-term adaptation to continuing care environments (Bramble, Moyle, & McAllister, 2009; Day, Carreon, & Stump, 2000). In addition, most studies do not attempt to include the perspectives and voices of all people affected by the transfer process – FCs, SCU staff

members, and PwDs – thereby often presenting a biased and limited picture of the transfer process (Argyle, Downs, & Tasker, 2010).

To summarise, most studies undertaken to date on the topic of how PwDs access and adapt to SCUs both in the short term and longer term have been limited (Bramble, Moyle, & McAllister, 2009; Butcher et al., 2001; Cioffi et al., 2007; Myers et al., 2007). Studies on FCs' and staff members' perceptions of the PwD's quality of life after placement (Cioffi et al., 2007) and staff members' perceptions of their own care-giving possibilities are also scarce (Cioffi et al., 2007; Zingmark, Sandman, & Norberg, 2002). Accordingly, a thesis investigating these issues was warranted.

Besides hoping to answer the research questions introduced in Chapter 4, I also hoped that findings from this thesis would make a contribution to dementia care research by acting as a springboard for future research activities. I also hoped that findings emerging from the thesis would help to improve current practice guidelines on admitting PwDs into SCUs. In conducting the research I hoped that a better understanding would be gained of the supports participants value, and the potential difficulties encountered by SCU service providers during the admission process. By investigating these issues, I hoped to provide guidelines to participants involved in SCU LTC admissions. Such guidelines I hope will result in improved admission practices, and supports for PwDs and families could be devised.

1.3 Aims of thesis

This thesis sets out to investigate in-depth the process of admitting a PwD into a SCU and the immediate and more long-term experiences these people along with their FCs have in adapting to the transition. An exploratory qualitative methodology is used and data collected at two distinct points in time; phase one, four weeks after the transfer, and phase

two, six months later. All FCs and PwDs were interviewed twice to develop a more thorough understanding of the process of moving to and adapting to a SCU. FGs were conducted with all SCU staff members at one point in time to explore in detail their experiences of deciding about and dealing with new admissions. A key aim of this thesis is to gain in-depth insights into the experience of the transfer into SCUs from the perspective of PwDs, FCs, and SCU staff so as to narrow the gap in current knowledge and understanding about several aspects of the process of moving permanently into a SCU.

In conducting this research I hope that information will be generated which will assist SCU staff to improve current admission practices and supports. By undertaking this thesis I also hope to provide a basis for further research work in this area.

1.4 Organisation of thesis

The thesis consists of nine chapters.

Chapter 2 reports on literature on the topic of demography and dementia, dementia care policy and SCUs.

Chapter 3 reviews the literature on the topic of caregiving and transitions into LTC.

Chapter 4 details the methodological approach used in the thesis.

Chapter 5 – the first findings chapter – presents key findings based on retrospective recollection pertaining to the time period leading up to PwDs' admission to SCUs, and when home care was being delivered.

Chapter 6 progresses to the time period at placement and reports data on FCs' reasons for making the placement decision, on who else was involved in this decision, on how news of the bed became available to them, how they conveyed news of the transfer to their relative and what it was like for them as well as for professional caregivers during this point in time.

Chapter 7 presents findings on FCs' and PwDs' experiences of adapting to the new environment immediately after placement and six months later.

Chapter 8 discusses key findings emerging from this thesis and compares these findings with the current literature.

Chapter 9 discusses the implications that findings emerging from this thesis have for improved SCU admission practices, policy, and research.

Chapter 2: Literature review I - Dementia policy and SCUs

2.1 Introduction

Dementia is considered to be one of the most significant public health challenges societies around the world will face in the coming decades (World Health Organization, 2012). As age is the single strongest risk factor for dementia, population ageing means that in both developing and developed countries, over the next decades, increasing numbers of older people worldwide will be affected by AD and the related dementias (Ferri et al., 2005; Wimo, Jonsson, & Winblad, 2006). AD and the related dementias by virtue of being progressive conditions exert substantial impacts on individuals and their social networks (Garner, 1997, p. 178). These illnesses affect broader socio-cultural contexts such as health care systems, political structures, and national economies by virtue of being hugely costly conditions that require highly specialised care (O'Shea, 2007; Trepel, 2011; Wimo & Prince, 2010). While the condition is progressing, PwDs and their FCs experience constant changes and losses in learning capacity, cognitive and physical functioning (ADLs, IADLs) and in well-being, behaviour, quality of life and in their relationships. I am aware of the fact that some PwDs are not being cared for by family members. However because the majority of informal carers are FCs (World Health Organization, 2012) and because the central focus of this research is on FCs' experiences of placing their relative with dementia in specialist long-stay care, I use the term 'family caregiver' (FC) to denote PwDs' main providers of informal care.

For some people affected by more moderate to severe dementia, one such change is the move into more supportive care environments as complex needs intensify. Most people in Ireland, who access LTC because of dementia, will move into general nursing homes but for some few and privileged cases that have access to specialised dementia care

services, dementia-specific LTC settings will be accessed. Yet very little is known about how and why these people access such facilities and how they settle into and adjust to these changed environments in both the short term and more long term. Little is known as well about how paid and unpaid caregivers deal with this transition period. There is also an absence of understanding about some of the choices and dilemmas facing carers (both professional and family) at this critical point in time. It is for this reason that I have undertaken this thesis to shed light on this important topic neglected in the Irish context.

This chapter reports on the literature reviewed for this thesis. The chapter opens with a discussion of some of the key demographic trends reported in the literature regarding dementia globally and in Ireland. The second part progresses to discussing the way LTC arrangements for PwDs have evolved over time in both Ireland and in other Western countries with particular reference to SCUs. The third part of this chapter presents literature findings on the principles and features of SCUs, the different descriptions of SCUs used by different Western countries, the common features of SCUs across these countries, and what the research literature to date tells us about the effects of SCUs on PwDs, FCs, and on staff working in these facilities.

2.2 Literature search

The data bases I used to conduct this literature review included CINAHL, FACTFinder, Google Scholar, Index to Theses, JStor, LWW Nursing Archive, Nursing and Allied Health Source (Proquest), Ovid Medline, PsychINFO, PubMed, Science Direct, Science Citation Index, Scopus, Social Sciences Index 1983-present, SpringerLink, and ISI Web of Knowledge. Sources of literature I examined included both international and national journals publishing in the areas of social science, health care, and nursing (see Bibliography). Other sources of literature I reviewed included international and Irish based

books on topics such as dementia care, care-giving, and care policy; government reports and documents; and statistical data (census data, population projections).

Key words I used in conducting this literature search included "dementia", "definitions", "prevalence", "incidence", "demographic", "development", "global", "Ireland", "projections", epidemiology", "long-term care", "Alzheimer's disease", "residential care", "specialist", "care unit", "dementia unit", "SCU", "nursing home", "hospital", "dementia care", "care-giving", "Kitwood", "person-centred care", "holistic", "individualised", "care policies", "practices", "changes", "development", "relocation", "transfer", "transition", "admission", "experience", "placement", "environment", "context", "caregiver", "family caregivers", "informal", "formal", "staff", "professional", "multiple roles", "men", women", "spouses", "adult daughters", "daughters-in-law", "nieces", "nephews", "quality of care", "living apart", "caregiver burden", "distress", "challenging behaviours", "dangerous behaviours", "respite care", "entrée", "supports", "health care", "social care", "decision-making", "reasons", "involved", "pressures", "truth-telling", "breaking news", "admission criteria", "assessments", "guidelines", "wait-listing", "emergency", "prioritising", "immediate", "short-term", "reactions", "outcomes", "meanings", "roles", "visiting", "emotional", and "care-giving theory". These search words were either used individually or in a combined fashion (for instance, "reasons for long-term care placement"). I also searched databases for specific journal articles, book chapters, and authors not included in the search words above.

2.3 Dementia and demographic trends

Dementia is a chronic progressive illness which often has devastating effects on the individual, on family members, on social networks, on governments and on society at large. Due to population ageing, more people will in the future present with dementia and in the absence of a cure, societies will be required to develop a broad range of different policies (economic, social and health) and a range of different LTC options for PwDs.

Such LTC options may include nursing homes, residential care, assisted living, housing with care, small-scale living facilities and SCUs (Macdonald & Cooper, 2007; O'Shea, 2007; Verbeek, 2013) and it is the latter – SCUs - which is the focus of this thesis. But before proceeding to providing a critical review of literature findings on SCUs, first an overview of how demographic trends are likely to play a role in planning future dementia care services will be provided. Following this discussion, some key demographic aspects of dementia care in Ireland will be reviewed.

2.3.1 Dementia: Some global demographic considerations

As mentioned, various demographic forecasts predict a substantial increase in the global population of older people within the next decades (Cohen, 2003; UN Department of Economic and Social Affairs, 2011; World Economic Forum, 2012). First, the proportion of people aged 65 to 80 years will grow significantly in developing countries while developed nations are predicted to experience a substantial increase in numbers of people aged 80 years and over (World Economic Forum, 2012). In fact, this cohort of people aged 80 years and over living in developed countries is predicted to grow faster than any other age group (Fratiglioni, De Ronchi, & Agüero-Torres, 1999; Saposnik et al., 2008) and these are people who are at a heightened risk of developing dementia. Secondly, the global population of younger and middle-aged people aged between 15 and 64 years will decline significantly over the next decades (Berr, Wancata, & Ritchie, 2005; Knapp et al., 2007; Wancata et al., 2003). This decrease will result in a decrease in the alleged reserve army of labour - informal carers (World Economic Forum, 2012). In other words, there will be fewer people around to provide care to a growing population of people aged over 80 years with diverse and complex care needs (Joensson & Berr, 2005; O'Shea, 2007). Thirdly, there are gender differences in ageing. Women aged 74 years and older have a higher life expectancy than their male counterparts, meaning that about twice as many females than males will survive into their 80s and beyond (for example, Kinsella & Phillips, 2005).

As mentioned earlier, advancing age is clearly related to the probability of developing a dementia (Berr, Wancata, & Ritchie, 2005; Gorelick, 2004; Kalaria et al, 2008; McCullagh et al., 2001; Meyer et al., 2000; Stephan & Brayne, 2008). For example, dementia prevalence rates are said to double every five years from the age of 65 years onwards (Hendrie, 1998; Kane, Kane, & Ladd, 1998). It has been estimated that 6% of those aged 65 years and older have a dementia; this number increases fivefold to 30% in those aged 80 years and older (Hendrie, 1998; Stephan & Brayne, 2008; pp. 9-10) and to 40% in people aged 90 years and older (Hendrie, 1998; McCullagh et al., 2001). Notably, people aged 85 years and older have the highest risk of developing a severe dementia, which generally increases the need for institutional care (Kane, Kane, & Ladd, 1998; Luppa et al., 2010, p. 35).

Some general conclusions for LTC provision for PwDs can be drawn from the close association found between age and dementia. First, as mentioned, a growing global population of older people will mean increasing dementia prevalence rates around the world (Knapp et al., 2007; Wimo, Jonsson, & Winblad, 2006). Prevalence rates will rise regardless of the developmental status of a particular country (Knapp et al., 2007; Wimo, Jonsson, & Winblad, 2006). These demographic developments, advances in health and social care interventions along with technology and a better overall understanding of dementia may ultimately result in more people surviving into the later stages of dementia. This stage is when it is most likely that people will need long-term residential care.

There is also likely to be a gender bias in the numbers of PwDs as women have a higher life expectancy than men and because of this are more likely to develop a dementia (UN Department of Economic and Social Affairs, 2011, p. 4 and 24). It is noted that women aged 74 years and older living in Western countries will represent the majority of persons either newly diagnosed or living with a dementia for a longer period of time (Alzheimer Europe, 2013; Berr, Wancata, & Ritchie, 2005; Joensson & Berr, 2005). Many of these women may live into the later stages of dementia, and may ultimately require residential

care. Indeed, some authors have already observed that the majority of nursing home residents are women in their 70s and beyond, who have been diagnosed with dementia (Engedal & Haugen, 1993; Magaziner et al., 2000; Matthews & Dening, 2002).

2.3.2 Irish dementia projections

Future predictions on the demographic profile of Irish population mirror international estimates. In 2011, it was estimated that 528,711 people aged 65 years and older were living in Ireland (Central Statistics Office, 2011). This number will nearly double to 909,000 by 2026 (Central Statistics Office, 2008, p. 6). There will be a significant increase in the numbers of people aged 65 years and older as well as 80 years and older, respectively, due to higher life expectancy (Department of Health and Children [DoHC], 2006; Knapp et al., 2007; O'Neill & O'Keeffe, 2003).

A recent research review conducted for Ireland's soon-to-be-launched national dementia strategy, revealed that there are currently some 41,740 Irish people diagnosed with dementia, and this figure will increase to over 141,000 by 2041 (Cahill, O'Shea, & Pierce, 2012). Similar to international findings, this population will be biased towards women aged 75 years and more (Alzheimer Europe, 2013; O'Shea, 2007). Based on this Irish research review, it was shown that circa 26,907 women are currently living with a dementia in Ireland compared to 14,833 men. In addition, 3,583 of these people are aged less than 65 and are living with early-onset dementia; most of them being men aged 64 years and younger (Cahill, O'Shea, & Pierce, 2012). In terms of estimates, some trends need to be considered which pertain to the Irish dementia population and include high prevalence rates of alcohol-related dementias (MacRae & Cox, 2003; O'Connell et al., 2003) and early onset AD type dementia in people with Down's syndrome (McCarron et al., 2002; O'Shea, 2007).

One key consequence from these developments is that care provision and funding systems need to be tailored to both an increasing variety of service users and their unique

complex care needs (Beattie et al., 2002; Bentham & La Fontaine, 2005). Public policy strategies for dementia would optimally incorporate community-based and voluntary resources (for instance, local initiatives), providing support to family and other informal caregivers, and allocating a sufficient range of supportive housing options to people with different forms and stages of dementia (Begley, 2009; Gallagher, 2006; O'Malley & Croucher, 2005, p. 576).

So far this chapter has pointed to the current and future challenge of dementia demonstrating how dementia prevalence rates are likely to increase worldwide and in Ireland over the next few decades, during which time a decline in numbers of middle-aged people (who otherwise might fulfil family caregiving roles) will be witnessed. It is important to note that besides adult children caring for aging parents, spousal carers/ partner carers are a growing and increasingly important carer group due to decreasing family size and dwindling differences between women's and men's longevity rates (Fisher, 1994; Hong & Kim, 2008; Pickard et al., 2000). These changes represent additional challenges because FCs will be older and may develop complex care needs themselves (Dahlberg, Demack, & Bambra, 2007; McGarry & Arthur, 2001). If this is the case, and in the absence of effective treatments or a cure for dementia, more people will be diagnosed who may ultimately require LTC and, many of them will be women.

Based on the literature reviewed for this thesis it has been shown that demographic trends in Ireland, currently mirror international trends and show the magnitude of dementia in Ireland today and the challenge the illness will pose in the future. The next section will review literature on policy aspects of SCU care. The section commences with a brief overview of how policy on dementia in general has evolved internationally and nationally.

2.4 Dementia and public policy

As stated earlier (see Chapter 1) compared with other chronic illnesses such as cancer, coronary heart disease and stroke, globally, AD and the related dementias have been neglected health conditions and dementia has not traditionally been the focus of substantive public health and social policy-making. As a result of this, both the development and the implementation of public policy on dementia at an international level have been slow to evolve (Rimmer et al., 2005). Likewise within Ireland, it has been noted that dementia-specific policy has also been very slow to develop (O'Shea, 2007). Not surprisingly, most countries until recently subsumed dementia-specific policy under aged-care policy, probably because traditionally dementia was not looked upon as a disease entity *per se*, but rather it was seen as a normal part of ageing.

For instance, one US study claimed that prior to 1971 the cognitive decline associated with AD and the related dementia subtypes was considered a typical sign of ageing – one which in the eyes of Health Service Providers (HSPs) and policy makers did not merit any attention to specific treatment, policy, or funding (Kraskie, Knight, & Liebig, 2001). According to the authors, the unique and complex needs of PwDs until the 1970s were not adequately assessed. It is argued that PwDs were often admitted to general LTC settings or psychiatric settings, which catered for all groups of older people including those with mental illness (Kraskie, Knight, & Liebig, 2001). In other words, traditionally, PwDs in the US were mostly cared for in general nursing homes or psychiatric facilities where they did not receive any specialist care. This was despite preliminary recognition of their unique and complex needs and despite initiatives taking place from the mid-1960s in the US to trial more purpose-built and customised environments for PwDs such as SCUs (Lacey, 1999). In fact, AD and the related dementias were only first acknowledged as a public policy issue by the American congress in 1980 (Kraskie, Knight, & Liebig, 2001).

A similar picture of a very slow growth in policy development and implementation for PwDs, and the way in which policy making lagged behind research and practice initiatives also emerged from other countries during the same periods. For instance, in terms of residential care policy, prior to the mid-1980s, Australia (Howe, 1997), the UK (Bartlett & O'Connor, 2007), and Spain (Longley & Warner, 2002, p. 13) failed to target the development of specific policy frameworks for access to and provision of adequate LTC services for PwDs. Ireland was also very slow to develop public policy on dementia during the same period. In fact, during the 1970s and 1980s in Ireland, most Irish people with AD or a related dementia in need of LTC were cared for in large-scale nursing homes or in psychiatric institutions where an emphasis was placed on their medical, psychiatric and nursing needs and not on quality of life or on non-pharmacological interventions (Wrigley, 1993).

2.4.1 International dementia care policy

The situation since the 1970s and 1980s has changed considerably and it is known today that around the world, countries with established public policies on dementia are committed to community care policies and to maintaining PwDs at home in the community for as long as possible (Charness & Holley, 2001; Stoltz, Udén, & Willman, 2004). For example, Moïse et al. (2004) in their study of the status of dementia care in nine developed countries (Australia, Canada, France, Germany, Japan, Spain, Sweden, UK, USA) identified certain policy objectives, which they argued were "universally accepted as desirable policy principles in the countries participating in this study" (Moïse et al., 2004, p. 20).

- Remain at home as long as possible - delay institutionalisation
- Support carers in order to achieve this
- Patients need as much control over their care as possible, but recognise limitations due to cognitive impairment (*e.g.,* in relation to having the capacity to make informed choices)
- Co-ordination of services at local level where possible

- Institutional care, when required, should be as home-like as possible
- Equate service provision with need
- Early diagnosis should be encouraged

(Moïse et al., 2004, p. 20)

As can be seen from this list, the first and foremost policy goal within these countries in the context of dementia is to enable the individual and their family members to continue to live at home for as long as possible and when this is no longer feasible, a desirable goal is to access institutional care that is home-like in configuration. It is worth commenting on the fact that home-like environments were viewed by people in each of the countries surveyed as desirable when LTC was required.

Home-like LTC environments have been in existence for PwDs in many countries across the world since the 1960s and were first inspired by the seminal work of the late Powell Lawton, an American behavioural psychologist who identified the close association between quality of life, ageing and the environment (Lawton, 1989; Lawton, Brody, & Turner-Massey, 1978; Lawton & Cohen, 1974; Lawton & Simon, 1968; Moore et al., 2003). Indeed, it was Powell who first argued that rather than PwDs having to modify their behaviour for their environment the reverse should happen and the environment should help compensate for the disability of dementia. Powell's thinking was ahead of his time and his contribution has left a major legacy to the field of dementia care and has influenced the design of care facilities across the world (Lawton, 2001; Lawton, Fulcomer, & Kleban, 1984; Slaughter et al., 2006; Wahl & Weisman, 2003).

For example, in France, "cantous" (i. e. homely settings providing PwDs with stimulation, autonomy, and social contact) have also been on offer since the late 1960s (Ritchie et al., 1992). Australia has been providing hostels (small-scale segregated home-like settings) to PwDs since the 1970s (Rosewarne, Bruce, & McKenna, 1997) whilst the 1980s saw similar living arrangements develop in countries including Sweden ("group living"), the Netherlands ("small-scale living"), and the U.K. ("domuses") (Verbeek, 2011, p. 31). In

Norway, "Green Care" farms are a more recent care option for PwDs (Meistad & Fjeldavli, 2004).

In particular, the Netherlands has a highly sophisticated range of LTC options available to PwDs including specialist stand-alone small-scale facilities, small-scale facilities attached to nursing homes, small-scale facilities attached to other homes, group dwellings, and life-style housing (Taylor, 2012; Verbeek, 2011; Willemse et al., 2011). In 2009, the Dutch government invested € 80 million Euros into LTC for PwD and its government is currently committed to expanding the numbers of small-scale facilities for PwDs from the current benchmark of 25% (of all LTC provision) to 33% of all LTC facilities by 2015 (De Lange et al., 2011; Pot, n.a.). There has also been a reform of traditional large-scale units for PwDs in the Netherlands (Verbeek, 2013).

Other European and overseas countries including Norway, France, Denmark, and Australia have followed suit and have more recently in their national dementia plans or strategies also made a strong commitment to providing SCUs for their respective PwDs (Alzheimer's Disease International, 2013; Alzheimer Europe, 2013). In Norway a principle underpinning its dementia care plans is "small is beautiful" and the Norwegian government like the Dutch is also committed to the expansion of small-scale day care centres and specialist units over coming years (Norwegian Ministry of Health and Care Services, 2008).

2.4.2 Irish dementia care policy

The Irish policy documents reviewed for this thesis include:

- "Care of the Aged Report" (1968)
- "The years ahead – A Policy for the Elderly" (1988)
- "Shaping a Healthier Future: A Strategy for Effective Health Care in the 1990s" (1994)

- "An Action Plan for Dementia" (1999)
- "National Health Strategy Quality and Fairness – A Health System for You" (2001)
- "Dementia Manifesto 2007-2009: Making Dementia a National health Priority" (2007)
- "Advancing the National Agenda" (2007)

Whilst each of these documents endorse the policy of keeping PwDs at home in the community for as long as possible and a policy of developing (for those without significant challenging behaviours) small-scale homely SCUs, attached to conventional LTC facilities, there is limited evidence of the rational planning and significant development in these services across Ireland. Ireland therefore differs somewhat from these other Western countries insofar as there remains a very limited spectrum of LTC options for PwDs in Ireland although calls for the provision of more home-like environments for PwDs have been in existence since the 1980s. Accordingly, compared with countries like Norway and the Netherlands where governments are committed to ensuring that a proportion of future new-builds will be purposefully designed for dementia, no similar government commitment is currently in evidence in Ireland (Alzheimer Europe, 2013).

For example, the recent research review (already mentioned) revealed that only about 21% of private providers currently have dementia-specific units and only 21 of the 151 public units representing 32 Local Health Office (LHO) areas have dementia specific beds (Cahill, O'Shea, & Pierce, 2012). Where then are most PwDs who need LTC in Ireland found?

2.4.3 Distribution of PwDs across Irish LTC settings

In Ireland when PwDs needs LTC, they usually access a variety of settings outside of SCUs. These include nursing homes (private and public) or welfare homes or long-stay county hospitals (National Council for Ageing and Older People, 2001). Most of these facilities are integrated, meaning that the providers do not segregate residents with

dementia from those cognitively intact (O'Shea & Walsh, 2013) despite recent evidence revealing that such integrated settings are far from ideal for people cognitively well (Buckley & McCarthy, 2009) and not favoured by older people themselves who are cognitively intact and live in such settings (Murphy et al., 2006). In addition, in Ireland, PwDs are sometimes cared for in LTC settings that are actually geared towards providing intermediate or transient care. Such settings mainly include different types of hospitals; for instance, acute hospitals, psychiatric hospitals, and geriatric hospitals (DoHC, 2010; National Council for Ageing and Older People 2001).

We know that in Ireland there are about 14,266 people likely to be in LTC because of dementia, most (8722) are located in private nursing homes (see Table 1), 3,712 (26%) are accommodated in public extended care units, and 1,071 (7.5%) are catered for by voluntary homes/hospitals (Cahill, O'Shea, & Pierce, 2012). A small number of PwDs are found in welfare homes (523 [3.6%] in public welfare homes and 237 [1.6%] in voluntary welfare homes). Based on the total estimate of people in Ireland in LTC it is therefore assumed that 63.1% of all LTC residents have AD or a related dementia sub-type in any of the five settings. Table 1 shows the distribution of these people.

Table 1: Estimated number of long-stay residents and percentage with dementia in Ireland by type of setting, 2008

Type of setting	Number of residents (From: DoHC, 2009)	Percentage with dementia	Number with dementia
HSE Extended Care Unit	5,884	63.1*	3,712
HSE Welfare Home	829	63.1*	523
Voluntary Home/Hospital	1,698	63.1*	1,071
Voluntary Welfare Home	376	63.1*	237
Private Nursing Home	13,826	63.1*	8,722
Total	22,613		14,266

(Reproduced from Cahill, O'Shea, & Pierce, 2012, p. 50)

* According to most recent calculations, 63.1% (N = 14,266) of all Irish LTC residents (N = 22,613) have dementia (Cahill, O'Shea, & Pierce, 2012). This percentage (63.1%) was used to calculate the ratio of PwDs (in numbers) to all residents (in numbers) across five different LTC settings under the assumption that this percentage was constant across all five types of LTC setting (i. e. 63.1% of all residents in any of the five LTC settings have dementia).

What is obvious from this table is that no breakdown presently exists on the numbers of Irish PwDs living in SCUs. This is because there is no official register of SCUs in Ireland so we do not know how many SCUs exist and where they are located. In the research review for the Irish dementia strategy, the authors estimated a total of 373 beds for PwDs in all public care settings, resulting in an average number of 18 beds per HSE-based dementia unit (Cahill, O'Shea, & Pierce, 2012, pp. 112-113). As mentioned, the same research review also reported that 21% of all private nursing homes in Ireland had SCUs; the average unit size in these facilities was 19 beds (Cahill, O'Shea, & Pierce, 2012, p. 115). As can be seen from these data (Cahill, O'Shea, & Pierce, 2012), it was extremely difficult to pinpoint exactly how many of the private nursing homes had SCUs.

These findings are not totally unique to Ireland as studies conducted in countries such as the USA, Australia, and Canada (Gruneir et al., 2008; Moïse et al., 2004, p. 82; World Health Organization 2012) have also shown that the majority of PwDs in these countries also live in non-specialised ("traditional") nursing home settings (Gruneir et al., 2008; Moïse et al., 2004). The key difference, however, being that in most of these other countries a broader range of LTC options has been in existence since the 1980s whilst in Ireland any growth that has occurred in this area has tended to be in the last ten years. Overall, SCUs in Ireland have been slow to develop and only very few alternatives to traditional nursing home care for PwDs exist in the country.

2.5 Dementia and SCUs

Dementia results in substantial impairment to memory, cognitive functioning and to psycho-social skills (see Chapter 1). Once in LTC, people with the illness, depending on the sub-type and stage, may experience continuous functional decline, challenging behaviours, or other symptom fluctuation. Overall, their care needs will intensify over the course of the illness to the point where, with advanced dementia, they may need constant monitoring and help with their ADLs and IADLs (Hancock et al., 2006). Supports in LTC therefore have to be responsive to these changing and complex care needs and to other co-morbidities and disabilities that the person may also experience apart from the CI.

As stated earlier, PwDs are extremely sensitive to the built and psychosocial environment (Brooke, 1989; Kerr & Cunningham, 2004; Sloane et al., 2002), and the literature shows how the latter can be used as a therapeutic tool to compensate for the disability of dementia (Judd, 1997; Van Hoof et al., 2010). In fact, the physical and social environment in which PwDs are placed has a very significant impact on quality of life and on how people experience their dementia (Marshall, 1997; Reimer et al., 2004). SCUs are specially designed to be homelike, domestic and safe, have different rooms for different functions, provide scope for everyday activities and offer security (Day & Calkins, 2002; Habell, 2012). The ultimate aim of SCUs is to improve and sustain well-being and quality of life in residents (Lawton, 2001).

According to some dementia experts (Alzheimer's Australia, 2004; Knapp et al., 2007; Wancata et al., 2003), and in the light of worldwide trends in population ageing, in the future there will be a need for both building dementia-specific nursing care facilities and modifying existent nursing home settings in order to adequately address the care needs of a growing proportion of LTC recipients with dementia. It also needs to be kept in mind that good design for dementia makes it a lot easier to provide person-centred care, however, quality of life and quality of care also very much depend on a myriad of other factors

including staff attitudes and the culture of care within the facility (Calkins, 2001; Kitwood, 1997; Marshall & Archibald, 1998). Accordingly, while purpose-built or adapted care environments can help stimulate good practice in dementia care, the point has often been made that improved outcomes for PwDs are also influenced by staff attitudes and the social culture of the residential setting (Brooker, 2004; Kitwood, 1997; Verbeek, 2011). The next section commences with an outline of how SCUs have emerged historically.

2.5.1 Emergence of SCUs

The first SCU documented in the literature was established in the United States (Weiss Institute, Philadelphia Geriatric Centre) in 1965 and served as an experimental unit designed to explore the responses of PwDs to a purpose-built setting (Day, Carreon, & Stump, 2000, p. 408; Hall & Buckwalter, 1990, p. 6). Although I could not retrieve any findings from the original experimental unit (i. e. from the 1960s) from the literature, a review synthesizing empirical outcomes of therapeutic environments for PwDs reported that residents who were transferred to the original unit in the 1980s were more likely to spend time outside their private rooms and were more interested in activities than before (Day, Carreon, & Stump, 2000).

Over the course of the late 1960s, 1970s and early 1980s SCUs further proliferated across the US and other countries; their development was accompanied by a great academic interest in the built environment for PwDs (Hall & Buckwalter, 1990; Norris-Baker et al., 1999, p. 166; US Congress Office for Technology Assessment, 1992). In Europe, first SCUs – "cantous" – emerged in France in the late 1960s and developed in other European countries such as the UK, the Netherlands, and Sweden throughout the 1980s (Ritchie et al., 1992; Verbeek, 2011).

2.5.2 Characteristics of SCUs

A consensus exists across the world on best practice for dementia and aspects of design such as principles underpinning the design (designing for disability, maximising independence, reinforcing personal identity), design features (designing small-scale, safe outdoor space, controlled stimuli, enhanced visual access) and design values (designing for meaningful relationships, personhood, autonomy). The thinking about other aspects of SCUs such as whether these units should be stand-alone or part of a larger institution, what the ideal staff-resident ratio is, which type of staff training is needed and what admission and discharge criteria are used, is not as unanimous.

SCUs vary across the world according to their location and according to whether they remain stand-alone or are attached (to nursing homes/ residential care settings) and according to the numbers they can accommodate and whether they are segregated or integrated (Gerdner & Beck, 2001; Verbeek et al., 2009).

Even within Europe, the size of SCUs differs according to how the respective facilities have evolved (Verbeek, 2011). Some, like those in the Netherlands and Belgium, cater for very small numbers – a maximum of six to eight people all of whom have moderate to advanced dementia and the social environment reflects an integrated role played by staff in person-centred care (Verbeek, 2013). Others (the German model) accommodate slightly larger numbers (six to 15) and are integrated i.e. mix residents with dementia with those who are cognitively intact. The latter are usually situated within nursing homes (Weyerer, Schaeufele, & Hendlmeier, 2010). Sweden for example has been subscribing to a "group living" philosophy of care for PwDs since the 1980s and Swedish facilities accommodate between five and nine residents (Verbeek, 2011). In the USA, like in Germany, small-scale facilities accommodate both cognitively intact and cognitively impaired people within the same unit. For example, "Green House" facilities (in the US) are always stand-alone units situated in regular residential communities (Kane et al., 2007) catering for between seven and ten persons (Verbeek, 2011). There appears to be

no consensus about the issue of integration versus segregation (Gutman, 1989; Lévesque & Cossette, 1994) and more research into this topic has been recommended (O'Malley & Croucher, 2005).

Despite such cross-national variation, as mentioned earlier, SCUs worldwide share key characteristics including a person-centred culture of care tailored to the residents' complex and unique care needs, non-hierarchical staff structures, ongoing staff training and purpose-built physical design features (Calkins, 2001; Day, Carreon, & Stump, 2000; Lai et al., 2009; Rabig et al., 2006). In fact, it is the physical design of these units that are considered pertinent to the ongoing care of people with moderate to advanced dementia as features of the design can be used to minimise communication problems and other challenging behaviours the resident may experience.

2.5.3 Physical design features

It is not surprising in the light of all of this that SCUs have been described in the literature in several different ways (Day, Carreon, & Stump, 2000; Marshall & Archibald, 1998; Rabig et al., 2006; Ritchie et al., 1992; Svensson, Edebalk, & Persson, 1996). According to one Dutch expert on the topic, SCUs should include the following key features:

> "(...) resemble a homelike environment with archetype symbols such as a kitchen, dining room, living room and a laundry area. The kitchen often has an important function as a meeting centre. Almost all residents have private rooms, and in some cases, a private bathroom. In addition, some concepts use technology to support care in many different ways." (Verbeek, 2011, p. 22)

Descriptions of the layout and design of SCUs such as given above are by no means authoritative and it is important to remember that to date, no "gold standard" or consensus exists on either a formal definition of SCUs or criteria for admission to these specialist settings (Chappell & Reid, 2000; Marshall & Archibald, 1998, p. 338; Morgan et al., 2004).

Best practice guidelines also differ in their recommendations on how to best design and maintain SCUs (Aud et al., 2005). These issues are highly relevant to this thesis where the sample (PwDs, FCs and staff) were recruited from facilities where the director or nurse manager considers it to be a SCU and where questions such as admission and discharge criteria, respective size of each of the units and the numbers of PwDs catered for will be explored (see Chapter 4).

Given such diversity, not only across countries but also within countries, it will be interesting to see if this is the case within Ireland. Besides physical set-up (stand-alone, attached) and policy regulations (see section 2.4), other aspects of SCUs such as financial resources, organisational factors, and societal values shape the design and organisation of an individual SCU (Aud et al, 2005; Kovach, 1998; Morgan et al., 2004; Zimmerman & Sloane, 1999). The literature shows how these contextual features, in turn, affect the culture of care developed within facilities (Crawford-Mead et al., 2005). Indeed, some authors have lobbied for the need to include more and broader dimensions when designing dementia specialist care, such as organisation, psychology, and culture (Cioffi et al., 2007; Morgan & Stewart, 1999). Others posit to focus on the interplay of resident characteristics, physical design features, and social context elements when formulating criteria of SCU care (Alzheimer's Australia, 2004; McCracken & Fitzwater, 1989).

2.5.4 Consensus on design principles

Returning to the topic of a consensus on design for dementia (see section 2.5.2), a consensus on universal design principles for dementia has been reached within the last decade (Aud et al., 2005; Cutler, 2000; Hepburn et al., 1995; Marshall 1997; Van Hoof et al., 2010, p. 206). According to these general principles, the design of SCUs should:

- Provide person-centred needs-based care
- Accommodate to changing needs and abilities
- Compensate for disabilities and support retained skills

- Provide optimal levels of stimulation and activation
- Be understandable and meaningful
- Support residents' rights of freedom, choice, privacy and control
- Maximise independence through dignity and autonomy
- Ensure maximal comfort and well-being for residents and caregivers
- Include staff, families, and communities into care
- Enhance self-worth and self-esteem of residents and caregivers

There is also a consensus in this literature that the physical design of any SCU should reflect goals of good quality care and the objective of helping to maximise quality of life for residents and carers (Alzheimer's Australia, 2004; Horttana, Ahlstroem, & Fahlstroem, 2007; Marshall, 1997; Zimmerman & Sloane, 1999). Ideally, the physical environment of a SCU should be small-scale, domestic, and fitted with age-appropriate furniture which should be functional and meaningful to PwDs. Individual rooms should be personalised. All spaces should be easily accessible and secure (Brawley, 2001). Residents should be protected from all inappropriate stimulation including excessive noise, glares, and overcrowding. PwDs' orientation skills should be supported by multiple signage and cueing (Habell, 2012). The physical design should be geared towards enhanced visibility by promoting adequate colour, contrast, and lighting. Individual and social activities should be supported by appropriate cueing and prompting. In addition, residents should have access to safe outdoor areas (Aud et al., 2005, Cioffi et al., 2007, Hepburn et al., 1995, Morgan & Stewart, 1999; Van Hoof et al., 2010). In a very recent review of design for dementia conducted by Innes and her colleagues in the UK and where PwDs were themselves consulted about their preferences, findings showed that what mattered most to them was living in a building which provided variety and choice of space (Innes, Kelly, & Dincarslan, 2011). They also favoured total visual access (views to entrances of offices where staff are based) and an environment that fostered opportunities to enable them to engage in everyday life in a meaningful way (Innes, Kelly, & Dincarslan, 2011).

In summary, therefore, the literature on design for dementia reflects a consensus about the principles, features and values underpinning dementia design but there is a lack of clarity about issues such as size, bed occupancy, integration versus segregation, admission and discharge protocols, and staff-resident ratios. The literature reviewed for this thesis also shows that while good physical design will help achieve high-quality dementia care it may not necessarily make it happen (Fleming, Crookes, & Sum, 2008; Marshall, 1997). Therefore, the social environment of a SCU (the social context within which PwDs are cared for and interacted with) should be equally well planned, realised, and constantly improved.

2.5.5 Caregiver characteristics

Other key elements of SCUs include staff training and specialisation (on an ongoing basis), increased responsibility and flexibility among all staff members, multitasking, team cohesion, organisational support and decreased hierarchies. Key elements also include the involvement of FCs into all care processes and the inclusion of significant others and communities into care (Aud et al., 2005; Brooker, 2004; Downs, Small, & Froggatt, 2006; Marshall, 2001; McAuslane & Sperlinger, 1994).

Studies show that staff members from a range of different occupational backgrounds are employed by SCUs (Drebing, McCarty, & Emerson-Lombardo, 2002; Gerdner & Beck, 2001). They are most often from both medical and non-medical backgrounds and include nurses, nurse assistants, and administrative staff (Blanton, 1995). If a multidisciplinary approach to care is used, however, team members may include other HSPs such as therapists, medical doctors, and nutritionists (Rabig et al., 2006; US Congress Office of Technology Assessment, 1992). Verbeek (2011) in her cross-national review of small-scale homelike environments described the complex roles and skills required from staff working in these specialist care settings:

> "Care staff have integrated tasks and are part of the household (...). They live together with the residents and provide individually tailored care. Residents are stimulated, encouraged and supported, emphasizing autonomy and choice. Daily life is organized around meaningful activities, such as cooking, with a lot of personal contact. This requires the care staff to have specific skills, such as high levels of social and communication skills." (Verbeek, 2011, p. 30-31)

As reflected in Verbeek's description and in that of others the culture of care promoted by care settings that call themselves SCU is invariably person-centred and needs-based (Epp, 2003; Kitwood, 1997). The section to follow outlines key aspects of a person-centred care philosophy as highlighted in the literature.

2.5.6 Person-centred care principles

The basic premise of a person-centred philosophy to care is that of putting the person rather than dementia first, and adapting all care structures and processes to the individual and his/her needs (Brooker, 2004) and valuing the person in her/his wholeness and uniqueness rather than focusing on the dementia (Adams, 1996; Kitwood, 1997). Person-centred care also means valuing the PwD and the caregiver as individuals endowed with the same inalienable rights as any other person. It means knowing the individual, taking the person's perspective, and creating a beneficial social environment (Brooker, 2004, p. 216; Kane, Kane, & Ladd, 1998). These principles are implemented by staff getting to know the individual person and his/her unique biography; exploring the person's physical, psycho-social, and cultural circumstances (including personal skill sets, likes/dislikes, and socio-demographic status); and establishing secure, sustainable, and positive relationships with the person (Kitwood, 1997; McCormack & McCance, 2006; Parker, 2001).

Person-centred care is also supposedly about "personhood". The latter is defined by Kitwood as that status bestowed upon the individual by another person (see page 4). By

implementing these principles of valuing the person and creating a supportive environment, person-centred care aims to foster individual personhood, needs, and strengths (Cowdell, 2006; Downs, Small, & Froggatt, 2006; Kane, Kane, & Ladd, 1998; Kitwood, 1997), actively understand and interpret individual actions (Kitwood, 1997), and plan for and adapt care (Adams, 1996; Brooker, 2004). The literature suggests that people with a more severe dementia may no longer be able to communicate to others who they are. They may also be no longer able to rely on others to construct and maintain their personhood by means of appropriate nonverbal communication, empathy, and impartial acceptance (Adams, 1996; Kitwood, 1997; Rao & Asha, 2009).

2.5.7 Resident characteristics

It has been argued that SCUs should primarily be built for persons with moderate dementia (Lichtenberg et al., 2005), and that those with more severe dementia may no longer be able to benefit from the social and activity-based approach to care available there while residents with mild dementia are best cared for in their own homes (Morgan et al., 2004). Other authors argue for SCU environments to be adjusted to dementia stage and resident group. For example, that there should be SCUs for persons with early-onset dementia, people dying with dementia and PwDs with specific ethnic backgrounds (Marshall & Archibald, 1998; McCracken & Fitzwater, 1989; Teresi, Holmes, & Ory, 2000). Such claims may be supported by empirical evidence. An international literature review of SCUs showed that dementia severity varied across settings and countries, with mean Mini-Mental State Examination (MMSE) scores ranging between 7.1 and 17.8 (Verbeek, 2011, p. 29). This diversity may indeed depend on setting objectives (for example, targeting PwDs with challenging behaviours) and service infrastructure (for example, palliative care facilities) (Verbeek, 2011).

It was probably during the early 1990s that researchers began to investigate the effects of SCUs on residents and caregivers by means of rigorously controlled evaluations (Norris-Baker et al., 1999, p. 166). Since then SCUs have continued to expand across Western

countries. They have further diversified to cater for unique care needs of different groups of service users (Marshall & Archibald, 1998, p. 340; Moïse et al., 2004). The next section will present international findings on the effectiveness, both short-term and more long-term, of SCUs for different groups of users (PwDs, FCs, staff).

2.5.8 Effectiveness of SCUs

Many different studies have been conducted around the world in an effort to assess the effectiveness of SCUs (Day, Carreon, & Stump, 2000; Doody et al., 2001; Lai et al., 2009) and in particular during the past two decades, efforts have been made to evaluate aspects of the physical and social design of SCUs and ascertain how they may impact on the individual, on FCs, and on care staff. Most studies have identified positive effects on quality of life for both PwDs and their carers as well as positive effects on quality of care, suggesting that SCUs are also superior to more traditional ward-style environments. Other findings have been inconclusive.

Many of the large studies have been quantitative (Day, Carreon, & Stump, 2000; Doody et al., 2001; Lai et al., 2009) including a Cochrane Review of SCUs for PwDs with challenging behaviours (Lai et al., 2009). In 2009, Lai and his colleagues showed that PwDs placed in these units were less likely to be physically restrained, were less depressed, and less agitated after placement compared to PwDs placed in non-specialised settings. Other studies have been qualitative (Cioffi et al., 2007; Morgan & Stewart, 1999; Myers et al., 2007; Zingmark, Sandman, & Norberg, 2002).

A general criticism of many of these studies evaluating SCU outcomes (both qualitative and quantitative) is that the researchers fail to identify exact timeframes used in their respective studies as for example when their research was conducted in relation to when the PwD was admitted to the unit. Two exceptions are found in the works of Lai et al.

(2009)[1] and Cioffi et al. (2007) where exact timeframes were identified and where the research was conducted at three months after admission and again at six months and more. Morgan and Stewart (1999) used a three-month time frame.

2.5.8.1 Effectiveness of SCUs for PwDs

Studies reviewed for this thesis, have shown that placement of PwDs in SCUs has been associated with positive experiences both in the short term and more long term. These studies have reported reductions in agitation, restlessness, physical violence, and injuries (Cioffi et al., 2007; Doody et al., 2001; Lai et al., 2009; Myers et al., 2007; Zingmark, Sandman, & Norberg, 2002). Lai and his colleagues showed how SCU placement had no effect on agitation in the short term but in the long term (at six months) agitation had lessened. Other studies have reported reductions in confusion (Cioffi et al., 2007), challenging behaviours (Doody et al., 2001), and in catastrophic reactions (Day, Carreon, & Stump, 2000; Lai et al., 2009; Zingmark, Sandman, & Norberg, 2002).

Small but significant improvements in mood have also been documented in the short term i. e. three months post-admission (Lai et al., 2009), in comfort (Doody et al., 2001; Morgan & Stewart, 1999), in contentment (Cioffi et al., 2007; Lai et al., 2009) and overall in quality of life at six months after placement (Cioffi et al., 2007). A reduction in psychiatric symptoms such as apathy, hallucination (Day, Carreon, & Stump, 2000) and anxiety (Cioffi et al., 2007; Morgan & Stewart, 1999) has also been noted. In addition, it has been shown that SCU residents have appeared to be less tired after placement (Zingmark, Sandman, & Norberg, 2002), and more interested in their environment compared with nursing home residents (Lai et al., 2009).

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[1] Lai et al. (2009) conducted a Cochrane Review on effectiveness of SCUs and provided information on timeframes used in the four studies examined in their review.

Other SCU outcomes include either no further or reduced deterioration in cognitive functioning (Zingmark, Sandman, & Norberg, 2002) as well as improved communication skills (Day, Carreon, & Stump, 2000; Myers et al., 2007), social functioning (Cioffi et al., 2007; Lai et al., 2009; Morgan & Stewart, 1999), and increased participation in activities (Myers et al., 2007; Zingmark, Sandman, & Norberg, 2002). PwDs admitted to SCUs have also been shown to have i) no or fewer deterioration in their ADL/IADL performance (Lai et al., 2009), ii) decreased functional dependency (Myers et al., 2007), iii) improved self-care skills (Day, Carreon, & Stump, 2000; Lai et al., 2009; Morgan & Stewart, 1999), and iv) more rekindled previous skills (Myers et al., 2007).

Multiple physical improvements (both short term and more long term) have also been noted including improved eating patterns, improved sleeping patterns (Myers et al., 2007), and weight gain (Cioffi et al., 2007). Increased mobility was also noted by several authors (Day, Carreon, & Stump, 2000; Lai et al., 2009; Morgan & Stewart, 1999; Myers et al., 2007). Other studies have reported a reduction in use of psychotropic medication (Doody et al., 2001), physical restraints (Lai et al., 2009; Verbeek, 2011), and chemical restraints (Lai et al., 2009). In particular, Lai et al. (2009) reported small significant improvements in physical restraint use for SCU residents at six months and at 12 months post-admission. Curiously, this evaluation study found no significant effects at three months and at 18 months after admission.

2.5.8.2 Effectiveness of SCUs for FCs

Several studies have demonstrated multiple positive outcomes of SCUs in both the short term and more long-term for FCs. They include a reduction in emotional distress (Day, Carreon, & Stump, 2000; Myers et al., 2007) and a reduction in subjective guilt about the placement (Cioffi et al., 2007) due to the enhanced care environment. An Irish qualitative study reported that FCs felt more reassured about the unit's high quality of care and their relative's improved well-being (Myers et al., 2007). In another study it was shown that at

follow-up, participants were more likely to visit and enjoyed visiting more, and also felt more compelled to bring along grandchildren (Cioffi et al., 2007).

Like Cioffi's study, research undertaken by Myers and colleagues in Ireland showed how after transferring their relatives into a SCU from a more general hospital ward, Irish FCs enjoyed visiting time more - due to the unit's homely atmosphere, stress-free ambience, and increased opportunities for privacy (for example, separate rooms) (Myers et al., 2007). In the same study, FCs also stated that their relatives were more receptive to visitors after placement – a change which encouraged FCs to visit the SCU very regularly (Myers et al., 2007, p. 70). Interestingly, Verbeek's study in the Netherlands showed that FCs visiting SCUs were more satisfied than other carers (visiting traditional nursing homes) about the level of contact they had with staff. In this same study, however, no difference was found in the amount of contact FCs had with their relatives in SCUs compared with those visiting traditional wards. SCUs in the Verbeek study had contradictory effects on caregiver burden (Verbeek, 2011).

2.5.8.3 Effectiveness of SCUs for staff

Existing literature has also shown some beneficial outcomes of SCUs for staff working in these environments. For example, increased levels of competence and work satisfaction have been reported in one study (Day, Carreon, & Stump, 2000), as have been reduced levels of staff burnout (Zingmark, Sandman, & Norberg, 2002). Two studies (Cioffi et al., 2007; Morgan & Stewart, 1999) found that staff immediately after the move and more long-term felt they were providing better quality care, had more access to and availability of resources necessary to perform care tasks, and had more opportunities for resident monitoring. Other positive outcomes reported in the literature include staff having more time for i) establishing relationships with residents, ii) providing truly person-centred care, iii) doing activities with residents (Myers et al., 2007), and iv) staff having better access to FCs and improved communications with FCs at six months after relocation (Cioffi et al., 2007).

These findings suggest that SCUs can have positive consequences for PwDs living in these units, for FCs visiting and monitoring the quality of care, and for staff working within. Findings also demonstrate that SCUs are generally experienced as improved physical and social environments by PwDs, FCs, and staff.

However, the overall picture is not quite as straightforward as other studies show contradictory findings (Cioffi et al., 2007; Day, Carreon, & Stump, 2000; Lai et al., 2009). Some report no effects on PwDs' pacing, cognitive status, functioning, and challenging behaviour (Day, Carreon, & Stump, 2000; Lai et al., 2009); and no and/or negative effects on staff's work satisfaction and perceived work-related distress (Day, Carreon, & Stump, 2000). Zingmark and colleagues (2002), somewhat contradicting aforementioned findings, related increased levels of burnout among staff due to very close relationships with residents, and being less well able to monitor residents because of the new unit's physical flaws (long corridors, enclosed nurses' room). Similar staff complaints were noted by Cioffi et al., (2007) whose participants expressed dissatisfaction with longer walking distances in the new unit at six months after relocation.

Overall, therefore, findings are inconclusive about the value and effectiveness of SCUs. However, on balance, having perused and critiqued this literature it seems to me that there is a preponderance of research articles reporting on the positive outcomes associated with SCUs rather than on their adverse effects. Therefore it may be concluded that SCUs must make some significant contribution to the residential care needs of PwDs (Aud et al., 2005; Sloane et al., 2005). Some experts also argue that this topic is very complex and difficult to evaluate (Lawton, 2001; Teresi, Holmes, & Ory, 2000) since SCUs vary considerably in their physical layout and level of specialty as well as there being methodological problems trying to conduct evaluations in the absence of control groups and sampling biases.

2.5.9 Chapter summary

Since this thesis topic straddles both community and residential care and attempts to address several different questions about transitions into SCUs from multiple perspectives, I have reviewed several broad bodies of literature for the purpose of this chapter. These include the literature on i) public policy for dementia, ii) the international literature on SCUs, how and when they first emerged, their effectiveness, and the principles and values underpinning them.

This chapter argues that public policy on dementia across the world has been slow to evolve and in most Western countries; dementia-specific policy has only evolved in more recent years. A review of both national and international literature shows that most countries endorse the central tenet of maintaining PwDs at home in the community for as long as possible. When LTC is needed, the review has shown that several countries around the world today offer a broad range of options to PwDs including nursing home care, residential care, housing with care, assisted living and SCUs. Some countries such as Norway, France and the Netherlands have policies in place to ensure that future years will see a significant growth in small-scale facilities for PwDs and their respective governments have committed resources in this direction. This is not the case in Ireland where the nursing home model of care still prevails and suitable LTC options for PwDs are few and far between with no substantive financial resources set aside for SCU development. Most Irish PwDs requiring LTC are admitted into private generic nursing homes where they do not receive specialised care.

As a model of LTC, SCUs have been in existence now for some 40 years and first originated in the USA. There is no gold standard for SCUs although the literature suggests that a consensus has been reached on the design features and principles which underline these LTC systems. There is ongoing debate in the literature about what is best suited to SCUs, in terms of dementia severity and whether PwDs should be allowed die in SCUs or be moved out once they reach end-stage dementia. Whilst some claim that those with a

moderate dementia benefit most from the specialised approach, others argue that SCUs should be adapted to meet the complex needs of different user groups, for instance people with early onset dementia or the "old old" with dementia.

Based on this literature review, findings on the effectiveness of SCUs have been mixed. A preponderance of positive outcomes of SCUs for PwDs and caregivers was however noted. Positive psychosocial outcomes reported for PwDs include reduced levels of physical agitation, aggression, and challenging behaviours; reduced levels of confusion; fewer catastrophic reactions; improved mood, reduced levels of psychiatric symptoms, and increased interest in their environment. Physical improvements for PwDs include improved eating and sleeping patterns, weight gain, and increased mobility; and reduced use of psychotropic medication, physical restraints, and chemical restraints. Improvements for FCs include reduced stress, better visiting experiences, and increased feelings of reassurance about both PwDs' improved well-being and quality of care provided by SCUs. Improvements for staff include increased levels of work satisfaction and competence, reduced levels of burnout, increased access to resources necessary to provide high-quality care, and more time to get to know residents and do activities with them. In addition, improved communications with FCs have been reported.

Chapter 3: Literature review II – Care-giving and experiences of admission into SCUs or LTC generally

3.1 Introduction

Chapter 3, the second part of the literature review, shifts its focus away from the SCU as care environment and to the experiences of those being admitted into SCUs and their caregivers. The first part of Chapter 3 reports on the care-giving literature. In particular, key findings from the literature on i) the complexity of LTC placement, ii) FCs' experiences of caring for a relative with moderate to severe dementia, and iii) reasons for LTC placement are presented. This is followed by literature on both FCs' and formal care staff's experiences of i) wait-listing people diagnosed for LTC placement, ii) using residential respite care as an entrée into LTC, iii) making the placement decision, and iv) communicating news of the placement to the person. The chapter progresses to discuss admission and discharge criteria used by SCUs. The chapter then advances to present findings from the qualitative literature on the outcomes and meanings, both short term and more long term, which the SCU LTC placement holds for both PwDs and their FCs. The final part of this chapter reports on key principles of the theoretical framework I chose – the relationship-centred approach - and outlines my reasons for selecting this approach.

Despite the expected increase in numbers of PwDs requiring residential care in the future, knowledge of experiences of relocating into SCUs is sparse (Day, Carreon, & Stump, 2000; Myers et al., 2007). Existing literature has mostly dealt with PwDs' and caregivers' experiences of relocating into LTC in general (Davies & Nolan, 2003; Gladstone, 1995; Lee, Woo, & Mackenzie, 2002; Naleppa, 1997; Nolan et al., 1996; Rodgers, 1997) and not the experience of moving into SCUs. Therefore in the sections to follow the literature on admissions to LTC in general will mostly be drawn on. Key issues identified comprise

experiences prior to admission, making the placement decision, and adapting to the residential care setting after placement.

3.2 LTC placement – A complex entity

Admitting a relative with dementia into LTC has been conceptualised as a complex, challenging, and life-transforming event for all affected (Aminzadeh et al., 2009; Kellett, 1999; Nolan et al., 1996; Reed-Danahay, 2001). PwDs, however, are likely to be most affected by the placement as they are very sensitive to their immediate environment (see pages 18 and 37) yet may lack the cognitive, emotional, and physical resources necessary to cope with the relocation or communicate these issues.

LTC placement often comes at a time when the person, due to having advanced dementia, may have no capacity to understand and cope with the transition process (Elliott, Gessert, & Peden-McAlpine, 2009; Meehan et al., 2004), and may also display challenging behaviour which can no longer be managed elsewhere. Admission into LTC has been shown to exacerbate existing challenging behaviours (such as extreme upset, catastrophic behaviour, physical violence) and confusion (Benoit et al., 2006). Much of the research focuses on attempting to elucidate in the context of the severity of dementia, (mild, moderate, severe) who is most adversely affected by the relocation. It has been argued that PwDs with severe dementia are more likely to feel excessively stressed by the transition both during and immediately after the transfer (Castle, 2001; Meehan et al., 2004; Nirenberg, 1983) and may be less capable of successfully adapting to their new environment in the longer term (Castle, 2001; Nirenberg, 1983; Vaehaekangas, Noro, & Bjoergren, 2006).

Other studies argue that moderately cognitively impaired people are most adversely affected by the placement compared to those with either mild or severe dementia (Castle,

2001; McAuslane & Sperlinger, 1994; Meehan, Robertson, & Vermeer, 2001; Nirenberg, 1983). For instance, those with moderate CI are more likely to become more withdrawn, engage in fewer activities, and be less physically active than those at either end of the CI continuum (for example, Nirenberg, 1983). People with mild CI may have retained more reserve to actively counter adverse relocation outcomes - for instance, by engaging in more social activities after admission (Nirenberg, 1983), whilst people with a severe impairment may be more dependent on their immediate environment and therefore less affected by potential stressors associated with planning, anticipating, and undergoing placement (McAuslane & Sperlinger, 1994; Meehan, Robertson, & Vermeer, 2001; Meehan et al., 2004). To date, studies have remained inconclusive; for example, stable or improved levels of functioning, well-being, and social activity were found in people with moderate CI after placement (Nirenberg, 1983; Smith & Crome, 2000).

Given that in this thesis I make efforts to include the voice of PwDs who undergo the relocation and their FCs (see Chapter 4), the next sections summarise qualitative literature on experiences and views of FCs of caring for a relative with dementia prior to his/her SCU LTC placement.

3.3 Role engulfment

"Role engulfment" denotes FCs' absorption by their care-giving responsibilities for the PwD, which become increasingly excessive and all-consuming and which are aggravated by multiple care and/or work commitments outside caring for the PwD (Twigg & Atkin, 1994). FCs are integrally involved in the placement process and as such are affected by the transfer (Gaugler, 2005). FCs, however, are not a homogenous population, and groups of FCs (for example, spouses, adult children, and children-in-law) differ depending on factors such as their familial relationship with the PwD, gender, role commitments, and living with or apart from the PwD. Indeed, some studies highlight differences between

these groups of FCs, indicating that each experiences their relative's LTC placement in distinct and unique ways.

The literature suggests that spouse carers of PwDs are more adversely affected by the placement of their partners in LTC than other carers (Kramer, 2000). Spouses share intimate emotional bonds and long-standing mutual commitments with their partner, and are often completely immersed in their care-giving role (Croog et al., 2006; Lindgren, 1993). Spouse caregivers tend to be more isolated than others due to the all-consuming nature of their care-giving responsibilities and absent informal and formal supports (Tebb & Jivanjee, 2000), a situation exacerbated by spouse caregivers usually being aged (Pot, Deeg, & Knipscheer, 2001) and possibly living apart from adult children. Some studies reported that spouses are more likely to be admitted into LTC at a later stage of their dementia because of the care-giving partner's resistance to institutionalisation and his/her care-giving commitment (Murray et al., 1999; Pot, Deeg, & Knipscheer, 2001).

A major and unique challenge for spouses, who decide to place their partner with dementia into LTC, is coming to terms with what has been termed "quasi-widowhood" (Baxter et al., 2002; Rosenthal & Dawson, 1991, as cited in Shanley et al., 2011, p. 327). Becoming quasi-widowed means that the PwD, whilst being alive and often physically fit, is separated from the carer (i. e. living in a nursing home) and is in most cases no longer able to relate to his/her spouse due to his/her cognitive and behaviour impairments (Kramer, 1997; Shanley et al., 2011).

Adult children caring for a parent with dementia are mostly women, namely daughters and daughters-in-law (World Health Organization, 2012). They are often in their middle life years and have along with caring for the PwD multiple other roles, such as working in paid employment, parenting children, and sometimes caring for other family members with chronic health problems (Cho, Zarit, & Chiriboga, 2009; Murphy et al., 1997). They have therefore been termed the "'sandwich" generation" (Brody, 1981, as cited in Cho, Zarit, &

Chiriboga, 2009, p. 65), denoting their putative high levels of role burden. The concept of role strain is used to describe the competing demands arising for these FCs from their multiple roles (Edwards et al., 2002). Role strain results from both role overload (i. e. physical burden) and role conflicts (i. e. psychological burden of meeting different role demands) (Edwards et al., 2002; Kramer & Kipnis, 1995). However, empirical studies show that it is not as straightforward – some FCs with multiple care roles experience role strain (which may result in their having to adjust work tasks and time schedules to their care-giving commitments); others do not and may even feel satisfied with managing different roles whilst others may feel as burdened as those without multiple roles (Edwards et al., 2002; Marks, 1998).

Cohabiting with or living apart from the PwD while caring for the latter during the time leading up to LTC may also contribute to carer distress (Stoltz, Udén, & Willman, 2004). Co-resident caregivers may deal with the PwD's care needs and behavioural changes on a constant basis, and may become socially isolated due to their all-consuming around-the-clock care role. Schneider and colleagues (1999) identified spouses living with a partner with dementia to be most at risk of increased carer burden and loneliness.

This "categorisation" of carer groups may however be too simplistic as individual circumstances of each FC need to be considered, such as non-spouses co-residing with the PwD (because of absence of support systems, cost issues, or societal norms) whilst ageing spouses may indeed have multiple care roles (looking after grandchildren, being in paid employment). The following section will examine why FCs decide to place their relative with dementia into LTC.

3.4 Reasons for placement

The decision to place a relative with dementia into LTC is usually made for a number of inter-related reasons. Factors relating to the person himself/herself include advanced age, physical health problems, marked functional and cognitive decline, increased challenging behaviours, and absence of informal support (Caron, Ducharme, & Griffith, 2006; Castle, 2001; Naleppa, 1997; Rehfeldt, Steele, & Dixon, 2000; Smith & Crome, 2000; Thorson & Davis, 2000).

In one study, challenging behaviours such as physical violence, pacing, and incontinence-related behaviours (in particular, if displayed during night times and therewith disrupting FCs' sleeping patterns) were shown to be most difficult to manage and resulted in FCs' committing to the PwD's LTC placement (Gaugler et al., 2000).

Factors relating to the FC may comprise excessive caregiver burden – defined as the "overall impact of physical, psychological, social, and financial demands of caregiving" (George & Gwyther, 1986, as cited in Pinquart & Soerensen, 2003, p. P112). Caregiver burden thus arises from the complex and ever-demanding care responsibilities a FC has for the PwD, and may lead to the FC's physical and mental exhaustion, social isolation, and even depletion of financial resources (Chenier 1997; Etters, Goodall, & Harrison, 2008; Pinquart & Soerensen, 2003). Ultimately, the PwD's care needs may exceed the care-giving capacity of his/her family (Crawford-Mead et al., 2005; Horttana, Ahlstroem, & Fahlstroem, 2007; Rantz & Egan, 1987; Smith & Crome, 2000) - resulting in a crisis suffered by the FC, which may drive the PwD's LTC placement.

Other reasons for placement of PwDs and associated with FC characteristics may include caregiver health problems, the carers' perceptions of residential LTC, and lack of adequate community support (Naleppa, 1997; Park, Butcher, & Maas, 2004). In particular, the absence of adequate community-based care services provided by HSPs (in particular,

help with ADLs and IADLs) was shown to contribute to carer distress (Philp et al., 1995; Sussman & Regehr, 2009) and make nursing home placement of PwDs more likely (Gaugler et al., 2007; Luppa et al., 2010).Other factors, such as the suitability/unsuitability of the care-giving environment prior to LTC admission, expectations of residential care, and prior experience with institutional care, may also be relevant for making the decision to admit an ageing relative into LTC (Davies & Nolan, 2003; Naleppa, 1997; Ryan & Scullion, 2000b).

One qualitative study found that the overall demands of caregiving including the need for personal care, monitoring food intake, shopping and overseeing the PwD's legal and financial matters were the main reasons why home care was discontinued (Butcher et al., 2001). A major concern for FCs in this study was their relative's increased safety problems, in particular, the risk of falling, having road accidents, and getting burnt (Butcher et al., 2001).

There are also a wide range of external reasons situated outside the immediate family context which may explain why people get placed in LTC. These may include changes to the social, political, cultural, and economic systems - such as the breakdown of family care, changing attitudes towards LTC, and facility closures/mergers - which might eventually increase the likelihood of transfer to a LTC setting (Horttana, Ahlstroem, & Fahlstroem, 2007).

3.5 Being wait-listed for placement

The practice of wait-listing people for nursing homes or other health services has been shown to have negative effects on potential service users and their families. A Dutch study showed that whilst wait-listing a relative for LTC was beneficial from the point of view of making preparations for the relocation, such benefits were outweighed by negative

outcomes including increased caregiver burden, additional stress caused by undefined waiting times, and physical health detriments for all affected (Meiland et al., 2001). In her study in the Netherlands, the mean waiting time for placement in a psycho-geriatric ward was 17.5 weeks in 1997, and it was 15 weeks (range 8-23) for those wait-listed for nursing home placement (Meiland et al., 1996), a time frame she believed was too long. Another study from Norway reported that those wait-listed for regular nursing home placement in Canada and the Netherlands had to wait for "several years after requesting NH placement" (Fjelltun et al., 2009, p. 737). Other authors exploring SCUs have not reported exactly how long participants had to wait for placement but uniformly stated that SCU waiting lists were long (George, 2003; Wood, Womack, & Hooper, 2009).

Meiland's work also explored the process of wait-listing residents of general nursing homes and how these lists were used in allocating beds from HSPs' point of view (Meiland et al., 1996). Wait-listing itself was described as a complex process involving ongoing needs assessment of those listed and ultimately making decisions about prioritisation once a bed vacancy arose (Eagle & de Vries, 2005; Meiland et al., 1996). The purpose of wait-listing was to achieve a fair allocation process (Meiland et al., 1996, p. 2). The same authors also found that allocation decisions were equally complex - whilst the place on the wait-list was a key decision factor, emergencies were prioritised (Meiland et al, 1996).

In the Meiland study, geriatricians and psychiatric nurses were shown to follow a complex set of criteria in terms of decision making. Time spent on the waiting list was merely one of several other criteria used, including level of dementia, other mental health problems, mobility and physical health problems, level of emergency, and characteristics of the facility where the person is to be placed (Meiland et al., 1996).

Meiland also showed that admission procedures based on wait-listing and other factors differed across localities (Meiland et al., 1996). Meiland et al. concluded that following this

in-depth investigation into the area, her findings revealed that those considered "most urgent or waiting longest are seldom uniquely selected, other 'forces' also determine the eventual selection" (Meiland et al., 1996, p. 8). She and her colleagues claimed that "the waiting list is merely used as a 'pool of work' which one would 'dip into'." (Meiland et al., 1996, p. 8)

An Irish study conducted more recently reported similar findings to Meiland's including anxiety and increased psychological distress among those affected by the wait (NÍ Shiothcháin & Byrne, 2009). The same authors also claimed that lack of information about one's wait-list status heightened feelings of uncertainty and distress, and emphasized the resulting need for improved communication between HSPs and families; in particular, staff actively informing families about their wait-list status (NÍ Shiothcháin & Byrne, 2009).

This notion of complexity was reflected in this same study which examined HSPs' management of waiting lists in the mental health services - thereby underscoring stressful aspects of working with waiting lists for formal staff (NÍ Shiothcháin & Byrne, 2009). These authors claimed that lengthy wait-lists may increase feelings of anxiety in paid staff; this may be particularly the case among staff with excessive work load, who in addition may be less likely to adequately prioritise new admissions (NÍ Shiothcháin & Byrne, 2009). Also in line with Meiland's et al. (1996) findings, they critiqued that wait-listing procedures in the Irish mental health sector may not be standardised, possibly resulting in unfair decision outcomes:

> "The management of waiting lists is not standardised and often takes place on an ad hoc basis, lacking in organisation and fairness." (NÍ Shiothcháin & Byrne, 2009, pp. 211-212)

NÍ Shiothcháin and Byrne (2009) further concurred with Meiland and colleagues (1996) in stating that besides the length of time spent on the waiting list, service users need to be

classified according to other components - in particular, possible consequences of continued waiting and possible gains of placement.

To conclude, wait-listing prospective residents and deciding about new admissions are complex processes (Eagle & de Vries, 2005). Although literature on this topic is extremely sparse, it may be inferred from such studies as Meiland's et al. (1996) that wait-listing and decision protocols for SCU staff may be equally complex and heterogeneous across countries and settings – the more so if SCUs are to implement a truly person-centred care, which requires adapting to individual needs and circumstances (for example, levels of distress and coping abilities of a particular family).

3.6 Respite care as an entrée into LTC

In Ireland different types of respite care, may, pending individual needs, be offered to PwDs and their carers. The three main types are in-home respite, day respite (provided by day care centres) and in-patient or residential respite care (in nursing homes, hospitals, or SCUs) (Gilmour, 2002; Lee & Cameron, 2008). Residential respite care is defined as a time-limited stay – usually ranging between one and two weeks - in a nursing home or any other formal care setting providing residential respite care services (Gilmour, 2002).

It has been claimed that residential respite care provides FCs with much-needed breaks from caring, offering them time for recuperation during which they can attend to their own physical health needs, do things for themselves, and socialise with others they may have neglected due to their care-giving responsibilities (Gilmour, 2002; Lee & Cameron, 2008). Such intermittent breaks from caring have been shown to help FCs continue care-giving and may help to avoid unnecessary or premature institutionalisation of their relative with dementia (Lee & Cameron, 2008). Other studies suggest that residential respite care helps improve challenging behaviours in PwDs - another aspect possibly postponing their

LTC placement (Brodaty & Gresham, 1992; Gilmour, 2002). Unsurprisingly, according to Gilmour (2002) respite care was identified by FCs as a most-needed source of formal support during the time leading up to LTC placement.

In contrast, some authors claimed residential respite care may have detrimental outcomes for FCs including feeling guilty about using the service; being afraid of their relative's future LTC placement; and having difficulty coping with disrupted routines after the respite break (Gilmour, 2002; Lee & Cameron, 2008). These adverse outcomes might explain why FCs, despite viewing residential respite care as a vital resource, were generally hesitant to use it (Gilmour, 2002; Lee & Cameron, 2008). Other – service-related - problems associated with the under-use of residential respite by FCs were identified in the literature and included insufficient financial means and lack of information about such services (Brodaty & Gresham, 1992); lengthy waiting-lists and failed referrals by HSPs (Brodaty and Gresham, 1992); and poor quality of residential respite services offered (Gilmour, 2002).

Residential respite care may also have adverse outcomes for PwDs such as increased levels of challenging behaviour and increased physical health problems (Gilmour, 2002), which in turn may speed up permanent placement (Brodaty & Gresham, 1992). For instance, Gilmour (2002, p. 551) reported that PwDs using hospital respite had weight loss, mobility problems, and constipation after the respite break.

Ironically residential respite, a service designed to promote continued community care, may actually hasten LTC placement of a relative with dementia (Brodaty & Gresham, 1992; McNally, BenShlomo, & Newman, 1999) due to carers becoming familiar with the setting where their relative is ultimately placed (Ashworth & Baker, 2000); perceiving the respite care as "training" for LTC placement (Brodaty & Gresham, 1992); becoming aware of how stressed they are as a result of the break (McNally, BenShlomo, & Newman,

1999); and due to staff becoming more aware of families' circumstances and thus being more prone to initiate placement (Brodaty & Gresham, 1992).

Indeed, empirical studies examining the association between residential respite use and LTC placement have so far yielded mixed results (Brodaty & Gresham, 1992; Lee & Cameron, 2008). For instance, McNally, BenShlomo, and Newman (1999) in their review on the relationship between in-patient respite care use and LTC placement identified five relevant studies, two of which associated with continuation of FC's care role, one with speedier placement (although no control group was included), one with continued care-giving in adult children but speedier placement of spouses, and one yielding insignificant results. Similar results were obtained by others: Brodaty and Gresham (1992) reported that one study reviewed by them found no association between use of residential respite care and LTC admission, whilst another identified increased admission rates to be associated with use of residential respite care. Brodaty, Green, and Koschera (2003) reviewed quantitative studies, five of which reported effectiveness of residential respite care in postponing LTC placement (i. e. respite users spent more days in the community, ranging between 53 and 329 days).

Overall, McNally and his colleagues summing up the effects of residential respite care conclude that based on "limited evidence (...) respite has the potential to influence permanent institutionalization but the direction of this influence remains unclear." (McNally, BenShlomo, & Newman, 1999, p. 9)

3.7 Decision to place

Several authors have described the decision to admit a relative with dementia into LTC as being driven by a crisis such as the acute and sometimes unexpected illness of the person or the FC. The latter it is said occurs in many cases without sufficient emotional

and practical preparation on part of the PwD and his/her FCs (Bramble, Moyle, & McAllister, 2009; Caron, Ducharme, & Griffith, 2006; Nolan et al., 1996; Park, Butcher, & Maas, 2004).

One study found that around-the-clock safety worries and vigilance as well as PwDs' need for assistance with ADLs and IADLs greatly increased FCs' physical and emotional carer distress prior to placement. The latter eventually resulted in what Butcher et al. (2001) described as "reaching a breaking point" (p. 475). In this study, FCs also felt poorly prepared for the impending placement despite a few feeling familiar with the SCU through visits made in advance of placement (Butcher et al., 2001).

Some authors have also shown how the PwD remains excluded from the actual placement decision and how alternative care options (other than residential LTC placement) are not discussed with the person (Nolan et al., 1996[2]; Tilse, 2000). FCs and HSPs were identified as key decision makers (Nolan et al., 1996; Ryan & Scullion, 2000b). The common practice of excluding PwDs from the decision-making process may be because it is believed by many FCs that the PwD is too impaired in his/her understanding and language skills for her/him to meaningfully participate in communications about the impending transfer (Ducharme, Couture, & Lamontagne, 2012, pp. 206-207; Ryan & Scullion, 2000b; Whitlatch, 2008).

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[2]Nolan and colleagues (1996, p. 271 ff.) identified four types of decision about LTC placement, namely the "positive choice", the "rationalized alternative", the "discredited option", and the "fait accompli". These four categories differ in the level of cognitive and emotional preparation for the relocation (anticipation), the extent to which the elderly person is included into the decision process (participation), the extent to which placement alternatives are deliberated (exploration), and the quality of information received about placement (information). These categories present a useful description of how, and for what reasons, placement decisions differ among families (Nolan et al., 1996).

Another study reported that families caring for relative with dementia tend to procrastinate the decision because of its emotional implications (intense wish for continuing to care, intense feelings of guilt about placement decision) (Caron, Ducharme, & Griffith, 2006). One qualitative study specifically investigating the topic of how FCs decided about SCU LTC placement also reported that intense ambiguous feelings of conflict and fear yet also relief and confidence about making the right decision accompanied their decision-making (Butcher et al., 2001; Butcher et al., 2002). Besides the FCs other family members such as siblings, PwDs' spouses, and grandchildren may be involved in the decision-making (Butcher et al., 2001; Caron, Ducharme, & Griffith, 2006; Davies & Nolan, 2003).

The literature has shown how FCs deciding about their relative's LTC placement felt under enormous pressure themselves to find a suitable setting (Caron, Ducharme, & Griffith, 2006; Davies & Nolan, 2003). In particular, FCs felt inadequately supported by HSPs, felt forced to decide about their relative's placement within very short periods of time (days), and felt pressurised by external circumstances (reacting to LTC bed vacancies, pressures exerted by discharging settings to free up beds) (Davies & Nolan, 2003; Nolan & Dellasega, 1999; Reuss, Dupuis, & Whitfield, 2005; Rodgers, 1997; Ryan & Scullion, 2000b).

Others have described the decision, made by FCs, to institutionalise a relative with dementia as being highly distressing and challenging (Butcher et al., 2002; Caron, Ducharme, & Griffith, 2006; Park, Butcher, & Maas, 2004). Placement was viewed as "a last resort" (Keefe & Fancey, 2000, p. 235) after all other care-giving arrangements failed (Naleppa, 1997, p. 88; Nolan et al., 1996). In particular, Butcher and colleagues (2001) explored in-depth the stressful nature of making the placement decision among FCs of SCU residents. According to this study, placement decisions were associated with intense levels of exhaustion due to the PwD's increasing care needs prior to admission; and with intense feelings of guilt and anguish over the decision (Butcher et al., 2001, p. 475). FCs

felt emotionally torn about the placement decision, they experienced relationship problems, and were sometimes apprehensive about the placement (Butcher et al., 2001).

3.8 Communicating news of placement to PwD

Only two qualitative studies were identified in the literature search which investigated the specific question of how FCs communicated news of the placement decision to a relative with CI (Ducharme, Couture, & Lamontagne, 2012; Golden, 2010). The study conducted by Ducharme, Couture, and Lamontagne (2012) showed that whilst a few FCs openly talked with their relative about the placement and included the person into the decision-making, others chose to exclude their relative from the decision due to impaired insight and a concern about the fact that this might cause distress . The study conducted by Golden (2010) examined the case of a caregiver wife placing her husband into LTC, and found that the carer used misleading information (a hotel) about exactly where the PwD was going to (a LTC facility) – pointing to the fact that FCs tend to avoid truth-telling in order to avoid combative or upsetting reactions in their relative (Baxter et al., 2002).

3.9 Admission and discharge criteria

Although a literature research revealed that SCU admission criteria may vary considerably across settings as well as countries (Miller & Weissert, 2000; Moïse et al., 2004; Verbeek, 2011), studies conducted in the USA and Europe point to dementia diagnosis and challenging behaviours being key eligibility criteria (Bellelli et al., 1998; Gruneir et al., 2008; US Congress Office of Technology Assessment, 1992; Verbeek, 2011).

A US report dating from the early 1990s stated that only some few SCUs had "written admission and discharge policies" (US Congress Office of Technology Assessment, 1992). According to this report, however, three quarters of all nursing homes in five

different states claiming to have SCUs reported they used admission criteria. Such criteria included i) dementia severity, ii) the need for supervision and iii) challenging behaviours or what they termed "the individual's behavioral symptoms" (US Congress Office of Technology Assessment, 1992, p. 27). The vast majority of these facilities (85%) had a preference for people with severe behavioural impairments, and about 33% of them stated that prospective residents had to "be able to ambulate independently" (US Congress Office of Technology Assessment, 1992, p. 27). The same report also mentioned that stated admission regulations might not always concur with how admissions were handled in practice (US Congress Office of Technology Assessment, 1992), possibly pointing to some degree of flexibility and adjustment to individual residents' and their families' needs. An Italian study reported very similar admission criteria used by SCUs namely, i) a dementia diagnosis reflecting a moderate to severe impairment (MMSE score of 14 or lower), and ii) significant behavioural impairments of PwDs (Bellelli et al., 1998, p. 457).

The OTA report also referred to discharge regulations in place in a state-wide SCU sample (US Congress Office of Technology Assessment, 1992). Whilst about 50% of all units claimed to provide end-of-life care for their residents, the other half admitted to discharging their residents from SCUs for a variety of reasons. Discharges were said to take place if residents had "become nonresponsive, physically abusive, or unable to ambulate independently" (US Congress Office of Technology Assessment, 1992, p. 27). Discharges were also said to take place from SCUs if the resident needed "intensive medical care" and if her/his "private funds are exhausted" (US Congress Office of Technology Assessment, 1992, p. 27).

It seems therefore that there is no consensus in the literature about whether SCUs are ageing-in-place facilities where PwDs live until they die as is the case in the Netherlands (Verbeek, 2013) or whether they offer care for a limited time following which PwDs are discharged to hospices or possibly home to die or to hospitals for end-of-life treatment. Some settings (the UK domuses, French cantous, and Scottish 'housing with care'

models) maintain they adhere to a "home for life" approach and claim to keep their residents with dementia within the same SCU until death (Verbeek, 2011). However, closer inspection of the literature on these settings reveals that many actually discharge residents, in particular if they develop severe challenging behaviours (Verbeek, 2011). Overall, SCU admission and discharge criteria vary as policies appear to differ between countries as well as within countries and across individual settings.

In the next section I review outcomes and meanings, both short term and more long term, of SCU LTC placement for both PwDs and their carers.

3.10 Meanings and outcomes of LTC placement

This part of the chapter commences by summarising qualitative findings on PwD's short-term and more long-term experiences of relocating to SCUs. Whilst in the previous chapter the literature on effectiveness of SCUs was discussed (see section 2.5.8), the next section presents literature on meanings and outcomes of LTC placement from the point of view of the individual.

3.10.1 PwD's immediate meanings and outcomes of placement

To date, only one Irish study was identified which explores the subjective experiences of PwDs being relocated to a SCU (Myers et al., 2007). In this study, the researchers interviewed a small sample of people with moderate dementia (N = 6) who were transferred from a generic unit to a SCU within a rural hospital. A criticism of this study is the fact that no information was provided about exactly when participants were interviewed after placement. Nevertheless, Myers et al. (2007) explained that they were interested in PwDs' experiences "since the opening of the unit" (p. 54), i. e. their more immediate experiences.

PwDs' accounts in this Irish study illuminated the complex and challenging nature of this type of relocation and concurred with findings from other studies (see section 2.5.8.1). Residents reported they enjoyed improved opportunities for socialising, partaking in meaningful activities, and being more autonomous following the SCU admission. They also expressed feelings of uncertainty about where they were, who they were surrounded by, and what they were supposed to do.

Some were also described by the researchers as severely struggling with increasing memory and cognitive decline, such as needing more time to find the right words, forgetting answers and being disoriented to persons. Interestingly, although SCUs are meant to be homelike settings conducive to new residents feeling at home quickly, only a minority of participants interviewed by Myers and colleagues felt immediately settled (Myers et al., 2007). Most PwDs participating in this study felt displaced and deprived of their freedom, missed their former home, and expressed their wish for leaving the SCU (Myers et al., 2007). This small-scale qualitative study clearly showed that being placed in a SCU is a complex experience for PwDs, challenging their emotional and cognitive resources, and may require an adaptation process over time.

The only other qualitative study I identified in the literature which drew on PwDs' own views about relocation was that undertaken by Aminzadeh and colleagues in Canada in 2009. Similar to Myers' et al. (2007) findings, the authors of this study concluded that the transition was associated with significant disruptions to participants' life-style patterns and relationships (Aminzadeh et al., 2009). For PwDs in their study the transition meant the end of a life they knew, accepting oneself as being old, and the loss of personal freedom (Aminzadeh et al., 2009). These findings were in accordance with an earlier study of people's experiences of nursing home placement, which included older adults with and without CI (Lee, Woo, & Mackenzie, 2002). Not surprisingly, relocating into LTC meant high levels of distress, ambivalence, and fear for most (Aminzadeh et al., 2009; Gladstone, 1995; Lee, Woo, & Mackenzie, 2002).

The literature shows that moving into LTC (in general) was in particular associated with multiple losses for PwDs (Aminzadeh et al., 2009; Davies & Nolan, 2003). Although referring to older people in general and not PwDs, the following losses have been identified – i) abstract losses such as autonomy, privacy, roles; ii) material losses such as individual possessions; and iii) social losses, in particular loss of former relationships to neighbours, friends, and pets (Lee, Woo, & Mackenzie, 2002, p. 22). Such losses and the accompanying negative emotions associated with LTC placement may in most modern societies be reinforced by negative attitudes prevailing towards institutionalisation (Heenan, 2000; Lee, Woo, & Mackenzie, 2002).

3.10.2 Longer-term meanings and outcomes of placement for PwDs

The challenge of being placed into LTC does not end with the physical transfer but continues to persist after placement (Karlin, Bell, & Noah, 2001). Existing qualitative research has shown that older adults including those with CI and dementia may continue to struggle with the multiple losses they experience and which are associated with placement (Aminzadeh et al., 2009; Lee, Woo, & Mackenzie, 2002). Coping with these losses may result in prolonged feelings of powerlessness, lack of self-esteem and abandonment (Aminzadeh et al., 2009; Lee, Woo, & Mackenzie, 2002, p. 22; Naleppa, 1997) and at the extreme might even trigger psychiatric problems, such as depression. Such negative reactions after placement may be intensified by negative emotional experiences the person had prior to placement such as feeling excluded from the placement decision, being disrespected in their choices, and ongoing resentment towards family members about the placement decision (Lee, Woo, & Mackenzie, 2002).

In addition to coping with their losses, PwDs upon placement in general nursing homes are confronted with the challenge of adapting to an institutional care environment where individual needs and choice may be restricted in favour of organisational needs (Naleppa, 1997). Adapting to the new setting and its routines is a long-term process which can take eight to 12 months, and depends on the individual and his/her adaptation skills (Chapin &

Dobbs-Kepper, 2001; Lee, Woo, & Mackenzie, 2002; Rehfeldt, Steele, & Dixon, 2000; Walker, Cox Curry, & Hogstel, 2007).

One notable study explored the settling-in experiences of LTC residents most of whom were described as "moderately to severely cognitively impaired" (Brooke, 1989, p. 66). Brooke (1989) identified four phases, each of which was characterised by certain adjustment tasks. "Disorganisation" was the phase lasting from admission to two months post-admission and was characterised by feelings of loss, loneliness, and alienation. The "reorganisation" phase lasted from two to three months after admission during which the person made active efforts to internalise the new routines, explore his/her new environment, and promote his/her needs. "Relationship building" occurred at months three and four post-placement. During this period, the new LTC resident developed relationships with staff members and peers. The final adaptation phase – "stabilization" – was observed at four to six months after placement and included fully integrating oneself into the new setting (Meehan, Robertson, & Vermeer, 2001; Rehfeldt, Steele, & Dixon, 2000; Wapner & Demick, 2000). In addition, Brooke (1989) emphasized the fact that these phases were not experienced linearly, rather newly admitted LTC residents would oscillate between the different phases according to their emotional experiences (Brooke, 1989, as cited in Lee, Woo, & Mackenzie, 2002, p. 25). Brooke (1989, as cited in Lee, Woo, & Mackenzie, 2002) also stated that individual characteristics such as cognitive functioning and the voluntary versus mandatory nature of admission, shaped individual adaptation experiences. Indeed, the process of adapting to a residential care setting is prolonged and more difficult for those with CI, physical health problems, and functional decline (Castle, 2001, p. 325).

The very limited evidence from these studies supports the notion that admission into SCUs (and other LTC settings) for LTC is a complex and challenging event for PwDs, which does not necessarily alleviate or stop existing distresses related to their dementia (such as health ailments, memory problems, emotional upset) but may bring about new

worries and concerns for these extremely vulnerable people. The next section will review literature on meanings and outcomes of placing a relative with dementia into LTC for FCs.

3.10.3 FCs' meanings and outcomes of placing a PwD into LTC

Several qualitative studies have explored FCs' experiences of adapting to having placed a relative with dementia into residential care (Davies & Nolan, 2006; Dupuis & Norris, 2001; Karlin, Bell, & Noah, 2001; Keefe & Fancey, 2000; Naleppa, 1997; Nolan & Dellasega, 1999; Rodgers, 1997; Ryan & Scullion, 2000a). The overall conclusion to be drawn from these studies is that informal caregiving responsibilities and distresses do not cease but rather shift and continue after placement (Zarit & Whitlatch, 1992). The exact timing of this shift in responsibilities and change in stress has been proven difficult to pinpoint (Bramble, Moyle, & McAllister, 2009; Haley, 1997; Lieberman & Fisher, 2001). For instance, one Irish study showed how care-giving roles and responsibilities continued and changed at four to six months after nursing home placement (Argyle, Downs, & Tasker, 2010). All carers in this study maintained continuity in their relationships with their relatives but they took on new responsibilities for their relative's care such as liaising with staff, visiting, and advocating roles.

Existing studies also demonstrate that FCs continue to experience complex and intense emotional responses to their relative's LTC admission for some time after placement (Chene, 2006). These reactions have been described as stressful and oscillating between feelings of bereavement, helplessness, guilt, and self-reproach (Gaugler et al., 2001; Gladstone, 1995; Karlin, Bell, & Noah, 2001). Carers may believe they have failed and that they have been left with no alternative (Ryan & Scullion, 2000a, p. 1192). Other studies have shown how FCs remain concerned about having made the right choice and worried about future discharge after placement (Caron, 2002; Reed & Morgan, 1999; Zarit & Whitlatch, 1992). In contrast, feelings of relief, a sense of having improved their relative's quality of life, and a sense of having acted in the person's best interests have also been observed among FCs after placement (Gladstone, 1995; Naleppa, 1997).

Butcher's study showed mixed reactions (grief, loss, relief and reassurance) on the part of FCs 12 months after the initial placement took place (Butcher et al., 2001).

In particular, married couples appear to be uniquely challenged by the LTC transition as the care-giving spouse becomes quasi-widowed and may find it extremely challenging to rebuild his/her life and identity after placing his/her long-term partner into LTC (Chene, 2006; Gladstone, 1995; Naleppa, 1997). In general, spouse caregivers appear to experience more intense conflicting emotions about their partner's placement including intense feelings of guilt, sadness, and loneliness (Tilse, 2000).

The literature shows how often new care-giving roles and responsibilities emerge for FCs who have placed a relative with dementia in residential care (Davies & Nolan, 2006; Naleppa, 1997). Keefe and Fancey (2000) provide a useful distinction between direct and indirect care-giving roles performed by FCs after their relative's placement. They claim that:

> "Indirect responsibilities refer to the responsibility of the family member to ensure that the activity gets done for the elderly resident whereas direct responsibilities are considered activities that the family member performs for the relative." (Keefe & Fancey, 2000, p. 239)

Indirect care-giving responsibilities include monitoring the person's well-being and care and ensuring that all care needs are adequately met (Butcher et al., 2001). Other important indirect care roles include developing a long-term rapport and trust with care staff; helping staff members care for the person (Keefe & Fancey, 2000, p. 239) and watching and commenting on the quality of care. For example, in the Butcher study, FCs whose relatives were placed in SCUs felt dissatisfied with poor staff resident ratios (low staff numbers), which they believed had an adverse effect on quality of care provided by these units (Butcher et al., 2001).

Direct care-giving responsibilities comprise "providing emotional and physical support, providing personal comforts, and being a link to the community" (Keefe & Fancey, 2000, p. 239). Emotional supports are provided by regularly visiting and being attentive to the relative's needs for physical and personal well-being. Physical supports include managing the relative's financial matters and taking on practical care-giving tasks such as dressing, doing the laundry and organising appointments. Personal comforts include ""little extras"" (Keefe & Fancey, 2000, p. 240) such as favourite foods or gifts for their relative in order to make him/her feel more comfortable in the new setting (Keefe & Fancey, 2000). Maintaining links with the community includes bringing in visitors from the community (neighbours, friends), reading news to the person, and taking the PwD on regular outings (Butcher et al., 2001; Keefe & Fancey, 2000). Keefe and Fancey (2000) added that FCs took on more indirect than direct care-giving roles after placement.

The next section outlines the theoretical framework, relationship-centred care, used for the purpose of this thesis. The theoretical framework emanated from thoroughly reviewing the literature relevant for the thesis topic (see Chapters 2 and 3), and represents my theoretical understanding or "lens" with which I approached the topic of admitting PwDs into SCU LTC. Therefore, I decided to incorporate the theoretical framework into the literature review and not into the methodology chapter. The section commences with an outline of the historical emergence of this particular approach and continues to present its key theoretical principles.

3.11 Theoretical framework: Relationship-centred care

As mentioned earlier, dementia care in the UK underwent a major, almost revolutionary shift in the late 1980s and early 1990s when a clinical psychologist, Tom Kitwood, and his colleagues at Bradford University began to challenge the biomedical approach for understanding dementia by arguing that dementia was more than merely an organic

illness and that the person experiencing the symptoms was as much affected by his or her built and psycho-social environment as by the neurological symptoms of the illness (see Chapter 1). Kitwood developed a theory on dementia which evolved from psychology and a philosophy of care which he described as person-centred. In his earlier seminal work he introduced the concept of person-centred care (Kitwood, 1997) and introduced the concept of "personhood" as status bestowed upon the individual by another (see Chapter 1). Undoubtedly, Kitwood's contribution to re-casting dementia and raising awareness about the individual's subjective experience has left a major legacy to the field of dementia care around the world. In fact the difference his approach has made to dementia care practices, policies and attitudes towards people known to have dementia and others including FCs affected by the illness cannot be overstated.

Despite Kitwood's major contribution and the legacy he has left to the field of dementia care, recent years have witnessed much criticism voiced about the person-centred approach in dementia care (Adams & Gardiner, 2005). A major criticism has been the fact that person-centred care principles tend to focus almost exclusively on the individual and his/her subjective experience, thereby ignoring the fact that every PwD is part of one or more care-giving relationships with his/her family members (FCs) and professional staff including SCU staff (Dewing, 2008; Nolan et al., 2002). The person-centred approach, it is argued, therefore does not account for the perspectives of both formal and informal caregivers (Hughes, Bamford, & May, 2008; Nolan, Keady, & Aveyard, 2001). Another criticism is that the person-centred approach fails to address the influence of broader social contexts and systems on the person and his/her experience – such as "gender, citizenship and marginalization" (Adams & Gardiner, 2005, p. 186). Other criticisms include the lack of clarity about the concept of person-centeredness, lack of clarity about how his theoretical approach was identified, lack of guidance on how to best implement person-centred care principles into practice (in particular in the context of institutional LTC), and lack of consideration of how 'personhood' may evolve (Dewing, 2008; Nolan et al., 2004).

3.11.1 Key principles of relationship-centred care

These criticisms have led to some further refinement of the person-centred approach to encompass a broader theoretical perspective for understanding dementia including the emergence of what has now been termed the relationship-centred approach. According to one definition, relationship-centred care denotes:

> "(....) the importance of the interaction among people as the foundation of any therapeutic or healing activity. Further, relationships are critical to the care provided by nearly all practitioners (regardless of discipline or subspecialty) and a source of satisfaction and positive outcomes for patients and practitioners. Although relationships are prerequisite to effective care and healing, there has been little formal acknowledgment of their importance." (Tresolini & the Few Petzer Task Force, 1994, p. 11)

This new approach was most notably brought to the forefront in the USA by Tresolini and the Few Petzer Task Force in 1994. It was a perspective which would synthesise both psychosocial and organismic perspectives, and their interconnections (Nolan et al., 2004, p. 48; Tresolini & the Pew Fetzer Task Force, 1994). Like in all aspects of dementia care and gerontological research, however, different terminologies have been used to describe essentially the same phenomena of relationship-centred care and include "'partnership approach'" (Adams, UK) and "'triadic interaction'" (Fortinsky, USA) (Adams & Gardiner, 2005, p.187).

The central tenets of relationship-centred care, however, are identical across countries and are as follows. First, relationships between the individual with dementia, his/her FCs, and professional staff (such as SCU staff) are the focus, and any individual experience is embedded within these relationships (Dewing, 2008; Hughes, Bamford, & May, 2008; Nolan et al., 2004; Ryan et al., 2008). Second, these relationships are reciprocal, interdependent, interactional (by nature) and dynamic (Brown-Wilson & Davies, 2009; Brown-Wilson, Davies, & Nolan, 2009; Hughes, Bamford, & May, 2008; Nolan et al., 2002)

– the so-called "dementia care triad" constituted by the PwD, the FC, and formal care staff (Brown-Wilson & Davies, 2009; Nolan et al., 2002).

Third, these meaningful triadic relationships and communications are based on equality, and on valuing each person's contribution to the care community and its relationships (Adams & Gardiner, 2005; Brown-Wilson & Davies, 2009, p. 1753; Nolan et al., 2002; Ryan et al., 2008) as well as their roles within other societal contexts – helping foster a sense of belonging (to the respective care community, for example SCUs) and citizenship among the members of a given dementia triad (Brown-Wilson & Davies, 2009; Hughes, Bamford, & May, 2008). These meaningful triadic relationships are also respectful towards all individuals involved (Nolan et al., 2002), considerate of needs (Brown-Wilson & Davies, 2009), and promoting uniqueness and personhood (Brown-Wilson, Davies, & Nolan, 2009), and autonomy (Nolan et al., 2004).

Fourth, roles evolving from such triadic relationships are ideally complementary (Brown-Wilson, Davies, & Nolan, 2009; Nolan et al., 2004). Higher-order systems, such as health care provision systems, cultural beliefs, and societal norms provide the broader context into which individual experiences of dementia as well as a given triadic relationship are embedded (Hughes, Bamford, & May, 2008; Nolan et al., 2004). Finally, individual experiences made by each member of a given care triad, relationships among members of a given care triad, and higher-order systems are interrelated entities, which mutually influence and shape each other (Nolan et al., 2004).

Such theoretical claims have been empirically supported by findings demonstrating that PwDs placed in regular nursing homes committed to relationship-centred care equated staff acknowledging their personal needs with high-quality care, and felt empowered and having choice (Brown-Wilson, Davies, & Nolan, 2009). The same authors also report that establishing positive and mutually respectful relationships with care staff is important for FCs, as is their remaining involved in the person's life after nursing home placement and

being fully included into all decisions relating to their relative's institutional care (Brown-Wilson, Davies, & Nolan, 2009, p. 1046).

The Senses Framework developed by Nolan and colleagues (Ryan et al., 2008) represents an extension of Kitwood's (1997) needs concept, postulating that every PwD has six basic needs (for love, attachment, inclusion, occupation, identity, and comfort) the meeting of which ensures his/her physical and psychosocial well-being. According to Nolan and colleagues, both PwDs and FCs and formal staff share the same essential need for a sense of i) security, ii) continuity, iii) belonging, iv) purpose, v) achievement, and vi) significance (Ryan et al., 2008); empirical studies have indeed demonstrated the importance of meeting these needs for establishing truly mutual respectful relationships among the three parties (PwDs, staff, FCs) and providing high-quality care (Nolan et al., 2004; Ryan et al., 2008).

For the purpose of this study, the Senses Framework represented a suitable approach to understanding SCUs which, being purpose-built physical environments and endorsing a holistic needs-based approach to care, are specifically designed to meet the afore-mentioned needs of all members of the dementia care triad. As environments where PwDs were living after placement, SCUs constituted the context within which admission experiences of all triad members were situated and which shaped their admission and adaptation experiences. SCUs where PwDs, FCs, and SCU staff members were interviewed (the research context), also influenced these people's experiences of partaking in research conducted for this thesis.

3.11.2 Choice of theoretical framework for this thesis

This relationship-centred approach builds on person-centred care and I have chosen it as a theoretical framework for this thesis, since this research is not just about FCs, but also about PwDs and about staff employed in specialist care settings. I considered it therefore important to select a theoretical framework that would acknowledge and integrate these

multiple perspectives. I considered other theoretical approaches but rejected them. For example, a stress coping model (Farran, 1997; Haley et al., 1987; Knight & Sayegh, 2010) is certainly helpful for understanding formal caregivers who were shown in this literature review to enter the PwD-FC dyad prior to the person's actual LTC placement, but in my view this approach fails to take into account the impact that dementia has on formal caregivers and on other people significant to the life of the person diagnosed such as the GP or Public Health Nurse (PHN). Another point of critique can also be made about stress coping models, namely, the tendency to focus on negative aspects of caring; in particular, FCs' caregiver burden.

The relationship-centred approach accordingly allows for including perspectives of others affected by the dementia care-giving process as for example extended family members - including children, grandchildren, siblings of the PwD - and others including all care staff involved in the day-to-day care of the person living in a SCU. In my opinion, the relationship-centred approach therefore goes beyond a family systems perspective as it recognizes the role that significant others (outside of the kinship system) – in particular formal care staff and HSPs, make to dementia care.

I am also of the view that the relationship-centred approach is more adaptive to and inclusive of the complexities of FCs', PwDs', and formal staff's experiences and interactions over time, which is particularly important given this study uses a follow-up design (see Chapter 4). The relationship-centred approach is therefore more open to the quality of individual experiences, which may be positive (for example, gratifications of caring for a PwD) and negative (detriments of caring) (Adams & Gardiner, 2005). As this literature review has shown, admitting a PwD into SCU LTC is an extremely complex process. Experiences of each member of the dementia care triad (PwD, FC, professional staff) have been shown to be distinct and having multiple facets to it, which may be paradoxical (for example, FCs' conflicting experiences of wishing to continue to care

whilst accepting the need for LTC placement). It was for all of these reasons that I chose the relationship-centred approach as theoretical framework.

The relationship-centred approach acted as a theoretical "lens" that helped me understand and "visualise" the complexities of the process of admitting a relative with dementia into SCU LTC. In particular, the framework chosen for this thesis influenced my understanding of the complex interactions among the members of the care-giving triad (PwDs, FCs, SCU staff) who were affected by the multifaceted process of SCU placement. The chosen framework helped me develop a co-constructive perspective on the topic under study i. e. that members of the dementia care triad mutually construct and shape their experiences of the admission process. The chosen framework also helped me develop a systemic perspective which included members of the wider family system (grandchildren, children-in-law, spouses) who were, despite not being part of the research, equally involved in, and affected by, co-constructing the process of their relative's SCU placement. Furthermore, as mentioned earlier (see page 79), the relationship-centred framework provided an in-depth understanding of the different roles SCUs played in constituting the context of the admission experience.

3.11.3 Other theoretical influences: Environmental perspectives

I was also influenced by environmental approaches, which despite their many different foci all share the basic assumption that the environment within which PwDs are significantly and inextricably impacts upon PwDs' well-being and quality of life. One of the most influential of these approaches is Lawton's and Nahemow's ecological model of environment and ageing (Norris-Baker et al., 1999, p. 168; Lawton & Nahemow, 1973, as cited in Corcoran & Gitlin, 1991). This model posits that the many dimensions of a given environment (physical social, organisational) influence the well-being and quality of life of those using it, and should ideally be adapted in a way that fully meets the person's needs and provides optimal levels of stimulation for PwDs (Teresi, Holmes, & Ory, 2000).

Similarly, the environmental docility hypothesis emphasizes the dependency of PwDs on their immediate environment, resulting in PwDs being likely to be adversely affected by any changes to or in their surroundings (Mirotznik & Los Kamp, 2000). Not surprisingly, these approaches have traditionally underpinned the design and approach to care of SCUs (Norris-Baker et al., 1991) and as the topic of this thesis (admitting PwDs into these specialised settings) will require research for this thesis to be carried out in SCUs I was also influenced by environmental approaches.

In the very early stages of conceiving the theoretical framework and designing the methodological approach of this thesis I also reviewed life course stress models, transactionalist environment-behaviour theories, and nursing models of transitions (Schumacher & Meleis, 1994; Wapner & Demick, 2000). These theoretical concepts whilst certainly addressing important aspects of the SCU LTC placement process such as carer stress, living circumstances prior to admission, and care-giving resources, were eventually rejected because I felt a more holistic approach was needed that allowed approaching the thesis topic from an interactional, dynamic perspective and integrated the viewpoints of all those affected by the transfer – hence the relationship-centred approach.

3.12 Chapter summary

This chapter has discussed the key findings and issues arising from a review of the literature on the experience of relocating into SCUs for PwDs, FCs, and SCU staff. Much of this literature pertains to admission of PwDs into LTC in general and not SCUs as literature on the latter including transition into SCUs is very limited. It has been shown that LTC placement is a critical event for PwDs and their informal caregivers. Placement often occurs when PwDs are at an advanced stage in dementia and have little cognitive and physical reserve – prompting increased levels of challenging behaviours and further confusion.

The literature on reasons for placing a relative with dementia into LTC shows that decisions to discontinue home care are made for many different reasons. These include the advanced age of the PwD, their physical health, marked cognitive and functional decline, increased challenging behaviours, and lack of informal and community-based support. Other major factors include carer burden, inability of FCs to meet the extensive demands of caring for the PwD, carer health problems, and perceptions of the LTC environment. Being wait-listed for LTC placement is a particularly difficult time especially when families have no definite time scale and do not know when exactly a bed will become available. Wait-listing of residents is a complex process, requiring staff to constantly assess those wait-listed and prioritising emergency admissions. Admission decisions are usually based on a complex set of decision factors other than mere wait-list status, such as dementia severity, physical health problems, facility characteristics, family coping abilities, and current living circumstances of the person to be placed. Therefore wait-listing is not only stressful for families but also for staff, who may feel anxious.

Residential respite care has effects on LTC albeit mixed. Empirical studies have yielded mixed results with regard to whether residential respite facilitates or hinders timely LTC placement. Some studies report residential respite hastens LTC placement whilst others state it prolongs home care.

The literature on decisions about placing a PwD into LTC reveals the complexities and challenges facing FCs at this stage in the illness trajectory. In most studies, it is argued that placement decisions are made under huge pressure and the decision is fraught with paradoxical and intense feelings including guilt, anguish, and exhaustion.

This chapter has also summarised literature on experiences of formal staff of admitting new residents. It has been shown that SCUs despite regional and cross-national variations use common admission criteria including dementia diagnosis, behavioural symptoms, and need for supervision. Another criterion is the ability of PwDs to physically

move about independently. Common criteria identified for discharging residents from SCUs include discharge criteria mostly related to end-of-life care decisions, increased physical care needs, and loss of independent mobility skills.

Studies investigating the immediate meaning and outcome of LTC placement for PwDs have shown increased levels of disorientation, forgetfulness, and aphasia in PwDs shortly after placement. Intense feelings of homelessness, displacement, and loss of freedom were reported by a group of PwDs moved to a SCU in Ireland (Myers et al., 2007). Other adverse experiences include significant disruptions to life-style patterns and relationships, heightened feelings of distress and fear, and multiple losses. PwDs appear to continue to struggle with these losses in the longer term and to experience ongoing feelings of powerlessness, lack of self-esteem, and abandonment. In addition, PwDs have been found to struggle with adapting to new routines, a longer-term process that can take between eight and 12 months (see Chapter 4).

It is widely recognized that FCs' care-giving does not end with placement but rather placement brings about new roles and concerns for them. Direct roles include visiting, providing extras to the PwD, and keeping him/her updated about the community. Indirect roles include monitoring care, developing a rapport with staff, and helping with practical care tasks.

Since relationships between PwDs, FCs, and formal (SCU) staff are a key focus of this thesis the relationship-centred care approach is a key theoretical framework underpinning the research for this thesis. It was chosen because of my desire to include all perspectives of those affected by the care-giving and SCU placement process - PwDs, FCs, and SCU staff – and to consider interactions among these perspectives and their embeddedness within broader contexts such as the care-giving environment over time.

Chapter 4: Methodology

4.1 Introduction

This chapter describes the research methodology used in the thesis and details carefully the various stages involved in the qualitative research process. As shown in Chapter 2, many studies on SCU environments and outcomes for caregivers (FCs, SCU staff members) and PwDs after relocating to these settings have been quantitative. Whilst such studies have merit, quantitative studies cannot generate a rich and comprehensive understanding of the complex processes involved in transferring PwDs to these specialised units. I therefore chose a qualitative research methodology for this study.

Section 4.2 outlines the study's key research questions and the qualitative research strategy. This is followed by an explanation of the epistemology and theoretical perspective underpinning the thesis, and a description of the research methodology and research methods (sections 4.3.2 and 4.3.4). Section 4.3.3 outlines the approach to sampling used to recruit the SCUs and later research participants. Inclusion criteria used to recruit both research sites and participants is outlined, and procedures for accessing same. Key features of both research sites and study participants are also described. Section 4.4 highlights the ethical principles adhered to by me in conducting this study. Section 4.5 describes the approach (IPA) used for analysing and interpreting data generated. Section 4.6 deals with the quality criteria including credibility, confirmability, and authenticity that guided the data collection and analysis. The final part of this chapter (section 4.7) briefly addresses key methodological limitations of this thesis.

4.2 Research questions

As stated in previous chapters, multiple aspects of the process of moving into a SCU for LTC are under-researched; such as deciding about placement, communicating news of placement, and adapting to SCUs in the short term and over a longer period of time. This thesis is particularly interested in seeking to narrow these gaps. Therefore, I generated eight key research questions, which are:

1. What is life like for FCs prior to their relative's SCU admission?
2. Why and by whom are decisions about the PwD's LTC placement made?
3. What are FCs' experiences of breaking news of the transfer to the PwD?
4. What are the experiences of FCs and PwDs of adapting to the SCU immediately after placement?
5. What are their more long-term (six months after admission) experiences of adapting?
6. What are SCU staff members' experiences of deciding to admit a PwD into LTC?
7. What admission criteria do SCU staff members use?
8. What can be learnt from participants' experiences for improving relocation practices and supports?

4.3 Research strategy

A wealth of philosophical and methodological frameworks is available to inform a particular research strategy (Bryman, 2008; Creswell, 1998) and it is the researcher's task to choose and justify a research strategy that optimally serves the purpose of answering the research questions (Crotty, 1998, p. 2). Broadly speaking, contemporary research strategies are divided into quantitative and qualitative although this dualism some argue is too simplistic (Bryman, 1984, p. 77; Malterud, 2001; Pierce, 2010, pp. 61-62).

Quantitative research approaches are geared towards producing replicable and generalisable data (Guba & Lincoln, 1994). Underlying philosophical perspectives are commonly objectivist-positivist and assume that the generation of knowledge and data occurs independently from the persons involved in the research process (Crotty, 1998, p. 27). Quantitative research is deductive (i.e. driven by theory), explanatory (i.e. assuming causality between variables), and subject to criteria of objectivity, reliability and validity (Gibson et al., 2004, p. 423; Malterud, 2001, p. 483). Data collection methods are standardized and structured (Bryman, 2008).

Qualitative research approaches, in contrast, are designed to generate comprehensive and in-depth insights into complex human phenomena and individual experiences which have not been sufficiently explored by previous research (Black, 1994). Qualitative research explicitly considers the wider social contexts and relationships within which phenomena are experienced (Carter & Little, 2007; Kuper, Reeves, & Levinson, 2008). Qualitative studies produce findings which are non-generalisable beyond their unique research context (Malterud, 2001). In contrast, the debate as to whether qualitative findings are non-replicable is ongoing; indeed, several authors claim that qualitative research should be replicable in terms of research methods and therewith – at least theoretically - its findings (Elliott, Fisher, & Rennie, 1999; Lewis & Ritchie, 2003; Onwuegbuzie, 2003). Underlying philosophical frameworks posit that the generation of knowledge and data cannot be isolated from the persons and processes involved in research (Yardley, 2000).

Qualitative research is thus well suited to investigate highly sensitive issues that might seriously affect research participants' living circumstances, well-being, and relationships (Creswell, 1998; Gibson et al., 2004; Yardley, 2000). Qualitative research is further defined as being inductive (i.e. driven by data from which theories are supposed to emerge), descriptive, exploratory, and more adaptive to changes in research foci, research circumstances, and participants' needs (Bryman, 2008, pp. 70-74, pp. 389-394;

Kuper, Reeves, & Levinson, 2008). By virtue of being more flexible, qualitative research is particularly suitable for investigating phenomena defined by transition and change (Bryman, 2008, p. 394).

4.3.1 Qualitative approach

For this thesis which broadly speaking is interested in the experiences of FCs, PwDs, and staff both immediately after admission and more long term, I deemed a qualitative approach to be the most appropriate approach. This approach is particularly suited to gaining insights into people's lived experiences of a phenomenon such as admitting a loved one with dementia into SCU LTC in a more in-depth, cohesive and holistic fashion than quantitative research would allow (Phinney, 2008). In addition, qualitative-inductive research is highly suitable for exploring phenomena that have remained under-researched - as is the case here - and thus enriching the limited knowledge base (Argyle, Downs & Tasker, 2012; Meleis et al., 2000; Myers et al., 2007).

As mentioned earlier, qualitative research focuses on people's experiences of a phenomenon and eliciting their own points of view. Qualitative research, therefore, lends itself to giving voice to the research participants and finding out about their issues and concerns at first hand (Stein & Mankowski, 2004). In particular, the importance of hearing the voices of PwDs and their caregivers has been emphasized as PwDs and their caregivers have much to tell and in turn society has much to learn from these vulnerable people (Bartlett & O'Connor, 2010; Gibson et al., 2004; Phinney, 2008). In addition, the SCU transition is a complex process unfolding over a period of time and needs to be explored in a more holistic, flexible, and in-depth fashion than delivered by quantitative research (Bryman, 2008, p. 388). Qualitative research is particularly useful in exploring process and change (Schumacher & Meleis, 1994).

For this thesis I chose Crotty's structural model (Crotty, 1998). This model posits four frames of reference, which were helpful for developing the approach to the research conducted for this thesis. They are outlined in the next section.

4.3.2 Crotty's structural model

Several approaches have been advised that help structure the development of a qualitative research strategy (Blaikie, 2007; Mason, 2002; Silverman, 2010). Such structural approaches are considered useful for developing a better understanding of philosophical-theoretical assumptions that underlie empirical research and ensuring that both research focus and methods are consistent with these assumptions (Blaikie, 2007). There is a shared perspective among qualitative researchers that these structural approaches should specify the researcher's views on what to research, what to know about the research object, and how to generate this knowledge (Grix, 2002). However, despite such overall commonalities, different authors advise different frames of reference within their respective structural approach, and use different terminologies (Creswell et al., 2007). The researcher must thus decide on which structural model to base the research design.

I considered different structural approaches developed by different authors including Blaikie (2007), Creswell (1998) and Crotty (1998). I examined three established approaches, namely, Blaikie's (2007), Creswell's (1998), and Crotty's (1998), on the basis of their suitability for the thesis topic (lived experiences of a phenomenon) and the frames of reference addressed by the respective approach. I chose Crotty's structural model (1998) because I deemed it most relevant to the purpose of this thesis. Crotty's structural model in particular focuses on the researcher's assumptions about generating knowledge about the research topic, which in this case – i. e. the lived holistic experience of admitting a loved one with dementia into LTC – is poorly understood (Crotty, 1998). The process of producing this new knowledge I believe needs to be particularly detailed in order to enable other researchers to understand how this knowledge was generated and ideally to build

upon it in subsequent studies (Creswell et al., 2007). I also consider Crotty's structural model to be exhaustive and to provide in-depth information about the philosophical-theoretical perspectives that can inform a qualitative research strategy. Crotty (1998) suggests four elements of research that are linked with each other and ordered according to their level of abstractness, namely, 1) epistemology (see section 4.3.2.1), 2) theoretical perspective (see section 4.3.2.2), 3) methodology (see section 4.3.2.3); and 4) methods (see section 4.3.4).

4.3.2.1 Epistemology: Constructionism

Epistemology is the philosophical theory or 'stance' that helps the researcher understand and explain how he/she knows what is known, and how this knowledge (in the following equated with meaning, construction, meaningful reality, and experiences) is developed (Guba & Lincoln, 1994, p. 108; Young & Collin, 2004, p. 375). A given epistemology can inform several theoretical perspectives and methodologies (Crotty, 1998, p. 3).

Crotty argues that there are three major epistemologies namely objectivism, subjectivism, and constructionism (Crotty, 1998, p. 5). Researchers accepting an objectivist perspective assume that knowledge is an entity that is created and located (i. e. can be discovered) independently from the individual mind (Raskin, 2002). Subjectivist researchers in contrast oppose this view somewhat and suggest that knowledge is created by the individual interacting with his/her external world but without the latter actively participating in the production of knowledge (Crotty, 1998, pp. 8-9). Constructionist researchers in contrast to objectivists argue that knowledge does not exist independently from the individual mind (Crotty, 1998; Raskin, 2002). Individuals always create and refine knowledge in interaction with their external social world, which is actively involved in generating individual knowledge (i.e. co-construction of knowledge) (Raskin, 2002; Young & Collin, 2004, p. 376). As construction of knowledge is always an individual process and the constellations of a person's social contexts are always unique, knowledge about a particular phenomenon is always idiosyncratic. Realities are therefore multiple (Crotty, 1998, pp. 8-

9, p. 42). For the purpose of this thesis I chose a constructionist epistemology for the following reasons.

First, constructionism is congruent with the research aim of exploring the knowledge of participants of the phenomenon of admitting a relative with dementia into SCU LTC and their adapting to the new facility both in the short term and more long term in a holistic fashion (Holstein & Gubrium, 2007; Phillips, 1995, p. 6). A constructionist perspective allows for the exploration of individual knowledge contents, processes of knowledge generation, and integration of new knowledge into existing knowledge structures (Burr, 2003). I view a constructionist approach as offering a more comprehensive understanding of individual phenomenological knowledge than objectivist and subjectivist approaches (Crotty, 1998).

Second, constructionism as implied by its name promotes a co-constructionist stance (Burr, 2003; Edley, 2001). In particular, generating individual knowledge about placing a relative with dementia into LTC can be viewed as being embedded in, shaped by, and co-constructed by social contexts and interactions (i. e. the co-constituents of individual knowledge about the SCU transfer). Social contexts and interactions relevant for this thesis include the social environments between which long-term SCU transfers take place, the cultures of these settings, social relationships and interactions of those affected by the SCU transition, wider socio-cultural systems, and interactions among all these contexts over time (Holstein & Gubrium, 2007). In my view, neither objectivist nor subjectivist assumptions adequately reflected the significant role of social-world factors in the construction of individual knowledge. Objectivists view social-world factors as irrelevant or even opposed to the discovery of (objective) knowledge, and therefore attempt to eliminate such factors (Kuper, Reeves, & Levinson, 2008). Subjectivists over-emphasise the individual's role and neglect the active role of social-world factors in generating (individual) knowledge (Crotty, 1998). From a subjectivist point of view, PwDs as any other person are the main 'creators' of their own experiences and knowledge; active

contributions by members of the PwD's social world including peers, professional carers, and family members to creating the PwD's individual experiences and knowledge play a minor role – regardless of the person's level of cognitive ability.

Third, constructionism is congruent with my view that phenomenological knowledge is individual and multiple (Finlay, 2009; Willis, 1999). This assumption clearly rejects objectivist ideas of knowledge being an objective and uniform entity (Crotty, 1998). Constructionist assumptions also converge with a relationship-centred approach to dementia, the key principles of which have informed the theoretical approach to this thesis. The relationship-centred model promotes respect for the individual's personhood and the right of each person - including PwDs, their FCs, and staff members - to be listened to and accepted in their uniqueness including unique individual knowledge (Kitwood, 1997; Nolan et al., 2004). The individual is thereby the expert of his/her knowledge, which can only be accessed and understood through the individual (Ashworth, 2008, p. 15; Bryman, 2008). Finally, constructionism not only frames the generation of non-scientific (i. e. individual phenomenological) information but also of scientific knowledge by assuming that all kinds of knowledge – including the researcher's scientific knowledge – are co-constructed (Edley, 2001). This thesis is designed to produce scientific knowledge. I thereby see myself as the provider and co-constructor of a specific context (the research situation) and as an active participant in the production of knowledge by for example translating participants' knowledge about the phenomenon of admitting a PwD into a SCU into research findings ergo scientific knowledge (Phillips, 1995, p. 6).

4.3.2.2 Theoretical perspective: Contemporary phenomenology

The theoretical perspective is "the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria (...) it is an approach to understanding and explaining society and the human world, and grounds a set of assumptions that (...) researchers typically bring to their methodology of choice."

(Crotty, 1998, p. 3). The theoretical perspective links epistemology with methodology (i. e. the ways of generating knowledge) and can inform several methodologies (Crotty, 1998, p. 5).

Experts argue that the most prominent theoretical perspectives in the social sciences are interpretivism, positivism, critical enquiry, feminism, and post-modernism (Blaikie, 2007; Creswell, 1998; Crotty, 1998, p. 5). Obviously each perspective offers a particular lens towards understanding a phenomenon, however, in the next section I will argue why I chose contemporary phenomenology as a theoretical perspective for this thesis, and why I deemed other theoretical perspectives less relevant.

Interpretivism is a philosophical-theoretical tradition that is highly compatible with, and most closely linked to, constructionism. It seeks to understand the individual person and his/her unique system of behaviours and attitudes (i. e. interpretations), which are assumed to be intertwined with, and shaped by, social, historical, and cultural contexts (Lopez & Willis, 2004). I chose interpretivism as theoretical perspective for this thesis. Three major interpretivist approaches are distinguished and include symbolic interactionism, hermeneutics, and phenomenology (Halldorsdottir, 2000, p. 49). In the next section I specify the chosen interpretivist framework.

Symbolic interactionism assumes that individuals generate meanings - which they then attribute to social-world entities - through interpretation (Crotty, 1998), a process which is contextualised by social contexts and achieved through means of symbolic interaction; for example nonverbal behaviours, spoken language, and role-taking (Blumer, 1969, p. 2, as cited in Crotty, 1998, pp. 72-76). Whilst some aspects of symbolic interactions – in particular, the importance of social contexts - are relevant for the thesis, I did not choose symbolic interactionism because it focuses more on language as key mediator of processes of meaning-construction than on the lived experiences of a phenomenon and their meanings (Crotty, 1998).

Hermeneutics is considered by Crotty (1998, p. 88 - 91) to be an approach used to explicate hidden meanings in texts through means of reflection and interpretation. The hermeneutic interpreter engages in the hermeneutic circle whereby he/she alternately relates part to whole and develops an understanding of the text that exceeds his/her own (Crotty, 1998, p. 89-92). Whilst some aspects of hermeneutics are again relevant for the thesis – in particular, the reflective nature of processes of meaning-making and interpretation, as well as the embeddedness of meaning into socio-cultural contexts – I did not choose hermeneutics because it focuses on the analysis and interpretation of written texts and rather neglects the specific situations and processes by which texts are produced (Draper, 1996; Lowenberg, 1993).

Phenomenology is an established philosophical approach (Finlay, 2009). Two major phenomenological traditions have evolved over the past decades including traditional or intuitive phenomenology and contemporary or empathetic phenomenology (Crotty, 1996, p. 272; Halldorsdottir, 2000, p. 48; Willis, 2001, pp. 2-3). Traditional and contemporary phenomenological approaches share key assumptions including focusing on the individual experience of phenomena and related processes of individual meaning-making (Crotty, 1996, p. 272; Halldorsdottir, 2000). Both approaches also acknowledge culture and language as factors that shape and contextualise these experiences (Willis, 2001). In addition, both approaches view individual preconceptions as culture-based (Halldorsdottir, 2000).

Traditional phenomenology, however, understands these individual preconceptions as opposing the construction of new meanings and interpretations whilst contemporary phenomenology views these preconceptions as being part of new concepts and meanings (i. e. factors that shape individual interpretations of a lived experience) (Dowling, 2007; Lopez & Willis, 2004). Exploring these pre-conceptions is understood as a major research activity and requires the researcher to reflect on own experiences and fore-

understandings of the phenomenon under study (Bryman, 2008, pp. 384-390; Crotty, 1996, pp. 273-274; Halldorsdottir, 2000, p. 50).

Contemporary phenomenology seemed to me the most appropriate perspective to use in this thesis since this approach aligns itself with the thesis goal of understanding the lived experiences of admitting a relative with dementia into a SCU (the phenomenon) in an in-depth holistic fashion (Halldorsdottir, 2000) and by means of taking participants' perspectives, describing their experiences in detail, and constructing their individual meanings and interpretations of the phenomenon under study in interaction with the researcher i. e. myself (Omery, 1983; Wojnar & Swanson, 2007). Contemporary phenomenology is highly compatible - and in fact shares several assumptions - with a constructionist epistemology: Individual meanings of a phenomenon cannot be understood independently from human consciousness; all individual understandings of a phenomenon including the researcher's pre-conceptions are co-constructed by social-world factors; and individual experiences and meanings can only be understood from the participants' perspectives – requiring me to view participants as experts of their own experiences (Annells, 1999, p. 17; Halldorsdottir, 2000, pp. 53-55) and familiarise myself with the participants' particular circumstances and contexts (Wojnar & Swanson, 2007, p. 176). In particular, viewing PwDs as experts of their own experiences (Annells, 1997, p. 17; Halldorsdottir, 2000, pp. 53-55) represented an ethical obligation for me - as researcher - to view and respect the person as owner of his/her experiences despite his/her impaired ability to share these experiences with others. By assuming that every PwD, independently of his/her stage of dementia, remains the expert of his/her own experiences I was also reminded of the fact that his/her personhood and autonomy remain intact beyond the disability of dementia. The focus on establishing an empathetic relationship with research participants is also congruent with principles of relationship-centred care and believed to render contemporary phenomenology particularly suitable for conducting research with highly vulnerable groups such as FCs, PwDs, and their formal caregivers (Bryman, 2008; Halldorsdottir, 2000, p. 55).

As mentioned, other perspectives considered were positivism, critical enquiry, feminism, and post-modernism (Blaikie, 2007; Creswell, 1998; Crotty, 1998, p. 5). The next section summarizes the strengths and weaknesses of these perspectives in the context of this thesis.

First, positivism is most closely linked – and in parts identical - with objectivism and was therefore not considered a suitable research strategy (Ashworth, 2008, p. 10). I gave consideration to using critical inquiry, feminism, and post-modernism since these are compatible with a constructionist epistemology but each I deemed not suitable for the thesis purpose. I dismissed critical inquiry as it is geared towards challenging socio-cultural norms and structures, illuminating patterns of dominance and injustice, and actively initiating social change (Crotty, 1998, pp. 157-159). This thesis was neither set up to investigate structures of power and suppression in care-giving environments including LTC settings nor to actively change such structures. I, however, acknowledge the fact that power imbalances are an issue relevant to care-giving and that findings might arise about such issues. Feminist research emphasizes the fact that society is largely influenced by patriarchal structures and cultures; that women are disadvantaged economically and socially; and that most contemporary societies are dominated by masculinist cultures (Crotty, 1998, p. 161). Feminist researchers aim to uncover these 'male' aspects of society and their historical development (Crotty, 1998, p. 161). A feminist perspective might have been useful had an emphasis in this thesis been placed on the gendered politics of care-giving but this was not the aim of this thesis.

Postmodernist theory challenges modernist (i.e. totalist) socio-cultural systems and assumptions of, for example, an objective reality and all-valid truths (Crotty, 1998, p. 185). Postmodernist theory promotes concepts of "ambiguity, relativity, fragmentation, particularity and discontinuity" (Crotty, 1998, p. 185). Whilst any contemporary research can be framed as 'post-modernist' I did not consider it a suitable perspective for this thesis

because it rather focuses more on abstract socio-cultural processes and systems rather than on individual experiences (Crotty, 1998, pp. 198-199).

4.3.2.3 Research methodology: Inductive multiple case follow-up design

The third component in Crotty's structural model is the research methodology. This is broadly defined as "our strategy or plan of action (...) that shapes our choice and use of particular methods and links them to the desired outcomes." (Crotty, 1998, p. 7). A given research methodology connects the chosen epistemological and theoretical perspectives to the research methods. A research methodology thereby consists of a unique combination of multiple components including types of case, phases of data collection, and research settings (Bryman, 2008, p. 54).

Similar to epistemological and theoretical perspectives, there is a range of different research designs available to conduct qualitative studies (Bryman, 2008). Research designs can be distinguished by multiple dimensions, such as epistemological perspective, temporality (cross-sectional, longitudinal), and data-theory relationship (inductive, deductive). In the next section of this chapter I put forward a rationale for choosing an inductive multiple case study follow-up design.

Case study designs are widely used in qualitative research and represent a classical idiographic research methodology (Luck, Jackson, & Usher, 2006). Case study designs allow for exploring in-depth the nature and complexity of one case including a person, a social group, a particular environment, or an organisation or multiple cases for example, members of a social group, different social groupings, or different organisations of a particular type under study (Appleton, 2002, p. 85). The focus of exploration is on the singular unique elements of each case and subsequent development of theories (Bryman, 2008, p. 54, p. 57).

I chose an inductive multiple case study follow-up design. I selected an inductive approach since this is a qualitative-exploratory thesis and there is very limited research undertaken to date on the topic (see Chapter 3). The thesis therefore aimed to examine the topic of how FCs, SCU staff members, and PwDs experience the transition into SCUs and how over time they adapt to the changed environment. For the purpose of this thesis multiple cases were explored in-depth. The unit of analysis was constituted by individual research participants - both PwDs and FCs, and SCU staff - and their lived SCU transition experiences (Appleton, 2002; Cavaye, 1996; Luck, Jackson, & Usher, 2006; Yin, 2003, as cited in Bryman, 2008, p. 54). I selected multiple cases in order to develop a more comprehensive and in-depth understanding of the complex phenomenon of admitting a relative with dementia into specialised LTC by exploring single cases in-depth and stratifying different individual experiences across cases.

Published studies into the experience of moving ageing people to LTC settings have used different time frames. Most of these studies are quantitative (pre-move and post-move), retrospective, and use time frames ranging from one month to five years post-admission (Castle, 2001). In a similar vein, qualitative researchers exploring the topic of relocating PwDs into LTC tend to mainly use post-admission designs with time frames varying between two weeks and three years post-relocation (Argyle, Downs & Tasker, 2010; Butcher et al., 2001; Cioffi et al., 2007; Iwasiw et al., 1996; Nolan & Dellasega, 2000). In fact, there is no consensus regarding the sampling of time frames for relocation research as the selection of the latter depends on the research topic and the research questions (Castle, 2001).

In this thesis I explored participants' experiences at two particular points in time. The first was at three to four weeks following the PwD's SCU admission (phase one) and the second was at four to six months after admission (phase two). I selected phases one and two in order to capture participants' short-term as well as longer-term adaptation, thereby gaining a more comprehensive understanding of changes over time.

I chose the three to four weeks post-admission time frame (phase one) of this thesis in order to avoid imposing additional distress on PwDs and FCs who were likely to be physically and emotionally exhausted at this stage of their care-giving journey and might feel overwhelmed by the environmental change and in particular by the immediate adaptation to their new living situation. I also felt that the chosen phase one time frame would give participants sufficient time to process their immediate admission experiences and build up opinion.

I chose the phase two time frame because I felt that the PwD would now be fully settled into the SCU environment and FCs would be fully adjusted to the new living situation (Brooke, 1989; Sandberg, Lundh, & Nolan, 2003). As outlined earlier (see section 3.10.2), some authors have suggested that fully adapting to a LTC environment may take between eight to 12 months (Brooke, 1989; Chapin & Dobbs-Kepper, 2001; Rehfeldt, Steele, & Dixon, 2000). However, I chose a shorter follow-up time-frame (six months) for pragmatic reasons i. e. time constraints under which this thesis was conducted, and because individuals differ in the length of time needed to fully adapt to their new environment (Chapin & Dobbs-Kepper, 2001; Lee, Woo, & Mackenzie, 2002; Rehfeldt, Steele, & Dixon, 2000; Walker, Cox Curry, & Hogstel, 2007). Hence, time frames reported in the literature are not prescriptive and need to be adjusted to a given study. The phase one and phase two time frames were synchronised for all participants.

Initially I planned to interview participants prior to the actual admission in order to explore their pre-admission experiences. However, this procedure was not feasible because of the rapid nature of most SCU admissions, which prevented me from getting to know the research participants (FCs, PwDs) prior to the SCU LTC transfer (see Chapter 6). Getting to know PwDs and their carers prior to admission might have enabled me to use a prospective design, investigating participants' reflections and experiences of the transition process while they were still caring for the PwD at home and being in the process of deciding about placement.

4.3.3 Sampling strategy

The key goal of qualitative sampling is to capture as many different experiences as possible by approaching a wide spectrum of research participants (Bryman, 2008). When conducting case study research, ideally cases are sampled in order to optimise variation (Coyne, 1997, p. 624). Sampling usually requires the researcher to access relevant research sites, recruit research participants, and ensure ongoing access and cooperation (Bryman, 2008, p. 461).

4.3.3.1 Purposive sampling

Purposive sampling is one of the most common sampling strategies of qualitative research (Coyne, 1997) and was chosen as the method of sampling for this thesis. It involves recruiting "participants in a strategic way, so that those sampled are relevant to the research questions that are being posed" (Bryman, 2008, p. 405, p. 415, p. 458). Purposive sampling requires the researcher to define the inclusion criteria used for selecting research participants and sites (Denzin & Lincoln, 2008). The choice of a purposive sampling strategy for this thesis was influenced by the research questions aimed to explore various different aspects of the SCU placement experience; by carefully reviewing the existing literature on the research topic, and by speaking to clinical practitioners working in SCUs who were familiar with the issue of admitting PwDs into SCU LTC.

4.3.3.2 Determinants of sample size

Sample sizes are often difficult to calculate or pre-determine in qualitative research (Coyne, 1997). There is ongoing debate about sufficient numbers of qualitative interviews and some authors have suggested a minimal number of 20 interviews for a publishable study (Warren, 2002, as cited in Bryman, 2008, p. 462). Qualitative researchers using purposive sampling commonly rely on theoretical saturation as the cut-off point for data collection (Kuper, Reeves, & Levinson, 2008, p. 405). Theoretical saturation means that participant recruitment and data collection are completed as soon as new findings can no

longer be extracted from the data (Bryman, 2008, pp. 415-416). Therefore, the key criterion for further recruitment of participants is the quality of existing findings and not the sample size (Denzin & Lincoln, 2008).

Time constraints and access issues were key 'external' factors determining the numbers of participants recruited for this thesis (Coyne, 1997, p. 624). The key 'internal' criterion for deciding to stop participant recruitment was the level of similarity of preliminary findings - in particular the common 'story line' inherent in FCs' accounts of their care-giving and adaptation experiences (Bryman, 2008, p. 461-462; see Chapters 5, 6, 7).

4.3.3.3 Inclusion criteria

In line with the requirements for a purposive sampling strategy (Bryman, 2008), inclusion criteria for SCUs and three groups of research participants (PwDs, FCs, SCU staff) were developed.

4.3.3.3.1 Inclusion criteria for SCUs

I included SCUs as research sites if they classified themselves as a SCU on the basis of i) offering care to only residents with dementia, ii) adhering to dementia care principles of specialist staff training in dementia, activity programmes, and a domestic home-like environment, and iii) having the possibility of having at least two admissions of PwDs during the fieldwork period.

4.3.3.3.2 Inclusion criteria for PwDs

I included PwDs as research participants if they i) had been recently admitted permanently to the SCU for LTC (i. e. being three to four weeks post-admission), ii) if they had a clinical diagnosis of AD or any other dementia subtype, iii) if they had a FC who was prepared to consent to study participation which meant their agreement to doing two in-

depth interviews and iv) if the FC was prepared to give proxy consent for their relative (PwD) to do two in-depth interviews and have two MMSE tests conducted.

I made every effort to rigorously apply the inclusion criteria for PwDs. Seven out of nine PwDs were interviewed within three to four weeks after placement and met all inclusion criteria as specified above. Two PwDs, however, were included despite their being within the first week (N = 1) and second week (N = 1) of admission. This was done for pragmatic reasons including FCs' time schedules and personal time constraints. Apart from being within the first two weeks post-admission rather than three to four weeks, these two persons met all other inclusion criteria as specified above. It is also important to note that by virtue of their being admitted into SCUs, all nine PwDs had a confirmed clinical diagnosis of AD or any other dementia subtype (see Table 2).

4.3.3.3.3 Inclusion criteria for FCs

I included FCs as research participants if they were the caregiver who had taken on the main responsibility for the SCU transfer and agreed to participate in two in-depth interviews and one self-administered questionnaire. Amongst the caregivers recruited, seven were also primary caregivers meaning that they had daily responsibility for the care of their relative.

4.3.3.3.4 Inclusion criteria for SCU staff

I included SCU staff members as research participants if they were working in the SCU on a regular basis and were willing to participate in the research conducted for this thesis. I included all staff members regardless of seniority, that is, I included both junior (nurse attendants, nurses) and senior/managerial levels (specialist nurses, manager nurses). This was for pragmatic reasons as FG participants were also recruited by gatekeepers. I thus left it open to anyone of the SCU team (junior and senior staff), who wished to participate.

4.3.3.4 Consent to participate in research for this thesis

The issue of obtaining consent from all participants (PwDs, FCs, SCU staff) to partake in research for this thesis was of crucial concern to me, and constituted an important link between the inclusion criteria I used (see section 4.3.3.3) and the ethical approach underpinning this thesis (Bryman, 2008; Dewing, 2002).

4.3.3.4.1 PwDs' consent to participate in research for this thesis

I carefully considered the consent of PwDs. However given that most of these people had a moderate to severe dementia, I chose to obtain written proxy consent from all their FCs. Their proxy consent for PwDs' participation was sought after having obtained written consent from them to their own participation in this thesis (see section 4.3.3.4.2). In addition, I obtained FCs' written proxy consent to access their relative's SCU nursing and medical records at phase one and at phase two (see Appendix B).

However, I also made efforts to gain written and verbal consent from PwDs themselves prior to each interview (see Appendix C and Appendix D). As stated, due to severity of CI, I only succeeded in obtaining this written consent from one person. However, I made strident attempts to gain assent from PwDs by describing to them in simple terms what the interview would entail including what topics would be covered.

I also made efforts to gain written and verbal consent from PwDs themselves prior to each MMSE. Once again, due to the severity of CI, this written consent for MMSE testing was only given by the same person who also consented to her participating in the interviews. I made identical strident attempts to gain assent from PwDs by describing to them in simple terms what the MMSE would entail and why it would be used.

I revisited the issue of PwD assent on several occasions during interviews. I informed PwDs about what was expected of them and their rights whenever necessary during the

interview (such as being free to withdraw from the interview at any stage or asking more questions about the purpose of the thesis). I also encouraged them to voice their concerns at any time. I handled the issue of their assent to MMSEs in the same way. In the context of this research I understood consent as a process rather than a one-time procedure (Dewing, 2002; Woods & Pratt, 2005, p. 426).

4.3.3.4.2 FCs' consent to participate in research for this thesis

I considered the consent of FCs equally carefully and ethically. Prior to my first meeting with them, and after their details were given to me by the gatekeepers (two Clinical Nurse Specialists, one Unit Manager), I contacted each to provide them with detailed information about the proposed research (see Appendix A) and to advise them about what was expected from them as research participants, and about their rights i) to have their data handled confidentially and ii) to withdraw from the research at any time and without giving reasons. Following this conversation, a date and time was set for the first interview. All nine FCs were approached by me in person immediately prior to this first interview (phase one) and in the SCU, when I obtained their written consent to participate in two interviews (phase one, phase two) and one self-administered questionnaire (see Appendix B).

I also sought FCs' (N = 9) oral consent repeatedly throughout the data collection process; for example, after interview pauses or when I felt caregiver participants appeared at unease with the research situation. I thereby kept seeking ongoing consent informally and used it as a means to monitor caregivers' well-being and comfort with the research.

4.3.3.4.3 SCU staff's consent to participate in research for this thesis

I used the same procedure that I used for obtaining FCs' written consent with the 12 FG staff members i. e. I obtained written consent from them to participate in one FG and written consent to complete one self-administered questionnaire (see Appendix E and

Appendix F). I also sought SCU staff members' (N = 12) oral consent repeatedly throughout the data collection process (see section 4.3.3.4.2).

4.3.3.5 Developing the sampling frame

SCUs are characterised as homelike and unobtrusive settings (Marshall, 1997). Safeguarding PwDs' privacy and freedom from external intrusions is thus a paramount goal of SCU care (Alzheimer's Australia, 2004). Therefore SCUs can be defined as closed and non-public research sites, which present the researcher with particular challenges in terms of gaining and ensuring access (Bryman, 2008, pp. 403-413).

I developed a sampling frame of 45 potential research sites based on internet searching, word of mouth, and discussions with some experts in the area of dementia. I contacted all potential research sites over the fieldwork period (March 2009 to November 2010).

I telephoned the person in charge at each setting to introduce the project and to ascertain if the facility was willing to participate in the research conducted for this thesis and check whether the inclusion criteria could be met. If inclusion criteria were met and interest in the project was signalled, I then emailed more detailed information about the thesis including its goals and ethical procedures to the person in charge (see Appendix G).

Following this initial contact, I visited a total of nine potential research sites which met the inclusion criteria (see section 4.3.3.3.1) and were interested in partaking in the research. The visit was designed to get to know the setting and relevant contact persons (mostly senior staff members) and to provide more information about the thesis aims, research methods, and time requirements. At these visits I also left information sheets, consent forms, and other information about the overall research programme (Living with Dementia Programme) for senior and front-line staff. In addition, through these visits I could ensure in personal conversation with the staff members in charge that the setting's inclusion

criteria were met and encouraged staff to address any issues that might have arisen at this stage (Bryman, 2008, p. 407).

I experienced enormous difficulty attempting to find suitable research sites for this thesis. There was no comprehensive list of SCUs and no information available either through the HSE or the Health Information and Quality Authority (HIQA) or the DSIDC on the issue as to where such units are located. This posed a huge problem and meant I had no option but to research potential research sites on my own initiative. This meant I had to dedicate a significant amount of time to looking up nursing homes and hospitals with SCUs on the internet; calling staff working in these settings and following up on phone calls; and asking experts in the area of dementia about potential research sites. Identifying these research sites and waiting for referrals from each delayed very significantly the whole research process and posed a huge challenge in undertaking this thesis. In addition, SCUs were generally very cautious about exposing their residents to research. This meant that SCU staff members which I initially approached by telephone or email needed to pass on my enquiry about a possible research cooperation to their seniors. Waiting for their feedback and following up SCUs that I had initially contacted took time and also delayed the research process significantly.

4.3.3.6 Initial access to SCUs

Contact with SCU A was mediated through the thesis supervisor who knew the Matron. I then emailed the Matron with detailed information about the thesis' rationale and the data collection procedures for different participant groups. Subsequently, a visit to SCU A was arranged in December 2008 where I, the thesis supervisor, the Matron, the SCU's Clinical Nurse Specialist and the SCU's Clinical Nurse Manager met. The meeting was used to check out the suitability of the SCU for research purposes. I found the meeting useful in highlighting protocols about LTC admissions and gaining information about frequency of new admissions and the fact that very limited notice is given about new admissions. For instance, I was told that only two to three new residents might be admitted annually, and

that new admissions occurred quickly within one to three days. This information helped me make decisions about the design of this thesis (i. e. use retrospective interviews conducted after admission instead of prospective interviews conducted prior to admission). Following this initial visit, I remained in contact with staff at SCU A and the facility formally agreed to participate in research conducted for this thesis. Data collection for the pilot study commenced in January 2009. Data collection for the main study commenced in March 2009.

I contacted SCU B in June 2009. Contact was initiated and facilitated by the Clinical Nurse Specialist of SCU A who knew the Clinical Nurse Specialist of SCU B and provided me with contact details. With regard to this initial contact, the exact same procedure was used as SCU A. I also remained in contact with SCU B's Clinical Nurse Specialist via phone and email and was informed about the facility's consent to participate in the research conducted for the thesis. Data collection commenced in July 2009 after the Clinical Nurse Specialist had obtained ethical consent from the hospital management.

I experienced great difficulty in attempting to recruit a third SCU to this thesis. After recruiting SCUs A and B, I identified 43 (out of the 45) potential research sites (via internet research, via referrals from HSPs working in nursing homes or hospitals) and contacted them over a period of six months (September 2009 to February 2010). During that period I visited seven of these. A key difficulty was that whilst most facilities contacted were willing to participate in research conducted for this thesis, many had no vacancies and maintained that they were not likely to be admitting new residents in the near future. It also needs to be kept in mind that the research was taking place during a period of policy change including the implementation of the HIQA inspections and the introduction of the Nursing Home Support scheme. Indeed, more than half of the facilities I approached during these six months openly admitted to feeling anxious about participating in the thesis and – by me being possibly affiliated with HIQA – drawing the attention of HIQA

inspectors to their facility. In addition, a seasonally increased demand for short-term respite care services was noticeable during the Christmas period.

I finally accessed SCU C in February 2010. I identified it as a potential research site via email, and arranged an initial visit with the Unit Manager. I again provided the Unit Manager with oral and written information about the thesis' purposes and participant tasks at this visit. I emphasised the major need for recruiting between two and three PwD-FC dyads as soon as possible and established that the inclusion criteria for research sites and potential participants were met. After the Unit Manager had received the nursing home management's consent I began data collection there in March 2010.

In all three SCUs, the gatekeepers (two Clinical Nurse Specialists, one Unit Manager) approached FCs who met the inclusion criteria and who they thought might be willing to participate in the thesis (see sections 4.3.3.3.2 and 4.3.3.3.3). These FCs were accessed by the gatekeepers on my behalf. During these initial contacts, all three gatekeepers informed potential participants about the research aims and objectives and what was expected from them and their relative with dementia as research participants. If interest was signalled, the SCU gatekeeper sought consent to forward their contact details to me. This type of consent (i. e. forwarding candidates' contact details to me) was in all cases negotiated between interested FCs and the gatekeeper, and was obtained from each FC informally (i. e. no written consent forms). None of the people who were approached refused to participate.

4.3.3.7 Ongoing access

The follow-up design used in this thesis required me to maintain ongoing contact with all three research sites. A major role in establishing such prolonged and sustainable cooperation with the researcher is commonly taken on by gatekeepers (Bryman, 2008). Whilst gatekeepers act as key informants and supporters of the researcher, they are also insider experts (Denzin & Lincoln, 2008). As such, they inevitably influence the

researcher's activities and autonomy by pre-selecting participants and biasing the researcher's views of the "social reality of the setting" towards their own (Bryman, 2008, pp. 409-413). On the one hand, the three gatekeepers might have been more likely to select FCs who were interested in research from the onset; who were fully supportive of their relative's SCU placement and felt at ease with the placement decision. On the other hand, the gatekeepers might have been less likely to recruit FCs who were extremely stressed, who signalled concerns about their partaking in research for this thesis, or who had serious conflicts with other family members about their relative's SCU admission. Similarly, the gatekeepers might have been more likely to select residents who coped well with the admission and/or were comfortable with the company of strangers (such as myself). Conversely, the three gatekeepers might have been more likely to exclude residents who were upset about the LTC placement and/or who were highly uncomfortable around other people. Such biases might have limited the spectrum of possible SCU placement experiences explored in this thesis. I did, however, not control for these potential biases because of pragmatic and ethical reasons. I was not able to recruit specific sub-samples of FCs (for example, spouses) or PwDs (for example, those admitted from other LTC settings) because of the very small turnover of new SCU residents. It would also have been extremely unethical (and might indeed have ended the cooperation between the gatekeepers and myself) if I had asked the gatekeepers to select very distraught FCs or PwDs who did not cope with the SCU LTC placement.

SCUs are specialised protected institutional settings and I depended on these gatekeepers and their varied and substantial support (Alzheimer's Australia, 2004). I needed their assistance in relation to recruiting the sample of PwDs and their FCs, who would satisfy the thesis' inclusion criteria, providing a suitable research environment (such as access to visitor rooms), and ensuring consent and support from facility management.

4.3.3.8 Characteristics of research sites

Each of three SCUs (A, B, C) was located in country towns outside Dublin. SCUs A and B were attached to HSE geriatric hospital settings. SCU C was attached to a larger private nursing home. All three SCUs were separated from other hospital wards (A and B) and from other parts of the nursing home (C), respectively. All units had a specialist interest in dementia. Each of the three SCUs provided both residential long-term and respite care. All beds in the three settings were occupied at the time of data collection, and all three units used waiting lists for LTC placement.

SCU A was reconfigured from a pre-existing environment and had been in operation for five years at the time of fieldwork. It had nine LTC beds and one residential respite bed. Residents of SCU A were accommodated in shared sleeping quarters with men and women in two separate five-bedded wards. This unit had shared bathrooms with one toilet and washing facility per five residents. It had a kitchenette equipped for preparing hot beverages, snacks, and small meals. This unit had no designated, separate dining room; meals were served in a central area that was also used as a living room and at times as an activity area.

SCU B was a completely newly-built unit and had only been in operation for eight months when fieldwork commenced. It had six LTC beds, one emergency bed, and one residential respite care bed. In contrast to SCU A, unit B provided single and fully furnished bedrooms to PwDs. Toileting and washing facilities were also shared – with one bathroom per two residents. With regard to meal times and other activities, unit B was equipped with the same facilities as unit A (kitchenette, shared dining and activity areas).

SCU C was reconfigured from a pre-existing ward and had been in operation for five years at the time of data collection. In contrast to the truly small-scale environment provided by the two HSE units, SCU C had 37 LTC beds and one residential respite care bed. Similar to SCU B, SCU C provided single and fully furnished bedrooms which – and in contrast to

both HSE units - had private en-suite washing and toileting facilities for each resident. SCU C had no kitchenette facility but it did have a designated dining room, which was separate from the unit's living room and activity area - the day lounge. Access to these areas was restricted to residents. SCU C also differed from the two HSE units in that it had a multi-sensory Snoezelen[3] room and a reminiscence room furnished in the style of an early 20th-century Irish farmhouse kitchen.

In all three units a central kitchen was used for catering purposes but dining took place in small group settings (bistro-style seating arrangements). In addition, all three SCUs had one or more small-scale living rooms which were segregated from other rooms (dining areas, activity rooms, and private bedrooms) and were used for different reasons such as for visitors or small-group activities. All three SCUs provided secure outdoor areas that offered opportunities for exercise, activities (gardening, putting laundry on washing lines), and sensory stimulation through walking paths, raised flower beds, and pavilions.

All of the three participating SCUs went to great efforts to create homelike settings by providing age-appropriate furniture; encouraging PwDs to personalise their private and shared surroundings through photographs and other personal items; and providing 'points of interest' (such as cupboards decorated with vintage dolls or porcelain cups) in order to stimulate their residents. Despite efforts to design domestic environments, it was interesting that other more clinical-institutional design characteristics were observed in all three SCUs. These included door alarms; linoleum floors; the centralised provision of meals, laundry, and cleaning services; and the mandatory requirement that most staff wear uniforms. All three units adhered to an approach to care that was person-centred

[3] Snoezelen is "multi-sensory stimulation" that "provides sensory stimuli to stimulate the primary senses of sight, hearing, touch, taste and smell, through the use of lighting effects, tactile surfaces, meditative music and the odour of relaxing essential oils." (Chung & Lai, 2002, p. 1). Snoezelen is aimed at fostering PwDs' sensory skills and enhancing the person's well-being through pleasant visual, acoustic, tactile, and olfactory experiences (Chung & Lai, 2002).

and needs-based. The researcher was informed about each SCU's philosophy by senior staff members (Clinical Nurse Specialists in SCUs A and B, Unit Manager in SCU C) during her initial visit to the respective setting. Senior staff members at these initial meetings also explained that all staff members in each SCU were trained and educated in dementia care.

4.3.3.9 Characteristics of FCs

A sample of nine FC–PwD dyads that satisfied the inclusion criteria was recruited for the main study. The nine FCs chosen were integrally involved in the transfer process. Seven were primary caregivers and two shared caring with a parent but these two caregivers had had the main responsibility for the SCU admission. Despite the death of one PwD during the course of the research completed for the thesis each of the nine FCs participated in both phases of the data collection (phase one and phase two). All nine FCs were interviewed prior to their relative with dementia because I felt it was important to establish a rapport with the FC before interacting with the PwD; for pragmatic reasons (obtaining FCs' written consent to both their own and their relative's participation in the thesis and conducting phase one interviews with FCs in one session), and for reasons of consistency in the sequencing of the research. All nine FCs were from rural backgrounds and lived in close vicinity to the respective SCU. Four FCs were recruited from SCU A, two from SCU B, and three from SCU C. Prior to partaking in this thesis none of the FCs had been involved in any research exploring their experiences of relocating a relative with dementia into LTC.

4.3.3.10 Characteristics of PwDs

A total of nine PwDs was approached to participate in the thesis. At phase one (three to four weeks post-admission), eight of these participated in the interviews whilst one PwD

due to discomfort with the research situation refused to be interviewed[4]. At phase two (six months post-admission), six out of nine PwDs participated in the interview. Three people did not participate in a follow-up interview. This was because one had died within two months of placement; one other person lacked concentration and language skills and the third person would not give assent to be interviewed. This was the same person who refused to give assent to the first interview.

A key problem encountered therefore was that these people (N = 9) were generally so severely cognitively impaired that most of the data collected from them at both time periods was uninterpretable or despite reading and re-reading their transcripts could not be used as an integral part of the thesis. This may, however, be more related to the instrument used.

4.3.3.11 Characteristics of SCU staff

A total of 12 SCU staff members were sampled for the FGs. FG participants were selected on the basis of meeting the inclusion criteria (see section 4.3.3.3.4). Staff members in charge for liaising with the researcher (Clinical Nurse Specialist in SCU A, Clinical Nurse Specialist in SCU B, Unit Manager in SCU C) were familiar with the inclusion criteria. Each approached SCU team members who met the inclusion criteria and were willing and available to participate. FG participants came from different occupational backgrounds (see Appendix R) and FG sizes differed slightly across the three settings (N = 5 in SCU A, N = 4 in SCU B, N = 3 in SCU C).

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[4] This lady was not uncomfortable with me as she smiled at me and drank a cup of tea while I was sitting next to her. She remained silent for most of the time that I spent with her and sporadically commented on aspects of her immediate environment, which she liked (for example, a fish tank in the entrance area). I felt that this lady was open to communication with me but she clearly refused to participate in the research by falling silent, avoiding eye contact with me and "freezing" (tense body posture) every time I attempted to administer any of the interview questions or the MMSE.

4.3.4 Research methods

Research methods, which represent the fourth model component, can be described as "the techniques or procedures used to gather and analyse data related to some research question or hypothesis" (Crotty, 1998, pp. 3-6). Research methods represent the specific instruments used to collect the data.

The research methods that were chosen for this thesis comprised in-depth interviews with semi-structured questionnaires for both FCs and PwDs, and FGs with semi-structured questionnaires for SCU staff. In addition, self-administered questionnaires were administered to FCs and SCU staff members where information about their age, gender, marital status, education, work experiences, and care-giving experiences was requested. The Mini-Mental State Examination (MMSE) was used to assess PwDs' level of cognitive functioning at both phase one and phase two. Additional data was collected from perusing PwDs' SCU nursing and medical records in order to gain information about their cognitive, functional, and health status. The information obtained from PwDs' SCU charts was considered important throughout the data collection and in the early stages of data analysis. As the analysis progressed, however, most of this information with the exception of PwDs' MMSE scores and clinical dementia diagnoses turned out to be tangential to the thesis focus (caregivers' and PwDs' narratives) and was hence not further incorporated into the thesis.

4.3.4.1 Interview schedules

One of the most commonly used qualitative research method is the individual in-depth interview (Lloyd, Gatherer, & Kalsy, 2006, p. 1386; Smith, Flowers, & Larkin, 2009). Individual in-depth interviews are divided into semi-structured and unstructured, and vary in their length of conduct and frequency (Bryman, 2008, p. 465). Semi-structured interviews enable the researcher to investigate more specific research questions or cases by using a more structured approach and at the same time applying more structured interview schedules than those used in unstructured interviews (Bryman, 2008, pp. 439-

442). Semi-structured interviews explicitly encourage a more flexible handling of the interview questions than quantitative structured interviews because they allow the researcher to deviate from the interview schedule and change the order of questions during the interview (Kvale & Brinkmann, 2009; Lloyd, Gatherer, & Kalsy, 2006, p. 1387). As such, semi-structured interviews are particularly well suited for PwDs with complex interaction needs and in need of highly adaptive research procedures (Hubbard, Downs, & Tester, 2003; Murphy et al., 2005).

Since this thesis sought to elicit an in-depth insight into a phenomenon and obtain exhaustive and rich answers from participants, a semi-structured interview was the chosen method. This in-depth understanding is the key goal of this thesis. Semi-structured interviews are also compatible with, and adaptive to, the aforementioned epistemological-theoretical assumptions (Crotty, 1998). As mentioned, semi-structured interviews prioritise flexibility over structure (Denzin & Lincoln, 2008; Kvale & Brinkmann, 2009). They support the investigation of new topics and can be flexibly adapted to the participants' needs (Bryman, 2008, pp. 437-442). This method therefore leaves room for the researcher to participate in co-constructing individual narratives, which was in keeping with the chosen approach (Crotty, 1998). Semi-structured interviews also allow for exploring broad research foci as is the case for this thesis, which attempts to generate a holistic understanding of the whole process of admitting relatives with dementia into SCUs (Kvale & Brinkmann, 2009).

For the purpose of this thesis five different interview schedules were devised. Two were for FCs at phase one and at phase two. Another two were for PwDs at phase one and at phase two. One was the interview schedule used for FGs. All schedules consisted of key questions that were each supplemented with multiple prompts.

4.3.4.1.1 Interview schedules for FCs

The phase one interview schedule used for FCs consisted of 15 questions designed to explore the experiences and perspectives of participants (see Appendix H). The issues investigated pertained to the family's living situation prior to SCU admission and the type of care responsibility the FCs had, reasons for making the SCU admission decision and who else may have been involved making the admission decision, the FCs' short-term reactions to the transfer, key changes arising for both them and their relative by the transfer at four weeks post-admission, meanings of the transfer, perceived differences between the SCU and the setting their relative had lived immediately prior to admission, supports, and FCs' wishes in terms of improving transfer and overall care practices. These questions were designed to allow participants expand on topics and talk about intimate personal issues.

The phase two interview schedule used for FCs consisted of 27 questions exploring the experiences and perspectives of FCs (see Appendix I). These follow-up questions focused on changes experienced in FCs' life since the transfer, changes in FCs' attitudes to the transfer and the new living situation, changes in FCs' attitudes to the SCU, longer-term reactions to the transfer, key changes brought about by the transfer at six months post-admission, key advantages and problems of having their relative with dementia in a SCU, experiences of their relative's settling-in progress since first interview, and FCs' wishes in terms of improving transfer and overall SCU care.

4.3.4.1.2 Interview schedules for PwDs

The interview schedule used for PwDs at phase one comprised 12 simple questions (see Appendix J). These questions were designed to examine PwDs' views about the new care setting, how they felt living in the SCU, aspects of the SCU that made them feel good, feel sad, the SCU transfer itself and its meanings, what FCs told the PwD about the transfer, key changes associated with the transfer, perceived differences between the SCU and former settings, and supports. All questions were worded simply and kept short.

The phase two interview schedule used for PwDs consisted of 16 questions (see Appendix K). These follow-up questions addressed PwDs' experiences and perspectives of living in the SCU at six months post-admission, overall living in the SCU now, attitudes to the new environment at six months post-admission, feelings about the transfer, subjective changes noticed since last interview, perceived differences between the SCU and other settings, and improvements in terms of the transfer and the SCU environment (see section 4.7).

The literature review shaped the type of questions explored and used in each interview schedule (see Chapters 2 and 3). Each question was formulated broadly and supplemented with prompts (Bryman, 2008). The questions were open-ended, conversational in style, and designed to elicit comprehensive in-depth narratives of participants' SCU admission experiences (Pierce, 2010). Different types of questions were used and alternated, such as introducing questions, follow-up questions, probing questions, structuring questions, and silence (Bryman, 2008, pp. 445-448). The prompts were key words or sentence fragments, which acted as cues for me to explore specific areas of interest and helped stimulate conversation. The prompts were used flexibly meaning not all participants were asked all prompts. I attempted to ensure that appropriate jargon-free language was used and leading questions were avoided (Bryman, 2008). In all four interview schedules, names of persons and places were denoted by brackets into which individual names were inserted. This way, all schedules were personalised.

All interviews (with both PwDs and FCs; at both phases) bar one with a FC at follow-up were conducted in the SCU facilities. This particular interview was held in a hospital ward where the FC had been admitted to because of an acute illness. This FC expressed her wish to be interviewed in these circumstances and assured the researcher she did not mind being interviewed in the multi-bedded ward she was admitted to. In most cases I was permitted to use separate visitor rooms that were located either on the SCU premises

or on neighbour wards and provided a private unobtrusive interview setting (Bryman, 2008; McKillop & Wilkinson, 2004). In one facility interviews were conducted with individual caregivers in a lounge area outside the SCU as the visitor rooms were usually dedicated to visiting family members. In these instances, I asked for the interviewees' oral consent to interview them in the lounge area and attempted to ensure that the participants' privacy was respected. For instance, I interrupted the interview if by-passers approached the interviewee to talk with him/her and made sure to sit apart from other lounge guests as to avoid being overheard. In most cases the interview atmosphere was quiet.

The interviews were recorded with an Olympus digital recorder, converted into digital audio files and then transcribed. The transcriptions were made verbatim and supported by Olympus DSS Player transcription software. I adopted formal transcription rules such as denoting missing parts, indicating pauses, and bracketing sections where participants talked over each other (Bryman, 2008, pp. 451-455). I took notes after each interview on interviewees, their behaviours, and circumstances under which the interview took place (Bryman, 2008, pp. 417-444). These notes were entered into a research diary. I used these field-notes mainly as a memory aide and did not incorporate them into the thesis.

4.3.4.1.3 Focus group and interview guide

As mentioned, FGs were also used as a method for data collection in this thesis. Three FGs were held at the three different SCU sites. These FGs were held with the SCU staff. Each FG took place at three to four weeks after the first PwD participating in the research conducted for this thesis had been admitted to the respective SCU. FGs have been defined as focused group interviews (Rabiee, 2004, p. 655). FGs are characterised by including multiple participants and a moderator, usually the researcher (Powell & Single, 1996). FGs serve two purposes, namely, to investigate a particular research topic in-depth and to gain insight into group interaction dynamics and shared processes of meaning-making (Bryman, 2008, pp. 473-476, pp. 485-487).

FGs are supposed to induce a deeper understanding of a phenomenon because group members are expected to provide a wide spectrum of subjective opinions and understandings and to challenge – and thereby elucidate – opinions and construct systems of individual group members (Millward, 2006, p. 280). FG participants are commonly included on the basis of their familiarity with the phenomenon and the intended thesis outcomes (Bryman, 2008, pp. 473-480).

For the purpose of this thesis FGs with SCU staff members at phase one were chosen for the following reasons. FGs are designed to illuminate in-depth the views and experiences of individual group members of the phenomenon under study. As such this research method is congruent with the research focus of exploring individual understandings of the phenomenon of admitting PwDs into specialised LTC. FGs are congruent with constructionist-phenomenological assumptions. The emphasis is explicitly on investigating group interactions and processes of shared meaning-construction in naturalistic contexts i. e. within SCUs (Frey & Fontana, 1991). This approach allows the researcher a more naturalistic insight into these processes and is thus congruent with the constructionist-phenomenological core assumption of co-constructing individual meanings (Bryman, 2008, pp. 476-479).

FGs encourage every group member to bring his/her individual views and attitudes towards the phenomenon under study to the fore (Millward, 2006, p. 287). As such they are also consistent with the constructionist assumption of multiple realities (Crotty, 1998). FGs share key features with semi-structured interviews, which also render them compatible with constructionist-phenomenological assumptions (Bryman, 2008, pp. 437-442). These features include exploring a broad area of interest rather than specific hypotheses (Crotty, 1998). This is the case in this thesis, which is designed to generate a comprehensive insight into the process of admitting PwDs into SCUs. Another shared feature is the fact that FGs prioritise flexibility over structure and thus allow for adapting the discussion to FG members' topics of interest (Millward, 2006, p. 287).

An interview guide for FGs was developed for the three FGs that were conducted in three different SCUs at three to four weeks after the first PwD participating in the thesis had been admitted to the respective SCU. This schedule consisted of 14 questions exploring the experiences and perspectives of front-line and senior staff members on the procedures that were initiated once a LTC bed becomes available, staff experiences of admitting PwDs into LTC, admission policies and guidelines, training, preparation and supports for PwDs and FCs, overall reactions of PwDs and FCs, the role of the LTC admission process for the SCU's culture of care, differences between this SCU and other SCUs with regard to admitting PwDs into LTC, and possible improvements of current admission practices (see Appendix L).

All FGs were conducted on-site and in a protected and private atmosphere (i. e. in separate living rooms). FGs were also recorded and stored in the same way as was the case with semi-structured interviews. Transcriptions were made verbatim and followed the same principles as outlined for semi-structured interviews. Complementary field-notes were also made after each FG on participants' characteristics, behaviours, and interview circumstances. These notes were also entered into the research diary.

Role issues and group interactions – unique to the FGs - emerged including senior staff members leading and in some cases dominating the discussion, some front-line staff members withdrawing from the discussion, and FG participants engaging in 'insider talk' about persons and subjects unknown to me. I addressed these issues by trying to encourage 'withdrawn' participants to express their views and asking staff members to elaborate on 'insider' topics in order to develop an understanding of their concerns and issues (Bryman, 2008, pp. 485-487).

FGs are guided by certain conventions that are specific to this research method (Bryman, 2008, p. 485) and I followed them. For example, I thanked group members for participating and introduced myself and the interview purpose. Participants were also

informed that they could leave the group discussion at any time if required by their work duties, that the interview would be adapted to their time needs, and that the perspectives of every participant were important and would be elicited (Bryman, 2008, p. 485). It has also been suggested to advise participants not to talk over each other and to introduce themselves to the group (Bryman, 2008, p. 485). However, I decided not to adhere to these conventions because group members were already familiar with each other due to the fact that they were team colleagues. In addition, I did not want to patronise participants or inhibit them in expressing their views by controlling communication behaviours that occur naturally among members of such groupings, such as the habit of talking over each other (Bryman, 2008, p. 485).

4.3.4.1.4 Complementary data collection instruments

Data from semi-structured interviews and FGs were supplemented by data derived from three other sources, namely the Mini-Mental State Examination (MMSE), self-administered questionnaires, and nursing home records. This data was used to enrich and contextualise the interview data. Using these additional sources for data collection is congruent with a constructionist-phenomenological stance as they support an in-depth understanding of the phenomenon of moving to a SCU and provide, as well as enrich, contextual information which is viewed as an important constituent of individual experiences of the SCU transition process.

4.3.4.1.5 Mini-Mental State Examination (MMSE)

The MMSE is a widely used tool in dementia research and is designed to assess levels of CI (Folstein, Folstein, & McHugh, 1975; Lopez et al., 2005). The MMSE consists of 12 items and measures cognitive functions such as orientation, registration, attention, recall, and language (Cockrell & Folstein, 2002; Folstein, Folstein, & McHugh, 1975). The maximum score is 30 (Lopez et al., 2005). The following cut-off scores have been suggested to denote different stages of CI: 30-27 meaning no CI, 26-21 meaning mild CI, 20-11 meaning moderate CI, and 10-0 meaning severe CI (Lopez et al., 2005).

The MMSE was chosen to help me identify the PwD's level of dementia and to adapt the subsequent interview to the PwD's cognitive and verbal skills (see Appendix O). Whilst MMSE scores were found in some of the SCU charts, I was particularly keen to acquire up-to-date MMSEs in line with the timing of this thesis. The MMSE was therefore administered to PwDs before each interview (phase one and phase two) in order to obtain most recent information about PwDs' cognitive status and to trace any fluctuations in their cognitive status between phase one and phase two. The PwD was thereby informed about the nature and purpose of the MMSE (a memory test used to give me an idea about what interview questions to select and to ask). I was aware of the fact that the correct use of the MMSE requires working through all 12 test items with the PwD (Merrett, 2003). I however was only able to administer the full MMSE in two cases at phase one. In all other cases, I abandoned conducting a full MMSE (see section 4.7). This decision was due to the fact that most PwDs in this sample had advanced levels of CI which made it impossible for them to engage in any challenging questions and answers. In addition, due to their impaired cognition PwDs were at an increased risk of feeling distressed by the test procedure. Inflicting undue distress to research participants with dementia through administering rigorous research methods would have seriously conflicted with the ethical principles guiding this thesis.

To provide some estimate of the PwDs' dementia severity, I therefore used whenever possible MMSE scores obtained by HSPs at both phases and documented in each participant's SCU nursing and medical records.

4.3.4.1.6 Self-administered questionnaires

On completion of first interview self-administered questionnaires asking information about socio-demographic and work profile were administered to FCs. They were also given to SCU staff upon completion of the respective FG. Self-administered questionnaires are a widely used means for collecting different kinds of data in a structured fashion (Denzin & Lincoln, 2008). Participants are requested to fill in the required information themselves.

Key principles for designing self-administered questionnaires comprise using closed and open-ended questions, devising an easy-to-follow structure, giving detailed instructions to participants, and brevity (Bryman, 2008, pp. 217-249).

Two different types of self-administered questionnaires were devised, the first for FCs and the second for staff members. Both questionnaires were designed to collect basic information on respondents' socio-demographic status and care-giving experiences. This information was used to contextualise and complement data from semi-structured interviews and FGs. Detailed instructions were given to participants on how to fill in the requested information.

FCs were asked nine open-ended and closed questions (see Appendix M). Questions asked covered topics such as their socio-demographic profile (age, gender, education, marital status, and occupational status), their relationship with the PwD, reasons for being caregiver, and care-giving experiences. The item dealing with FCs' care-giving experiences asked questions about the PwD's age and former occupational status, date of dementia diagnosis, the dementia sub-type, years of caring for the PwD, whether PwD and FC cohabited prior to the SCU LTC admission, and contexts of SCU LTC admission (date, key reason, LTC admissions prior to SCU transfer). The questionnaire was handed out to FCs after the phase one interview. I remained present during completion of the self-administered questionnaire to help with any queries.

Using a mix of closed and open-ended questions SCU staff members were asked six key questions (see Appendix N). The questions comprised age, gender, marital status, educational status, and occupational status. The questionnaire was handed out to SCU staff members after the FG. I also remained present with the SCU staff during completion in order to help with any queries.

4.3.4.1.7 Self-generated forms for medical and nursing record materials

It is noted that external documents such as nursing home records provide a major data source if they contain information relevant to the research (Appleton & Cowley, 1997; Bond & Corner, 2001, p. 105). They represent a non-obtrusive and non-reactive measure (Denzin & Lincoln, 2008). Medical and nursing home records, which represent the key document resource for this thesis, can be defined as official and non-public documents (Bryman, 2008, p. 522).

I devised a data collection form for assessing information from PwDs' SCU nursing and medical files (see Appendix P). Files were provided by senior SCU staff and consisted of medical and nursing records produced by multiple HSPs working in the SCU and other health and social care settings (for example GPs, acute hospitals, and nursing homes). The records provided 'chronological' information on topics relating to the PwD's health and well-being as they covered the period of time ranging from immediately prior to SCU admission until immediately afterwards.

Developing this tool was challenging because established instruments and templates are sparse. The data collection form consisted of eight structured pages. On the first page I noted the date of data collection, the name of the SCU facility, the participant code, and the SCU staff member (i. e. his/her job title) who provided the documents. I then classified the content information taken from the nursing home records into four key categories. The four categories included document characteristics (number, title, and type of document), reasons for selecting this particular document, author(s) of document, and key content information. The four categories were structured into columns, into which I entered relevant document information manually. These four key categories were chosen to structure the content information and to render the data collection process transparent. In addition, a list with key domains that were considered to be relevant background information about PwDs was attached on the last page and acted as a prompt for me. These key domains included i) socio-demographic information, ii) dementia status, iii)

physical health status and comorbidities, iv) psychiatric health and comorbidities, v) functional status, and vi) psychosocial status (Bjoervell, Thorell-Ekstrand, & Wredling, 2000). The data collection form was deliberately kept open-ended in order to adapt to the different levels of document quality.

In addition to other research methods used in this thesis, nursing home records were perused at phase one and at phase two and information from them was extracted whenever possible immediately after interviews at phase one and at phase two, respectively. The purpose of conducting a nursing home record review at phase one was to gain further insight into the person's health, and his/her biographical and psychosocial circumstances at admission and immediately afterwards, and at phase two was to trace any changes in the person's physical health, care needs, and psychosocial status since first interview.

4.3.5 Pilot study

Qualitative pilot studies are commonly implemented prior to the main study and serve a variety of purposes (Bryman, 2008; Teijlingen & Hundley, 2001). These include detecting potential shortcomings of research designs and protocols; establishing the suitability of research methods and instruments; exploring response and sampling difficulties; training the administration of methods; and developing a rapport with study participants (Denzin & Lincoln, 2008; Sampson, 2004; Teijlingen & Hundley, 2001). Pilot studies can be seen as part of the cyclical process of developing and improving research methods (Bryman, 2008, p. 446).

For this thesis a pilot study for both phases was carried out in order to pre-test data collection instruments and their intended sequence of administration. In addition, I wished to gain more experience with different aspects of using the data collection instruments, and wished to gain practice in relation to informing participants about the thesis aims and methods, explaining to participants their tasks and rights, and obtaining both oral and

written consent from participants. Moreover the pilot study was intended to help me establish a rapport with PwDs and their caregivers and familiarise myself with the research environment.

The sample of this pilot study was recruited from SCU A. The pilot dyad (PwD and FC) was pre-selected by SCU senior staff members and consisted of a 71-year old man diagnosed with AD and his 47-year old daughter caregiver (see Appendix Q). The sequencing of methods was also piloted. Both participants took part in the pre-testing of all methods in the intended sequences. The nursing home record analysis was conducted separately from the participant meetings.

The pilot study conducted both at phase one and at phase two resulted in some minor changes to interview schedules and to data collection forms used for nursing home record analysis. Contents and numbers of pilot-tested items were by and large not changed but adopted unaltered into the main study interview schedules. Key changes were re-formatting and re-wording of items; reducing the number of prompts and changing written-out prompts into key words. In addition, some double-barrelled questions were removed. I also eliminated personal identifiers, such as names of SCUs and participants. Key changes to the phase two interview schedules for PwDs included removing sub-headings and colourings for different sub-sections (such as views of the admission and attitudes towards the SCU) which I found distracting.

Unfortunately in doing this pilot study, some of the obstacles to communication with PwDs which were later experienced were not encountered. Hence I continued using the interview schedules (phase one, phase two) and the MMSE in the main study.

The phase one pilot study also resulted in changes to the form used for nursing home record analysis. The structure of this form was improved by introducing the descriptors "date", "facility", "participant code", and "provider of documents". Other changes included

deleting the two categories "type of information" and "annotations" and providing examples for each category. I furthermore removed five sub-headings (dementia diagnosis and severity, aetiopathology, physical comorbidities, psychiatric comorbidities, PwD's age, educational status) from the actual form, which were used for the purpose of thematically structuring the information extracted from SCU resident records as filling in this information under each sub-heading was too time-consuming. The sub-headings were subsequently extended and summarised into a list that was attached to the last page of the form (see Appendix P).

4.4 Research ethics

Ethical considerations are an essential part of any research study. They guide the researcher's actions towards participants and protect participants' psychological and physical safety. PwDs are a highly vulnerable group whose abilities to comprehend complex research strategies, gauge the risks of partaking in research against its benefits, and decide autonomously and voluntarily about their participation are often significantly impaired (Berghmans & Ter Meulen, 1995; Kitwood, 1995). Accordingly, ethical concerns need to be especially carefully considered when conducting research with PwDs (Bjorneby et al., 2004; Fry, 1999; Keyserlingk et al., 1995).

Several authors agree that major ethical principles need to be addressed when research participants can no longer make an informed and autonomous decision about their participation in research. These major ethical principles comprise respect, beneficence, and justice (Berghmans & Ter Meulen, 1995; Bjorneby et al., 2004; Fry, 1999; Keyserlingk et al., 1995, p. 319; Slaughter et al., 2007).

Respect is defined as "the obligation to treat individuals as autonomous agents and to protect those individuals with diminished capacity for autonomy" (Fry, 1999, p. S55). This

principle requires the researcher to provide participants with understandable and sufficient information about the research - in particular about the participants' tasks and risks – on which they can base both their decision and consent to participate (Fry, 1999). This is the principle of informed choice and informed consent (Bryman, 2008, p. 406). This autonomy of choice must be respected throughout all stages of the research process (McKillop & Wilkinson, 2004, p. 119; Woods & Pratt, 2005).

Beneficence is defined as "the obligation to not harm and to maximize possible benefits and minimize possible harms in research" (Berghmans & Ter Meulen, 1995; Fry, 1999, p. S55). The researcher is obliged to assess all types of benefits and risks involved in the research and the extent to which participants might be exposed to them (Keyserlingk et al., 1995).

Justice is defined as "the obligation to treat equally those who are like in similar respects as well as the obligation to be fair and to not discriminate between individuals in an unfair manner on the basis of illness, age, economic status, gender, or social standing" (Fry, 1999, p. S55). The researcher is required to avoid exclusionary sampling – for instance, on the basis of participants' gender or ethnicity - and sampling participants with a high level of distress whilst "less burdened populations are available" (Berghmans & Ter Meulen, 1995; Fry, 1999, p. S55).

In addition, Berghmans and Ter Meulen (1995) consider other ethical principles important in conducting research with PwDs. These principles comprise significance and relevance of research, informed proxy consent, and taking special precautions for PwDs with impaired insight. The principle of significance and relevance means that research involving PwDs needs to be meaningful and pertinent to participants' life worlds, and should also be of "substantial benefit" for all those affected by the research outcomes (Berghmans & Ter Meulen, 1995, p. 650).

The principle of informed proxy consent is aimed at promoting the "values and well-being" of PwDs who due to a more progressed level of dementia are no longer able to advocate for themselves (Berghmans & Ter Meulen, 1995, p. 651). The principle of taking precautions for PwDs with impaired insight means for the researcher to be aware of the fact that the person can no longer verbally express his/her concerns and therefore to be highly attentive to the person's non-verbal signs of distress (Berghmans & Ter Meulen, 1995, p. 651).

Taking on board these experts' views and conscious of the particular vulnerability of PwDs, I identified and addressed the following ethical issues in order to fulfil the abovementioned ethical principles (Berghmans & Ter Meulen, 1995; Fry, 1999).

4.4.1 Cognitive and other sensory and/or physical impairments

I was aware that PwDs participating in this thesis had multiple impairments associated with their dementia and other age-related health problems. I was also aware that specific needs might arise from these impairments and needed to be addressed within the research context. In order to avoid placing undue stress on PwDs I attempted to get information about individual cognitive and other sensory impairments (for example, hearing, sight, gait, or challenging behaviours) and associated needs prior to undertaking the interview. This information was in most cases provided by formal and informal caregivers on the phone and before my meeting with the PwD. Throughout the data collection I monitored the PwD's physical and psycho-social needs and adapted to them as best as possible. For example, I asked staff for help with transferring them from the unit to the interview room and back; spoke out loud and slowly; and offered refreshments to the PwD.

4.4.2 Learning and communication problems

I was aware of the fact that the research situation presented a particular challenge to PwDs with severely compromised cognitive and verbal skills. I thus tried to adapt the way the MMSE and the interview was conducted to suit the individual's cognitive and verbal skills and to facilitate the PwD's self-expression as much as possible. This was achieved by strictly focusing on the person's experiences and emphasizing to the PwD that his/her experiences were most important and interesting to me. Attention was also paid to keeping the interaction conversational, refraining from creating any kind of 'exam' situation, using simple language, repeating information whenever necessary, and paraphrasing PwD's statements to ensure that they were properly understood.

4.4.3 Experience of psychological distress

I made every effort to be aware of potential sources of distress for these participants resulting from the research experience (Dewing, 2002; McKillop & Wilkinson, 2004). Minimising the individual's psychological discomfort was achieved by not probing too deep into any stressful or difficult comments, and continuously observing the PwD's verbal and nonverbal language for any signs of psychological distress. If any such signs were noticed, potential causes of distress were explored and the PwD's further participation in the research conducted for this thesis was carefully negotiated. For instance, I made every effort to enable the PwD to choose between taking a break from the interview, continuing, or withdrawing from further participating in the research conducted for this thesis. In addition, I encouraged PwDs to express any feelings of distress at any point in time.

I was also acutely aware of the importance of validating the PwD's feelings and his/her personal point of view on an ongoing basis. I made every effort to give PwDs the choice to have the FC be present or absent from the interview with me. Interestingly, none stated that they wished their relative to be present during their interview. In four cases, caregivers, however, were present. In one case, a husband caregiver insisted on being

present during his wife's (i. e. the PwD) phase one interview. In a second case, the same husband caregiver and his daughter also insisted on being present during his wife's follow-up interview. In the third case, a granddaughter was present during the PwD's phase one interview as she had to take her grandmother to an appointment. In the fourth case, the PwD had deteriorated in her language skills to an extent that it was felt necessary to have a staff member - who was very familiar with this person's verbal expressions – join the interview (follow-up) in order to support the person and help minimise possible distress.

These strategies of minimising psychological distress were mainly used with PwDs. I was aware of the fact, however, that caregivers might become distressed as well, and subsequently applied these strategies to them wherever necessary. This was in particular the case when FCs became very upset and tearful while recalling sensitive experiences during their interviews.

4.4.4 Generating and storing personal data

I was aware of the need to protect participants' privacy and ensure confidentiality of personal information (Denzin & Lincoln, 2008) and attempted to provide a comfortable yet unobtrusive research setting wherever possible by using separate rooms and stopping the tape-recorder if a disturbance arose. All data collected were stored safely in my office. All paper documents have been locked into a drawer. All digital data (audio tapes, verbatim transcripts) have been stored on a pass-word protected PC.

All research participants (N = 9 FCs, N = 9 PwDs, N = 12 SCU staff members) were assured by me both in written and verbal form (information letters [see Appendix A, Appendix C, Appendix E]), personal conversations) about the fact that all written and taped/digitalised records (including verbatim transcripts) obtained from them will be destroyed after completing the thesis. I decided to destroy rather than archive participants' data after reviewing information letters and consent forms used for other qualitative

studies; reviewing the literature on qualitative research ethics; and obtaining feedback from experts in the area of qualitative research about my ethics proposal (see section 4.4.5).

All participants were given pseudonyms in order to protect their confidentiality. All information relating to participants and research sites was coded and anonymised. Only the pseudonyms and only the coded anonymised information will be used in the thesis and subsequent publications (Bryman, 2008, p. 422).

4.4.5 Ethical approval

Ethical approval was sought from the School of Social Work and Social Policy Trinity College's Research Ethics Approval Committee (REAC) in December 2008. Approval was granted in January 2009 subject to a few minor changes being implemented such as obtaining consent to access PwDs' nursing home records, specifying the need for two interviews, and simplifying consent forms. Additional ethical issues arising at a later stage included respecting the privacy of other residents who did not participate in the research but whose private living environment was intruded by me and respecting the fact that participants were sometimes disclosing important issues (so-called "unsolicited accounts") after the interview had been stopped (Bryman, 2008, pp. 407-410).

I ensured the privacy of other residents by being cognisant of the fact that this was their home and every effort was made to avoid being intrusive (such as me introducing myself, refraining from disrupting ongoing activities, and asking for permission before entering bedrooms or other restricted areas). I did not obtain consent to record individual unsolicited accounts. If any such accounts were given after the tape-recorder had been switched off which I considered important for the research topic I took notes on them in the fieldwork diary.

4.5 Interpretative Phenomenological Analysis (IPA)

IPA is a qualitative data analysis strategy rooted in phenomenological philosophy and psychology (Smith, Flowers, & Larkin, 2009). Researchers using IPA are "committed to the examination of how people make sense of their major life experiences" (Smith, Flowers, & Larkin, 2009, p. 1) and are "interested in what happens when the everyday flow of lived experience takes on a particular significance for people" (Smith, Flowers, & Larkin, 2009, p. 3).

Aspects of a major life experience usually unfold over a prolonged period of time yet they are connected by a "common meaning" (Smith, Flowers, & Larkin, 2009, p. 2)[5]. IPA's key goals are thus to "recall the parts and their connections and discover this common meaning" (Smith, Flowers, & Larkin, 2009, p. 2) and to actively participate (i. e. interpret) in the reflections and feelings the individual holds about the event as well as its meanings and significance (Smith, Flowers, & Larkin, 2009, p. 3). The researcher's task is thus to interpret the person's interpretations of the life event. This interpretive process is called "double hermeneutic" (Smith, Flowers, & Larkin, 2009, p. 3).

IPA was used for data analysis in this thesis for several reasons. First, it allows for exploring in detail the person's reflections and understandings of a phenomenon and the personal meanings ascribed to it - in this case, the phenomenon is the admission of PwDs into SCUs (Smith, Flowers, & Larkin, 2009, p. 3, pp. 46-47). As such, IPA is congruent with this thesis' focus namely exploring the lived experiences of caregivers and PwDs being admitted into SCUs.

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[5] For example, being diagnosed with an illness might mean undergoing surgery, recovering, and taking up work again; the theme combining these different experiences might be 'growing stronger'.

Second, IPA is rooted in phenomenological and hermeneutic traditions and as such is congruent with the chosen epistemological framework (Smith & Eatough, 2006; Smith & Osborn, 2008). As outlined earlier, contemporary phenomenology comprises both descriptive and interpretative aspects. By taking the research participant's stance and interpreting it I should gain a more holistic in-depth understanding of the experience of admitting a loved one with dementia into a SCU.

Third, IPA is congruent with the chosen theoretical view framing the SCU transition as a major life event. Fourth, IPA is highly compatible with the chosen qualitative methodology - in particular, the in-depth idiographic exploration of individual cases, the purposive small sample recruitment, and the comparing of themes within and across cases (Smith, Flowers, & Larkin, 2009). IPA equally lends itself to research designs that use a follow-up component and are geared at exploring multiple perspectives on a lived phenomenon (Smith, Flowers, & Larkin, 2009).

In addition, IPA considers contextual information associated with a certain phenomenon (such as the living circumstances of participants and the research context) as valuable and helpful for developing a better understanding of the topic under study. With regard to research methods, the use of semi-structured interviews and FGs is equally compatible with IPA (Smith, Flowers, & Larkin, 2009, pp. 3-52). There is no standardised way of conducting IPA which it is argued is a flexible and iterative analytical method (Bryman, 2008, pp. 539-552; Smith, Flowers, & Larkin, 2009, p. 79).

Smith and colleagues (2009, p. 79) in their discussion about data analysis describe the following IPA components: Cases should be analysed line by line. Emerging themes should be analysed within and across cases. Data interpretation should link original data to the researcher's theoretical knowledge. Relationships between themes should be established and result in a theoretical structure. Conclusions should be rendered more plausible and transparent by presenting the original data, interim interpretations, and the

final structure in one format. The adequacy of one's interpretations should be tested via supervision. A comprehensive 'narrative' of all themes should be developed whereby this narrative should be guided by the final structure and be interwoven with original interview quotes. It is also important for the researcher to adopt a reflective practice on his/her own thoughts and conceptions (Bryman, 2008, pp. 550-552; Smith, Flowers, & Larkin, 2009, pp. 79-80).

I was a novice to IPA and for this reason underwent training and enrolled in a three-day workshop designed to learn amongst many things how to prepare a transcript for IPA (i. e. leaving columns on left and right for descriptive and interpretative comments). Taking part in practical exercises on interview techniques and conducting descriptive and interpretative analyses were also part of the workshop learning. In line with Smith's, Flowers', and Larkin's (2009) claim of IPA being a flexible and adaptable analytical framework, I devised the following IPA strategy for my thesis:

Box 1: Steps of IPA as adapted by myself

1) All semi-structured individual interviews (FCs, PwDs) and all FGs were transcribed fully. Notes on participants' non-verbal behaviours and peculiar incidents (as for example, long pauses) were inserted into the text. Skipping of any text parts was avoided.

2) All transcripts were line-numbered. A margin was left on the right side for analytic comments.

3) The analytic comments were inserted via the Microsoft word comment function. Each comment was assigned to a meaning unit that included a particular verbatim-transcribed statement made by an individual (for example, wife caregiver Mrs. Kelly) on a particular aspect of his/her experience (for example, Mrs. Kelly's feelings about deciding to place her husband into a SCU).

4) Each comment contained a descriptive summary of the participant's statements, followed by my interpretations.

5) Each comment also included my thoughts and 'chains of reasoning' (i. e. 'links' between descriptions and interpretations)[6].

6) Transcripts were then re-read and re-interpreted in order to achieve higher-level interpretations.

The strategy as described in Box 1 was developed and revised while engaging in the data analysis. It has to be noted, however, that I deviated from recommendations given by the IPA workshop tutor, the latter suggesting that two separate columns for descriptive and interpretative analysis, respectively, be used. I felt that for practical reasons using the comment function allowed for a better assignment of lines to analytical statements. If columns (i. e. textboxes on the right and left sides of the transcript) were used, text segments often shifted and could not easily be attributed to relevant lines in the transcript.

I acknowledge the benefits of software programmes including NVivo and NUDIST (Bryman, 2008; Denzin & Lincoln, 2008; Welsh, 2002). However, the use of software in analysing qualitative data has not been without critique: First, software programmes do not perform the actual analysis and thus do not 'relieve' the researcher from the task of making sense from the data (Bryman, 2008). Second, IPA researchers in particular do not recommend that inexperienced novice researchers perform a software-supported IPA as such programmes might transform initial stages and outcomes of the analysis, and also impact on researcher's options of presenting the complete findings (Smith, Flowers, & Larkin, 2009, pp. 74-75). It was for these reasons that I chose to perform a manual analysis.

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[6] The reasons for doing so were to better organise and interlink interpretations and descriptions and to make my thought processes more transparent (i. e. reasons for a particular interpretation given and linked to the interpretation). This technique has been viewed as part of the reflective practice of IPA (Smith, Flowers, & Larkin, 2009, pp. 79-80).

4.6 Quality criteria

Quality criteria have been developed in order to evaluate the academic impact and validity of a research project (Seale, 1999). According to Bryman (2008, p. 34), qualitative research criteria can be united under the topic "trustworthiness" and comprise credibility (are the findings believable), transferability (are the findings relevant for other contexts), dependability (are the findings applicable to other times), confirmability (are the findings biased by the researcher's fore-conceptions), and authenticity (are the findings representative and inclusive of all perspectives).

Credibility is achieved by adhering to good practice standards and ideally by feeding the findings back to the research participants in order to ensure that their narratives and contexts are represented correctly (Cohen & Crabtree, 2008, p. 334). This strategy is called 'member validation' (Denzin & Lincoln, 2008; Rolfe, 2006, p. 305). Credibility can also be achieved through method triangulation (Tracy, 2010, p. 843). Whilst member validation is considered a useful strategy to enhance research credibility, some authors argue that it may not be applicable to all cases and types of research (Buchbinder, 2010; Sampson, 2004).

Member validation was not used in this thesis since I made every attempt to ensure the appropriate understanding of participants' accounts during each interview and in order to minimise burden for participants. It must also be noted that three different participant groups were included in the thesis. Two of these groups, FCs and SCU staff members, had extensive workloads and had already given up considerable time to enable me conduct interviews with them. One of these participant groups, PwDs, was excluded from the analysis due to their advanced levels of CI.

Transferability is achieved by providing a very detailed and comprehensive depiction of the research context in order to help the reader judge whether the findings are applicable

to other settings or not (Morse et al., 2002, p. 15; Rolfe, 2006, p. 305). In order to ensure this, rich descriptions of all three research sites and participants' personal backgrounds were provided in the thesis.

Dependability is achieved by providing meticulous descriptions of all research stages. This audit-type approach increases transparency and helps the reader estimate if, and to what level, appropriate research standards have been adhered to (Bryman, 2008). High dependability was achieved by outlining in detail the thesis' philosophical and theoretical foundations, its research design and methods, its sampling strategy, characteristics of research sites and research participants, ethical and consent issues, quality criteria used in this research, and its limitations.

Confirmability is achieved by the researcher preventing any subjective attitudes and ideologies from infiltrating and contorting the research activities, and facilitating peers to judge the level of confirmability (Denzin & Lincoln, 2008; Malterud, 2001, p. 483). I have been open to this type of judgement from the very beginning by presenting my work in progress at seminars and conferences inviting critical feedback, and by availing of supervision. I also attempted to achieve high confirmability through detailing all encounters with participants in a fieldwork diary and by keeping all research-related records. I also consider it an advantage not having had in-depth knowledge of the topic in advance as no in-built bias was present. I was thus less likely to impose any personal prejudice on the research subject.

Authenticity is achieved by representing the viewpoints of all participants (fairness) and by generating a better understanding of the researched social milieux (ontological authenticity) (Bryman, 2008). In designing this thesis I attempted to include the perspectives of multiple groups of participants and to represent each individual viewpoint thereby ensuring that the process was fair. Through attempting to interview FCs, PwDs, and SCU staff members working in dementia care, every effort was made in this thesis to

be inclusive of all participants and therefore achieve high authenticity. Authenticity was also achieved by transcribing and analysing all parts of each interview. In addition, I avoided at all times quoting only from a few interviews and neglecting other interview data. In addition, I have attempted to enhance an understanding of the researched settings by carefully describing them as well as those using the research settings.

4.7 Limitations

One major limitation to this thesis was the fact that, despite every effort being made to include the perspective of PwDs, much of the interview data was uninterpretable because all had a moderate to severe dementia. In addition and for ethical reasons I could not pursue MMSE questions with most of these same people since they failed to understand the questions and were at an increased risk of experiencing distress due to this test.

Administering the interview schedules to PwDs proved equally difficult since most were severely cognitively impaired and had poor language skills. Poor comprehension and moderate to severe dementia led to PwDs not understanding interview questions, being unable to concentrate, and relating experiences that were not associated with the SCU admission. Hence I had only very little input from these people.

In judging PwDs' ability to partake in the interviews (at both phases), I thus relied mainly on proxy information received from caregivers about the PwD's cognitive and verbal status prior to the interview as well as my own impression of the PwD's verbal skills, obtained from administering only a few MMSE items and observing the PwD's reactions to these.

Full interview schedules could not be administered to most PwDs either at phase one (N = 7) or at phase two (N = 7). The full interview schedules could be administered to one man

and one woman at phase one (N = 2), and two women (one of whom was the same lady who was administered the full schedule at phase one) at follow-up (N = 2). Although I attempted to focus any questions on PwDs' present well-being (i. e. in the room where the interview was held, feelings at the moment), most PwDs were no longer able to verbally provide meaningful insights into their perceived current well-being (see Chapter 7).

Another important limitation of the thesis was the fact that I was completely reliant on the three gatekeepers for subject recruitment and was concerned at the onset that I might not get a broad spectrum of people representing different genders, class, educational levels, and ages. Despite these concerns, the approach taken did result in the sample of FCs being diverse in terms of age and relationships to the PwD. The sample of formal caregivers was equally diverse.

In terms of conducting interviews with PwDs it might also have been useful to integrate visual aides into interviews in order to facilitate PwDs' reminiscence of admission experiences. However, I believed that PwDs might not have benefited from this and besides this approach may have been unethical in placing further demands and challenges on these people. For instance, PwDs may have felt under pressure and increasingly confused during the interview due to their being disoriented to depicted persons and events. They may also have felt overburdened with the demand of verbally communicating about what was represented in pictures/photos. Due to a poor attention span they may also have been unable to meaningfully respond to pictures/photos. If I had opted to use personal photographs of each PwD-FC dyad as memory aides, other issues including taking pictures, clarifying copyright permission issues, and obtaining consent to using such pictures, might have imposed additional distress on caregivers and PwDs prior to data collection.

The option of videotaping PwDs and their caregivers during the SCU admission was also not pursued. I felt that in order to capture the whole process of relocating into SCU LTC I

would have to spend a significant amount of time with each FC-PwD dyad prior to the SCU admission and following the admission in the SCU environment. This approach would represent a significant invasion of PwDs' and FCs' privacy and add to the strain families were already under during the admission period. Due to the very short space of time within which families were notified about bed vacancies and had to make the placement decision (half a week) it was impossible for me to seek out these families and establish a trusting relationship with them prior to data collection. In addition, filming PwDs and their caregivers in SCUs after admission would require consent to being filmed from all persons (PwDs, families, SCU team members) remaining in the SCU because their right to privacy would be affected by conducting video-based research (Clark, Prosser, & Wiles, 2010).

4.8 Chapter summary

This chapter has highlighted the key research questions which are investigated in this thesis. Since this is an exploratory thesis designed to gain a better understanding of complex and intimate phenomena, an argument is forwarded in this chapter that a qualitative research strategy is most relevant for this thesis. This chapter has also outlined the structural model which is used to underpin the methodology, namely Crotty's (1998) structural approach. This was deemed most suitable on the basis of its relevance to the research topic and its four frames of reference (epistemology, theoretical perspective, research methodology, research methods). A constructionist epistemology was chosen because its key tenets were deemed most suitable for answering the research questions.

The chapter has shown how an inductive multiple case follow-up design was the chosen research methodology because it was deemed i) particularly suitable for exploring a novel research topic (such as admitting a relative with dementia into specialist LTC) and ii) most congruent with the chosen constructionist and phenomenological assumptions. This research design was also suitable for developing a comprehensive understanding of the

thesis topic through exploring individual experiences in-depth, comparing these across cases, and following participants' adapting to the new living situation over time (at three to four weeks post-admission and six months later).

A purposive sampling strategy was used and three different sets of inclusion criteria were devised to recruit three different groups of participants, namely, FCs, PwDs and SCU staff members. A total of nine FCs were recruited into the research, all of whom participated in both phase one and phase two interviews. A total of nine PwDs were recruited, eight of whom were interviewed at phase one (one refused to interact with me) and six at phase two (one had died before second interview, another refused to be interviewed, and one was no longer able to verbally communicate). A total of 12 staff members were recruited to participate in three FGs, one held per SCU.

This chapter has also outlined the approaches used to gain consent from PwDs, their FCs and SCU staff and the ethical principles I adhered to in conducting this thesis. The chapter has shown that data was analysed using IPA as it allowed for an in-depth exploration of a novel phenomenon such as admitting a relative with dementia into SCU LTC. IPA was used because it was iterative, and allows for an in-depth analysis of individual cases as well as across cases.

Chapter 5: The emotional and physical strain of dementia care in the period leading up to SCU placement

5.1 Introduction

This, the first of three findings chapters, reports findings on FCs' experiences of the time period leading up to the placement of their relatives with dementia in three different SCU settings in three different counties in Ireland. The chapter commences with a brief overview of the socio-demographic profile of these nine FCs, outlining their age, gender, occupation, living arrangements and other care and/or work roles that several of these people had. It then progresses to a discussion of the type of caregiving duties they had responsibility for in the period immediately prior to placement, the type of challenging behaviours they were expected to manage, and the community supports they received. Data is presented on the length of time these FCs had their relatives wait-listed for LTC and the additional strain wait-listing caused several of these people. The difficulties these FCs had trying to access more service support and fit their own routines in around the availability of service providers is highlighted.

The way in which respite care acted as an entrée into LTC is also outlined. All of the data reported on in this chapter was collected during the first in-depth interview with the FCs. Throughout the chapter an argument is marshalled that FCs were under enormous emotional and physical strain during the lead up to placement; key concerns centred around the safety of their relatives and the management of in some cases very complex challenging behaviours. In most cases FCs provided a level of care way beyond the call of duty with limited support from HSE health and social care services.

5.2 Socio-demographic characteristics of FCs

Table 2 summarises information on each of the nine FCs, their relationship to the PwD, age, the length of time they cared for the PwD in the community, their other work and caring commitments, and their living arrangements immediately prior to the relative's transfer to the SCU.

Table 2: Socio-demographic characteristics of FCs including work and care profile (N = 9)

NAME	RELATION-SHIP TO PwD	AGE (IN YEARS)	LENGTH OF TIME CARING	OTHER WORK/ CARING COMMITMENTS	LIVING ARRANGEMENTS OF FCs
Mrs. Ryan	Daughter-in-law cares for 81-year old mother-in-law who has VD and MMSE = 1 and 13[7]	53	6 years	Sales consultant (part-time) Also cares for 89-year old father-in-law who has a cardiac condition	Living with mother-in-law prior to placement
Mrs. McNamara	Daughter-in-law cares for 80-year old mother-in-law who has VD and MMSE = 14 and 22	51	3 and a half years	Housewife Also cares for own dying father prior to PwD's SCU transfer Also cares for a young daughter	Living apart from mother-in-law prior to placement but brings mother-in-law over to her home in the evenings to sleep over
Mrs. Philbin	Daughter-in-law cares for 85-year old mother-in-law who has VD and MMSE = / and /	37	2 and a half years	Housewife Also cares for two young daughters	Living apart from mother-in-law prior to placement. Relative was using residential respite and stayed in SCU entering permanent SCU from

[7] First number in bracket denotes PwD's MMSE score at phase one; second number denotes MMSE score at phase two (both scores obtained from SCU nursing and medical records). "/" means respective MMSE score was not available from PwD's SCU records. "0" means MMSE score is zero.

					respite
Ms McCourt	Daughter cares for 75-year old mother who has VD and MMSE = 10 and /	52	1 year	Employment Officer (full-time)	Living apart from mother. The latter was in hospital and entered permanent SCU placement from coronary care unit
Mrs. Forbes	Daughter cares for 77-year old mother who has AD and MMSE = / and /	50	10 years	Housewife Primary caregiver is PwD's 80-year old husband. Mrs. Forbes shares caring with her father	Living apart from mother prior to placement
Mr. Kiely	Husband cares for 81-year old wife who has AD and MMSE = / and 12	76	4 years	Retired from workforce. Takes anti-depressant medication	Living apart from wife prior to placement. Wife was resident in general nursing home prior to SCU placement
Mrs. Conor	Wife cares for 70 year old husband who has Parkin-son's disease and dementia and MMSE = 0 and /	57	3 years	On sick leave Takes anti-depressant medication	Living with husband prior to placement
Mrs. Breslin	Niece cares for 84-year old aunt who has Mixed Dementia and MMSE = 7 and 0	43	10 years	Self-employed (full-time) Also cares for own mother with dementia	Living with aunt prior to placement
Mr. Donohue	Nephew cares for 86-year old uncle who has AD and MMSE = 15 and /	56	3 years	Farmer (full-time) Primary caregiver is PwD's 78-year old sister-in-law Mr. Donohue	Living apart from uncle prior to placement

				shares caring with his mother	

Table 2 shows that seven of the nine FCs were women and two were men. Seven out of the nine FCs were primary caregivers and two whilst they did not consider themselves primary caregivers had been integrally involved in the placement process, satisfied the inclusion criteria and were therefore recruited to the study. Their mean age was 53 years (range 37-76). Three were daughters-in-law, all of whom had additional care roles, with two out of the three also caring for other ageing relatives with chronic health problems. Two were middle-aged daughter carers, one of whom worked full time. The two spouse carers neither of whom was in paid employment both suffered from depression and were on medication. One of these – Mrs. Conor had stopped work because of caring and was now on sick leave. The niece and nephew carer both worked full time, one ran a business and the other was a farmer. The niece also cared for her mother who had dementia.

The data therefore show that four of the nine participants were in paid work; and five had multiple care roles looking after other family members along with their relatives with dementia (three of these five cared for ageing family members with chronic health problems, and two minded young children). One of the five FCs, Mrs. McNamara, had two additional care-giving roles – she cared for her father and also parented her young daughter. The time spent caring for the PwD prior to admission ranged from one year to 10 years; the mean was five years.

Six of the nine FCs reported they lived apart from their relative prior to the SCU admission. In two cases the PwD had already moved into long-stay care (in one case a nursing home, and in the other a hospital) prior to SCU LTC admission. In two other cases, whilst the PwD was allegedly living alone, their carers (both daughters-in-law) stated they took their relatives to their own homes during the day or in the evenings. In one case the lady with dementia had her main meals (lunch, dinner) in the FC's house but

was transferred back to her own house at night where she also spent most of the day. In the other case, the lady spent nights in the FC's house but was transferred back to her own house during the day. Both of these women with dementia were widowed and lived alone. Both caregivers did not directly talk about the reasons why they decided not to live full-time with their respective mothers-in-law.

Only three caregivers interviewed reported that they lived permanently with the PwD prior to admission. Two of these had other extensive caregiving and work responsibilities. In fact, one of these ran her own business and looked after both her aunt with dementia and her own mother who also had dementia. The other lady, Mrs. Ryan, was caring for her father-in-law who had a cardiac condition; she also worked part-time. Overall, these findings show that most FCs were not caring exclusively for the PwD in the time period leading up to placement but had additional care and work roles which placed competing demands on their time and made caring for their relative with dementia extremely stressful.

Table 2 also shows that seven PwDs were women and two were men. Their mean age was 80 years (range 70-86). Completed MMSE scores were only available on three PwDs. One lady, Mrs. Ryan, whose phase one MMSE score was 1 (severe CI) had a MMSE score of 13 at phase two indicating moderate severity. No explanation was given by FCs or staff (in written documents) as to why her MMSE scores had improved. Another lady, Mrs. McNamara, had a MMSE score of 14 at phase one which increased to 22 at phase two, indicating a shift from moderate severity immediately after admission to mild severity at phase two. This lady had undergone a medication change immediately after placement which might be related to her cognitive improvement. The third person who had completed MMSEs at both phases had scores which reflected deterioration in cognitive status over time (MMSE was 7 at phase one and 0 at phase two).

As can be seen from Table 2 MMSE scores were not available for all residents and across both phases. In fact, MMSE scores were only available for six out of nine PwDs at phase one and four out of nine PwDs at phase two. This finding might point to the fact that six months after admission some PwDs had deteriorated to an extent where participation in a cognitive and memory test was no longer possible. Based on available MMSE data provided in Table 2 it may be assumed that PwDs had in general a severe dementia at phase one; four out of six had scores of 10 and below. Where available (N = 4) these had scores reflecting a moderate dementia at phase two (scores between 11 and 20 in N = 2). At phase two, however, scores also reflected a mild dementia (score of 22 in N = 1) and a severe dementia (score of 0 in N = 1).

5.3 Dementia care responsibilities prior to SCU admission

When asked about their home circumstances and precise caring duties prior to their relatives' SCU admission, FCs described in great detail what it was like for them looking after their relatives with moderate to severe dementia living at home. The tending tasks many of them were obliged to undertake included dressing, cooking, grocery shopping, toileting, showering, administering medications on time, laundering clothes, organising doctor and other appointments, and in some cases maintaining the PwD's house (doing repair works and house-cleaning). The majority (N = 7) claimed they regularly performed several of these tasks for their relatives in the period leading up to the SCU admission. It is important to point out that by and large, these tasks were done by both co-resident caregivers and those living apart. Having such care responsibilities along with working in the paid labour market and caring for other sick family members was often very difficult for some of these FCs:

> "It got really, really difficult at the end. She [Aoife] was always a very strong-willed independent sort of a person, and to be, you know, dealing with this person that she regarded still as a kid, that was, that was really hard. And you do worry that you lose it.

That's a huge concern, you know. You do worry that you'll be pushed over the edge" (Mrs. Breslin, niece caregiver, aged 43 years)

Apart from the aforementioned tending tasks one third (N = 3) discussed in-depth how their relatives' eating habits had deteriorated in the time period leading up to placement, to the point where they had lost significant amounts of weight and needed their food intake to be monitored. This sometimes resulted in caregivers having to coax their relatives to eat and monitor their food and beverage intake:

"She stopped eating which was a major issue (...). We couldn't get her to eat." (Mrs. Breslin, niece caregiver, aged 43 years)

"Her appetite was up and down." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)

"She ate with us, and I'd have to keep an eye on her constantly." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

In one case, trying to ensure that medication was given on time in accordance with medical advice placed additional strain on a daughter-in-law carer who was obliged to call to her relative's home every day at a certain time. This same carer was also looking after her own terminally ill father:

"A Zanex was to be given to her at four o'clock. So I made a point coming around ten to four every single day." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years)

It was not just the actual tending tasks that were problematic for these caregivers because of the dementia, but often their relatives were quite resistant to care and needed much encouragement and coaxing:

"If you thought that she needed the toilet trying to persuade her to go and then fixing her up and changing her clothes." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

"I was trying to get her to wash in my house and that was a non-starter. She just wouldn't do that for me [Pause]... in the early stages." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years)

"Cleanliness was a huge issue. But mostly it was that we couldn't convince her to do things. We couldn't get her to eat. We couldn't get her to sleep. She didn't want to go to bed. She didn't want her clothes changed." (Mrs Breslin, Niece caregiver aged 43 years).

A major theme that emerged from data analysis was the difficulties in particular FCs encountered attempting to deal with a variety of complex challenging behaviours associated with their relative's dementia. Behaviours talked about in particular included paranoia, agitation, hallucinations, wandering (including getting lost on the roads), and dangerous or potentially dangerous behaviour (including risk of scalding and setting houses on fire). Their narratives provided rich accounts of what it was like caring for someone exhibiting these types of behaviour:

"For the last number of years as well he used to go off, walk, and along the roads. He'd go, uh, maybe towards [the local village]. But he'd always come back. This went on for I'd say the last couple of years. But, uh, over the, over the, say, couple of months before he came in here he didn't come back a couple of times. I had to go looking for him. (...). In the kitchen now, at home you had to be watching out, like, in case he'd set fire to something or something like that or even burn himself. And also I'd scenes with him, like, there where he could, uhm, fill out, uh, maybe what he thought was tea, like, just, and, and he'd forget to put the tea bag in. He'd just put out the boiling water in, and if you weren't watching him like, he could maybe go to take a drink out of it."" (Mr. Donohue, nephew caregiver, aged 56 years)

"[One day we] went in [the PwD's house] and the place was full of smoke [due to the PwD overstuffing the fireplace], and you could hardly see her. She was sitting in the chair, and I'd run back out, I opened all the doors and run back out for her son. I said, 'Come in', while

my husband was turning in the car. I said, 'Come in, quick'. And the place was covered in smoke." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years

"I came in [the kitchen] one day, and she was walking around with the stool in one arm and a bread knife in the other." (Mrs. Breslin, niece caregiver, aged 43 years)

Other FCs reported they worried excessively about their relatives' abusive behaviour and in some few cases their potential to self-harm. Their accounts demonstrate how even when living apart FCs were under enormous pressure to oversee and monitor their relatives' behaviour:

"He'd been hurting himself and I just couldn't control him. I mean you are trying to make a cup of tea and he's at things (...). You were living on the nerves the whole time with him. It was very difficult." (Mrs. Conor, wife caregiver, aged 57 years)

"She was always hitting herself at home. She would hit her legs and they would bleed, and Mummy wouldn't leave the plasters on. If you put, put bandages on she wouldn't leave them on and she'd pick them off and then bleed again. And she would fall across things 'cause things weren't the way they are here. So I-I was always worried about Mummy at home." (Mrs. Forbes, daughter caregiver, aged 50 years)

Apart from dangerous or potentially dangerous behaviour, other challenging behaviours identified by FCs as being problematic included physical aggression, restlessness, sleep disturbance, and apathy. Accounts given by FCs of physical aggression, apathy and wandering with the added risk of some of these people getting lost outside the house were quite extraordinary and one was left wondering why these home care arrangements were allowed to continue for as long as they did:

"He would be kicking out at you. Maybe if he was at home he'd run straight out and kick the door of the press, you know, or throw things across the room. (...). I'd come home terrified in case he was after hitting you with something because he was getting very aggressive." (Mrs. Conor, wife caregiver, aged 57 years)

"At the time [immediately prior to admission] she [Pause] was being [Pause] nearly vegetable, I would think. She was doing nothing in the house. She was unable to, uh, think, uhm, she was sitting in the chair all day looking at the fire." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years)

"The humours, I'd nearly be afraid of her. She might turn around and hit me if I tried to stop her from going, you know. Our neighbours picked her from the road a few times [laughs], bringing her back." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

Sleep disturbance was not uncommon for these PwDs. One FC who whilst living apart always had her mother-in-law sleep over at her home gave a very chilling account of how home care clearly disrupted normal family life and resulted in her young daughter sometimes being awoken at night and her having to become involved in elder care:

"She'd be up at four or five o'clock in the morning, and what we were having was that, uh, she'd come in to the bedroom to us (...). She'd wake my [10-year-old] daughter and she'd say 'why aren't you up for school?' And my daughter would say 'Nanny, it's only four o'clock in the morning' or 'it's only five o'clock' or whatever. And she would say 'oh, sorry' and go back. And she could sit in the kitchen. Now I get up. I'd hear what's going on. I'm a light sleeper, and I'd get up and I'd say 'do go back to bed. [Pause]. It's in the middle of the night.'" (Mrs. McNamara, daughter-in-law caregiver, aged 51 years)

Other FCs talked about unusual and sometimes obsessive compulsive behaviours now adopted by their relatives as a result of the dementia. For instance, Mrs. McNamara talked about her mother-in-law's obsession with stacking up the fire at home:

"The only thing she was doing at the time was putting more and more and more turf and briquets into the fire [Pause]. Now, she had a little tube that we filled with briquets, an old-fashioned thing that, uh, would just have her hot water. It only heated the room she was in and, uh, her whole preoccupation was to stuff it with briquets. She [sighs] wouldn't turn on

the television. She wouldn't read, she wouldn't, uhm, have the radio on." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years)

Apart from dangerous or potentially dangerous and aggressive behaviour, and sleep disturbance, the challenge of dealing with incontinence was also highlighted by several as being particularly distressing, since it often resulted in hard physical work - cleaning up after episodes of incontinence, having to shower and clean a relative, washing clothes and cleaning furniture; and sometimes dealing with incontinence in the middle of the night:

"She had started to get incontinent. Going to the toilet was a big issue. So we found that the most trying because, uhm, especially her number two, you know, not, not the number one, number two because she couldn't push, ok. So in that way she got very agitated 'cause she didn't know what to do with the toilet. So we found that was the biggest issue, in the toilet, and then she might wake up then after soiling, you know, the content of the toilet. (...). That makes it worse 'cause you'd be changing bed clothes at three or four o'clock in the morning." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)

"When I'd go over in the morning I used to have to just try and get her into the shower and try and wash her and it was very bad and all the smell and it was terrible, just like a baby looking after her, so that's how bad it was." (Mrs. Forbes, daughter caregiver, aged 50 years)

The qualitative data demonstrate very powerfully the type of care-giving duties these FCs undertook immediately prior to their relative's placement. As the data show, FCs had to support their relatives who had high dependency needs; they had to deal with very serious challenging behaviours. Most were providing care around the clock, monitoring and supervising their relative. A third were also caring for other family members each of whom had age-related health problems; four carers also worked in the paid labour market whilst caring, and another two had child care responsibilities.

Behaviours identified by them that caused them much stress included dangerous or potentially dangerous behaviour, physical aggression, unusual behaviour, incontinence, and sleep disturbance. Coping with these behaviours - especially dangerous behaviour such as self-injuries and accidents, harming others, and causing fire hazards and other such damage to properties and to themselves - was reported as most difficult to manage and very distressing.

Some participants during the interviews talked about having to be constantly on the alert monitoring their relative's activities inside and outside the house. They also reported how they had ongoing worries about their relative's physical health and safety. Indeed, in one extreme case a FC talked about having to resort to locking her mother-in-law in her own house at night such was her concern about this lady's safety:

> "It got to the stage where we were so worried that we actually put a lock on the door that we kept the key, and all we could do was locking her in and then at least you'd know she is contained in the house." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

The literature talks about informal caregivers who are "engulfed" (Twigg and Atkins, 1994) and who cannot see outside or beyond the caring role, such is their level of feeling trapped and consumed by caregiving. Certainly the narratives of these nine caregivers demonstrate how many may have been engulfed in caring due to its excessive, all-consuming and relentless demands:

> "I had it all day. I had the, the stress of her, the worry, the wandering, the feeding, the constant care, the toileting, the, you know. When I look back on it I don't know how we managed (laughs)." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)
>
> "We were reeling only. Everything was kind of a progression. (...). I was really at my wits' end in trying to get her minded during the day." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years)

"It was a constant worry, like, and, uh, you know, over the last few months before he came in. (...). I was, I think, under, I probably didn't even know I was under stress we had, like, but now looking at, like, since he got in I know I was under stress, you know, concerned about it like, and, uhm, you know, it's never it never, you know, it's never out of your mind, really, for, for much of the time, like, you know. It's always there at the back." (Mr. Donohue, nephew caregiver, aged 56 years)

A niece caregiver who ran her own business and also looked after both her mother with dementia and aunt, both of whom lived with herself and her husband, referred to the almost impossible workload she was undertaking:

"When you're in a situation you don't realise how incredibly crazy it is, you know. My day would start at whatever time Aoife woke up and put her feet on the floor and set off the mat. And then my alarm would go off at half five and I'd go and check on Mum and make her tea and toast and have a chat and whatever, because she only sleeps in three-, four-hour groups. And then the alarm'd probably go off again, just after I got back into bed, and that'll be my husband's turn to go and then I'd get up at half eight and start the day, do everybody's breakfast and all the rest of it. And when, when you go through your day, when you tell somebody else about it that's when you realise, wait a minute now, this is insane. If somebody else was telling me what, what I do I'd think they were nuts." (Mrs. Breslin, niece caregiver, aged 43 years)

The data also show the way in which dementia is not a one-person illness but adversely affects other family members including adult children, grand-children and older spouses. Two younger carers spoke about how distressing this time period was for their parents and parents-in-law:

"We knew Daddy had reached the end for himself. He wasn't able to take [care] of her any longer." (Mrs. Forbes, daughter caregiver, aged 50 years)

"We were trying to keep the two of them (the PwD and her husband) together for as long as we could. But then, uh, we decided then when she was in [name of generic respite care

> ward] the last time we had to look at long-term because it was getting too much on all the family." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)

There were two cases where the PwD was already in a residential setting immediately prior to the SCU placement. In one of these cases the PwD had been placed in a general nursing home for six months. In the other case, the lady with dementia had been admitted to a hospital coronary care ward for two months leading up to her SCU placement. Whilst one might assume that these caregivers might have had an easier time in the period leading up to their relatives' SCU placement this was clearly not the case. Both caregivers complained at length about the quality of care their relatives experienced. They talked about what they perceived as neglect and the sub-optimal care their relatives received from untrained staff in these two settings.

The daughter whose mother had been in a coronary care unit (CCU) talked about the lack of attention paid to supervising her mother's dietary and food intake and the fact that supervision in the hospital was so bad that on one occasion her mother actually left the hospital grounds and took off on her own:

> "In the hospital they'd say 'You haven't downed your bread today' or 'You haven't [done] this today, and if she said 'No' – and she often said 'No' – they just walked by. There was nobody there to make sure she'd eat a meal or would she eat right. (...). [She] actually did pack her bag one day and walk out. She got a taxi back to her own place in [name of urban district], and they rang me, looking for me, d'you know, did I, did I know where she was? And I couldn't believe it." (Ms McCourt, daughter caregiver, aged 52 years)

Like this daughter carer, the husband carer whose wife had spent six months in a general nursing home was also very dissatisfied with the quality of care received there. He talked about the way physical and chemical restraints were used inappropriately. He said that after she was admitted she was taken off the anti-dementia drugs and put on Valium and was also strapped into a chair. He also said that his wife was exposed to pop music

(karaoke) and a foreign language being spoken by non-national staff in front of her and other nursing home residents:

> "When she was in the nursing home, they took her off her tablets which she was on for the past about three years (...). That [medication] was controlling her Alzheimer's and helping her to eat (...). So they took her off that and put her on, on Valium, which drove her crazy. (...). I mean I was probably going a little mental as well when I saw her restrained - with two-, with two restrainers, not one but two. The staff were all Philippinos, and they talked a lot among themselves in their own language. And so they did endure talking in front of the patients. So they (the residents) didn't know what they were talking about. And on a Sunday they would have a karaoke and they (the staff) played all the songs that they wanted listen to. (...). These eighty and ninety year olds they wouldn't know whoever they were." (Mr. Kiely, husband caregiver, aged 76 years)

The findings about the bad experience the lady with dementia had in hospital may not be surprising given (in the context of dementia care) the alleged inappropriateness of hospitals (Anderson et al., 2005; Cowdell, 2010; Dewing, 2001; Nolan, 2007). It is interesting that both caregivers here claimed that they felt powerless and distressed about such inadequate formal care practices. In particular, the husband carer felt very distressed by being silenced and feeling unable to complain or report his concerns about poor practices lest this might mean his having to take his wife home again. During the interview he described in detail his wife's frustration with being strapped to a chair and her efforts to set herself free:

> "[My wife did] this [Mr. Kiely makes a gesture of snipping scissors], kind of 'Cut the restraints' all day [trying to cut the belt tying her to the chair]. It was heart-breaking [sighs]. I should not have let it happen. (...). But you see what was going to happen was if we had complained they would have told us 'Take her home'. But that's something we couldn't, something we just couldn't, no, we couldn't take her home. And then we couldn't get her anywhere else in. So we had to put up with it." (Mr. Kiely, husband caregiver, aged 76 years)

Both of these carers claimed that communication between staff and family members (hospital, nursing home) was very limited and that they were given inadequate information about their relative's care and care-related decisions - information which they believed was their right:

> "They were very bad at communicating to us any tests they had done with my mother. (...). They did a test with her, say, in the middle of December. We didn't get that, the results of that until she was being transferred to here, you know. We got, they were very, very bad and there was no communication among themselves, among the staff in the hospital, really, really bad, really bad. (...). As I said she was in the wrong unit in __ Hospital, and they had cardiac care patients. So I can understand the point but at the same time I don't know why they left her in that particular part of the hospital for two months." (Ms McCourt, daughter caregiver, aged 52 years)

And the husband caregiver referring to taking his wife off the anti-dementia drugs said:

> "I don't know why, I don't why they did all that [putting Mrs. Kiely on Valium tablets]." (Mr. Kiely, husband caregiver, aged 76 years)

To summarise this section of the chapter overall these findings show the high levels of emotional and physical strain FCs experienced during the time leading up to their relative's SCU placement. Caring for a person with moderate to severe dementia including challenging behaviours required huge input from family members; it required skills and knowledge of how best to handle complex situations. In short, often the level of care required was beyond the capacity of these people, many of whom had additional work and family care commitments. Dementia care was extremely stressful and left many of them feeling emotionally drained. Most carers were worried about their relative's health and safety. Even in the two cases where relatives had been placed in residential settings prior to their SCU admission, both caregivers were distressed by the inadequate and unethical care provided to their loved ones including the use of restraints, provision of inadequate activities, and inadequate monitoring of the PwD's physical well-being. Both FCs felt

helpless and disempowered to alter these formal care practices. They also felt excluded from involvement in their relative's care and complained about the poor communication channels between staff and families.

5.4 Experience of using community care services

During the in-depth interviews, participants were also asked about what community care services they used during the period leading up to their relatives' placement in the SCUs. Findings show that those whose relative lived at home used at least one and in some cases several different community care services prior to placement. Support services used included home help (N = 6), in-home respite (N = 5), home care packages (N = 1), day respite care (N = 7), and residential respite care (N = 7). Other formal supports used included educational and information services provided by local Alzheimer Society of Ireland (ASI) groups. In response to questions about which services were deemed particularly helpful to caregivers, data showed that residential respite care was regarded by several as a particularly supportive service. It was beneficial in that it enabled families to continue caring for their relative at home. In most cases (N = 6), this respite care took place in the same setting as where the PwD was ultimately going to be placed long term.

The majority of participants said they found service providers very competent in dealing with the needs and the challenging behaviours of their relative with dementia. A few FCs described the information and education services provided by their local ASI as being accessible, hands-on, and highly relevant to care-related issues. Two daughter-in-law carers praised the ASI services and commented on how such information/educational support helped them and other family members:

> "I went to a few talks, you know, in the [name of a local pub] and I found them very good. (...). It helped you 'cause you'd meet other people with family that had, that had, that had Alzheimer's, and I found that great. And Daddy went to them as well, every one of them he went to. (...). He found that very good." (Mrs. Forbes, daughter caregiver, aged 50 years)

One of these carers was also complimentary about the practical hands-on support delivered by the ASI - services she believed she could rely on:

> "We had girls coming from the Alzheimer's to, to the house. So I mean if we, if it got too much for us at anytime I just had to lift the phone. [Name of ASI case worker] is 'cross the way here who is, who would be with the Alzheimer's, and she was just brilliant." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)

Findings also showed that these same community-based HSPs along with SCU staff (where residential respite was being used) also played a key role in helping FCs access the permanent bed in the SCUs. This was done by their being made aware of the location of SCUs and of protocols for wait-listing. Indeed, most participants stated that their access to SCUs had been facilitated by community-based service providers including PHNs, (generic) day care staff, (generic) residential respite care staff, ASI case workers, district nurses, community nurses, and GPs. The data showed that often these same service providers had recommended the SCUs as improved environments for the PwD. They had also on behalf of the families liaised with SCU staff arranging assessment and respite care admissions. They were the first to mediate contacts between SCU staff, FCs, and PwDs as illustrated by these two quotes:

> "SCU A would have come to our being when we were looking for our first time, looking for respite care. And, uh, it would have been through the Public Health Nurse who would organise. And they introduced us to SCU A." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)
>
> "It [SCU respite care] was suggested by [name of ASI case worker] who'd be the, over in the Alzheimer's, so only for that we wouldn't know." (Mrs. Forbes, daughter caregiver, aged 50 years)

Despite the fact that these caregivers used HSE services and in several cases received support from the ASI along with residential respite, several complained about the limited

amount of service supports they received given the level of care they were expected to provide. For example, it was argued by several that in-home services such as home help, in-home respite, day care, and information and education services were only provided intermittently (for a limited number of hours on certain days) and services were not always tailored to address caregivers' needs. In fact, a third of the sample claimed they were obliged to adapt their own schedules to fit in with the availability of their in-home help and respite service providers. These participants complained that service support was very patchy and inadequate.

As mentioned earlier, several of these carers were essentially running two houses. A young carer with two small children talked about the difficulties she experienced trying to co-ordinate care when there was no consistency with regard to when services would be offered. According to her, it seems that service providers chose the time and day to visit that suited their schedules and not the carer's:

> "We got a care worker. So she was in for an hour and a half every day, depending on the day it was a different hour, and, like, it could have been two to half four. It could have been one to half two, things like that. So I tried to work it, especially just before Granny moved in here I tried to work it that I was covered for my children coming in from school." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

Others spoke explicitly about the major gaps in service support they experienced during this time period:

> "We still would have had the [home help] carers kind of coming in for a couple of hours a day. But you still had good gaps there, you know, that she would have needed to be looked after." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)
>
> "I got two hours home help a week. But you know, like, it was more for the company than anything else [laughs], yeah, somebody to call in and talk [laughs]." (Mrs. Conor, wife caregiver, aged 57 years)

Attempting to mobilise community support services was not easy for some. Several had their names placed on lengthy wait-lists and had the additional trouble of lobbying and advocating for more service assistance. The accounts given by these FCs showed that battles had to be fought before service supports were granted even to carers who had multiple care roles. For example, a daughter-in-law also caring for her own father who had a terminal cancer, talked about how she had to fight and repeatedly ask to get a home help for her mother-in-law. She said:

> "We asked the Public Health Nurse could we get somebody in to give her a bath because she didn't want me doing it. (...). We were a long time waiting for that service, uh, it was granted and passed that a woman would come in, uh, for two hours on a Wednesday. When it was due, the day wasn't actually figured out at that time. But I had to keep going and going and going to the Public Health Nurse and I spent I think for two weeks I would have been in every morning, and there was [laughs briefly], you know, all the girls not on or 'oh she is off on her own', 'she's dealing with that', and 'oh I can't deal with it' and all this sort of bureaucracy, and I think they got fed up looking at me. (...). So, uhm [Pause] that turning had come after a lot of, of wrangling." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years)

In another case a FC resorted to using private home help which in itself placed additional strain on her as she felt obliged to clean the house before the home help arrived. During the interview she reported how she felt uncomfortable having strangers staying in her family house and minding her aunt with dementia. This same carer worked in a family business and apart from caring for her aunt also cared for her own mother with dementia. In talking about the pressures involved in using in-home workers, she explained:

> "We tried the, the [name of home help organisation] thing, you know, the leased people you hire in. But if strangers are wandering around your house after a certain point it's just a bit creepy, and I even started cleaning the house before they're coming, uh [sighs], you know." (Mrs. Breslin, niece caregiver, aged 43 years)

5.5 Absence of elective or emergency SCU residential respite care

During the in-depth interviews, several FCs spoke about the support offered to them by SCU staff during the time period leading up to their relatives' SCU admission. Five of the seven community-based FCs reported that SCU staff were very aware of the type of stresses they were being subjected to and stated that there were times when SCU staff attempted to offer these families extra day care or residential care. A number spoke at length about the real benefit of respite care in terms of giving them much-needed breaks:

> "They were very good to me in that way. They realised how bad my husband was getting. So, uhm, they gave me plenty of respite." (Mrs. Conor, wife caregiver, aged 57 years)
>
> "The unit were very good in that, uhm, [Pause]. My mother-in-law was in when my dad died and, uhm, they offered to keep her, uh, an extra week" (Mrs. McNamara, daughter-in-law caregiver, aged 53 years)
>
> "We had a wedding, a family wedding and we did not know what to do with his Mum. So we decided we would avail of the respite. It was the first time she came in. She was due in for a week. They had a second week available. We took it." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

Two other carers provided accounts of situations where SCU staff was proactive in their initiating contact with FCs and offering them respite care. One of these said:

> "The first time I was invited in to join the hand massage and have a cup of tea with other carers. And it was the worst possible day that she could arrange. I, Mum was having one of her, her peculiar days (...). Everybody was out to get her, and I was poisoning her, all this sort of thing. It was going to be an extremely busy weekend in the shop, and I had to get set up for that, and here was somebody inviting me for a hand massage, and I just felt like 'Where am I, seriously, lady?', you know. If I had time for that sort of thing now I would be doing very, very well. But, uhm, I-I think something in my voice, uh, gave Francis [SCU A's Clinical Nurse Specialist] the hint that I was falling off the edge of the world a little bit, and I

had a call a few days later saying there was a, a few days, uhm, available, and would I like it." (Mrs. Breslin, niece caregiver, aged 43 years)

Analysis of data show that seven of the nine FCs who were providing home care immediately prior to SCU placement used residential respite care and all but one of these used respite in the same SCU setting where their relative was ultimately placed long term. All six FCs stated unequivocally that the SCU-based residential respite care was by far the most important support they used at this stage. Data also show how respite benefited other family members:

"She also used to come in here for a week of respite. (...). That gave Daddy a break. Oh, it was very, very good." (Mrs. Forbes, daughter caregiver, aged 50 years)

"First of all they were taking him for a week, you see, because my mum was finding it difficult. So we kind of needed some kind of assistance we felt and, you know, she, she was under stress." (Mr. Donohue, nephew caregiver, aged 56 years)

"It really took the pressure off, knowing there was hope of respite, knowing that, you know, in a couple of weeks' time I'd get a night's sleep, oh, that was a big one. So even, even the hope of respite is actually respite in itself." (Mrs. Breslin, niece caregiver, aged 43 years)

Data analysis shows much variability in the timeframe people had been using residential respite care services during the period prior to long-term placement. The longest period of time residential respite had been used was over a five-year period, and the shortest was over a six-month period.

During the interviews carers talked about the value of respite care from the point of view of enabling FCs to have breaks from the hard, relentless chore of full-time care-giving and how the service facilitated them to care at home for longer:

"All of those services are absolutely brilliant because they are there you are able to keep them at home that little bit longer." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)

For those with multiple care roles respite was especially valued:

> "In the early stage it was a total relief because I was minding my dad as well. (...). Dad had cancer and, uh, I'm the nearest and, uh, I was bringing him for his check-ups, bringing him for, uhm, [Pause] to the doctor appointments because we, we knew he was ill. Uh, but we didn't get the diagnosis that he was actually, that nothing can, could be done until, uh, April. But before that he was progressively getting worse. Now I was juggling between Olivia [and] Daddy, and, uhm, when she went in [for SCU respite care] and he would be really the first who said it 'oh that's a great relief for you'. And it was." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years)

In fact, the benefits of residential respite care for some were even evident in improvements noted in the PwD's overall health and well-being:

> "If she had two weeks in here then she came back a new woman. She was rejuvenated, she had had sleep and physiotherapy, and her nails were done, and her hair was done, and, you know, the little things that make such a huge, huge difference." (Mrs. Breslin, niece caregiver, aged 43 years)

Using residential respite at the same setting where staff had built up a rapport with the person and where both residents and carers were familiar with staff and the setting was also important:

> "She probably doesn't know that she knows it but she's been here so often. She knows that they know her in there, all the staff seem to know her so well. And, you know, I, the way it just happened that I thought, well, this is the best thing for her, you know? She is in the right place. She's well cared for, they all know what to expect of her, they know her humours." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)
>
> "Whenever there was a week [of residential respite care] here we took it. Yeah. And that was very good for Mummy because she got used to the surroundings and she got gradually used to being out of the house." (Mrs. Forbes, daughter caregiver, aged 50 years)

"I've kind of got to know them, like, since we'd kind of, you know, had been coming in for the week's respite, and, uh, so it was easy enough, like, you know, because, I think, he'd been in and I think, four or five times on respite, like, before that. (...). I knew exactly where he was going and, you know, what it's gonna be like, yeah." (Mr. Donohue, nephew caregiver, aged 56 years)

However, data show that respite beds were not always available on demand and often carers considered themselves lucky when offered breaks:

"I was lucky. Sometimes I would just get a few days and sometimes I'd be able to book in advance. Like, I was able to get a couple of weeks before Christmas because with the shop and everything that's a really busy time." (Mrs. Breslin, niece caregiver, aged 43 years)

"The Alzheimer's have a [respite] bed here [in SCU C] and Mummy used to get it whenever it was available." (Mrs. Forbes, daughter caregiver, aged 50 years)

In one unusual case the FC stated that she had only once been successful in securing respite for her relative at the SCU, and that on all other occasions respite was provided in more generic settings which were not as satisfactory:

"After that [PwD's first and only residential respite stay in SCU A], uhm, the respite care came up in, in [name of generic respite ward] 'cause she wouldn't always have a bed. I think there is only one respite bed here. So when, when we'd be looking at for respite care or when the respite care came up it would have, it was, after that it was in [name of generic respite ward]." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)

Overall, the data show the way in which residential respite care helped families cope with the relentless around-the-clock labour of dementia care. Respite provided them with much-needed breaks and they felt secure knowing their loved ones were safe and being cared for by professional staff. It enabled FCs get on with life, sometimes allowing them

time for other caring duties. The data show that the benefits of respite often extended to other family members including older spouses.

5.6 Distress of waiting for a SCU LTC bed

The first part of this chapter discussed the type of emotional and physical strain caregivers were experiencing because of the very high level of care their relatives required. Many of these people had severe dementia and exhibited multiple challenging behaviours. Many needed close and regular supervision as they would otherwise have been at risk or indeed may have placed other peoples' lives at risk. The data shows that whilst community services were used by most, in general these supports were limited and were often provided at times which suited the service providers rather than the carer. Answers to other questions posed during the first in-depth interview with FCs show the additional sources of strain they were subjected to. One such strain was wait-listing a loved one for SCU placement and having no knowledge as to when exactly a bed would become available. The next section reports FCs' accounts of this phenomenon.

In response to a specific question asked about wait-listing all of the nine FCs had their relatives' names wait-listed for LTC, but most felt powerless in terms of accessing a permanent bed. Indeed, data show that some were quite desperate for a permanent bed and would have gone to any lengths to secure their relative's speedy admission into the SCU. Analysis of data showed that waiting times varied from between two to twenty-four months; with most caregivers waiting between two to six months. Not knowing when a bed would become available and being worried that they might never get their relative successfully placed was not uncommon. Some of these carers' accounts of the discussions they had with SCU staff and their own attempts to speed up the process of getting their relative into LTC show the type of additional strain they were experiencing around this time:

"I said we needed [a LTC bed], like, you know, that my mum is no longer able to cope, you know, and they said there's just no permanent bed available, and I have to wait, you know. At that time it seemed a long time." (Mr. Donohue, nephew caregiver, aged 56 years)

"When did we put her name down [for SCU LTC placement]? I honestly cannot remember (...). Probably in hindsight she wasn't that long. It just felt like [laughs]. It probably was only a couple of months, you know." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

Interestingly, and in terms of wait-listing, six caregivers said that they would never consider placing their relative in any alternate long-stay facility besides the SCU which by now was familiar to them through respite care:

"The only place we were interested in was here. We, we would have, uh, possibly held out under the, the respite care for as long as we could do it. But ideally we wanted her here." (Mrs. McNamara, daughter-in-law caregiver, aged 53 years)

"We wanted this here, and we would have kept her. Ye don't, this is a situation where do not take second best. You-you really, you can't, this is her life, this is where she will, this is her home, it's not a home, it's home, and you always want to go for the best. So it was us or here. There was no plan C." (Mrs. Breslin, niece caregiver, aged 43 years)

"She hadn't been on the waiting list for [other nursing homes], uh, we hadn't gone down that route at all because we we're just hoping that, you know, because she was so familiar with here, you know, with [name of town] and with [name of generic respite ward]." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)

In the lead-up to placement, some participants described how they were obliged to repeatedly ring SCU staff reminding them about their very difficult home circumstances and questioning them about bed availability. Despite their urgent needs, few FCs liaised with community-based HSPs or used HSE staff to lobby for their cases in order to accelerate their relative's placement. The extreme levels of pressure and distress

associated with waiting for a SCU bed and the need for family members to keep the pressure up was well illustrated by some:

> "I remember phoning, uhm, [name of matron], the matron and him saying they were full and really I'd just have to wait. 'I have her on the waiting list and there's no more we can do', and I remember phoning him again another day. I had a bad day at home. I rang him and I said 'is there any news yet?' And I felt so bad about doing that. But I was so stressed." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)
>
> "When I heard she got here, when the, when the girl rang me in the Health Board, she rang me and I was absolutely delighted 'cause I had that poor girl pressed very hard and I had annoyed a lot of people to get it [the SCU LTC bed]." (Mr. Kiely, husband caregiver, aged 76 years)

The rich and detailed qualitative data collected from these FCs show very clearly the type of difficulties these people experienced in the time period leading up to the placement of their relatives in LTC.

5.7 Chapter summary

Findings reported in this chapter demonstrate the hard physical and emotional labour of dementia care and the type of tending duties carers undertook both within their own homes and at a distance and the type of anxieties and stresses they experienced in the time period leading up to the placement of their relatives in LTC. In particular, findings show the difficulties many FCs encountered trying to manage dementia-related challenging behaviours such as aggression, incontinence, sleep disturbance and dangerous behaviours, and the way in which dementia care often involved around-the-clock labour and affected other family members not merely the FCs.

Whilst as the data show, most carers were using some HSE community care support, findings show that the level of assistance available to them was inadequate and the timing of services was often based on service providers' availability and not on caregivers' needs. Findings also show that in a small minority of cases where PwDs were placed in hospitals or general nursing homes prior to SCU admission, the care received there was far from ideal.

The data show that services used most often by them were home-helps and in-home respite services. According to FCs, community-based service providers played a key role in helping them access SCUs. However, FCs complained about the sporadic provision of these services, which often were not effective in relieving FCs from their care-giving strain.

Data analysis shows that six out of the nine FCs involved in this research regularly used respite care in the SCUs where their relatives were finally placed. These carers talked about the supports provided to them by SCU staff immediately prior to LTC placement. FCs commended the extremely supportive stance of SCU staff members who in many cases went out of their way to accommodate FCs' individual needs. Residential respite was described by FCs as the most important support available to them prior to placement because it provided much-needed breaks from their relentless care duties. However, FCs complained about the fact that a SCU residential respite bed was not provided to them according to their needs but based on bed availability and wait-list status.

The qualitative data also shows that the uncertainty of not knowing when a permanent bed would become available to these FCs acted as another stressor for many of these already exhausted FCs. Wait-listing peoples' names did not guarantee SCU admission and no information was provided on how long people would be wait-listed. Each had to wait for an indefinite period of time and this waiting period was very stressful for FCs,

leaving them feeling worried about their relative's future care and failing to provide relief from their care-giving distress.

These findings point to the need for a much more realistic level of support to be made available to families where a relative has dementia and is wait-listed for LTC. In particular, a lot more support should be available to caregivers with multiple care roles and those who work and provide full-time dementia care. There is a need for better information to be communicated to FCs about wait-listing processes. It seems that many carers believed that once wait-listed, a permanent bed would be imminent in the very near future whereas this was rarely the case.

The data show that SCU respite care was found to be a vital support service for families during the time leading up to their relative's LTC placement. Various reasons were given by FCs for considering SCU residential respite care as a central support but a key reason was the fact that residential respite care eased the burden of care and enabled them to take much-needed temporary breaks from caring. However, this specialist service was considered difficult to access, with families being wait-listed and not being able to avail of these services on demand.

The data are in accordance with findings from the literature which show that providing care to someone with moderate to advanced dementia is hugely demanding (Kellett, 1999; Ryan & Scullion, 2000; Twigg & Atkin, 1994). Caring can have a profound negative impact on family life and can adversely affect not only the carer but other family members as well. The carers in this thesis received inadequate support from the state by way of community-based services.

There is a need for more community care services to be developed which are designed around carers' own needs. In the context of dementia care, the caring tasks that appeared most difficult for this group of participants included dealing with safety issues,

incontinence and personal hygiene care, coping with dangerous behaviours, and dealing with resistive and aggressive behaviours shown by the person. The data suggest that there is a need for a great deal more counselling services in the community to deal with the emotional aspects of caring. There is a need for more practical physical help such as home help to provide ongoing support with particular care responsibilities such as incontinence care; and case managers who liaise with HSPs and manage the person's timely and smooth admission into SCU LTC on behalf of the family.

Had these family members had more dementia-specific training and had they known more about dementia, the impact of the environment, and the diverse factors contributing to challenging behaviours, they may have been better equipped to handle day-to-day situations. As it was, they coped as best as they could, sometimes silenced from complaining and sometimes living in fear of what they were to confront the next day. The data show very powerfully the pervasive impact dementia has on family life. The next chapter goes on to discuss FCs' experiences of making the decision to place their relative into SCU LTC, their reasons for making this decision, and how they communicated news of the decision to their relative with dementia. The next chapter will also discuss how SCU staff decided about and coped with new LTC admissions.

Chapter 6: Making and communicating decisions about SCU placement – FCs' and staff perspectives

6.1 Introduction

This chapter reports data derived from in-depth interviews with nine FCs on the reasons why they placed their relatives with dementia in SCUs and on how information about transfer into LTC was communicated to these PwDs. In addition, data emerging from three FGs held with 12 SCU staff members from across three different SCUs is presented. These FGs were held to elicit information from staff members about their respective SCU assessment and admission policies (including admission criteria), and how these front-line and managerial staff actually managed these new admissions. The chapter follows up on a theme introduced in the last chapter, namely, the role of respite care as an entrée into LTC and the role of wait-listing in admission protocols. It provides new insights into some of the stresses and dilemmas confronting HSPs along with FCs responsible for making decisions about new admissions.

6.2 Experiences of FCs

The last chapter reported on some of the caring arrangements these family members found themselves in, trying to provide extremely high levels of care to their relatives diagnosed with moderate to severe dementia. The nine FCs got limited support and cared for ageing relatives with complex dependency needs and in some cases with very serious challenging behaviours, which endangered their own as well as their carers' health and safety. The data was powerful in highlighting the level of strain these carers were subjected to irrespective of whether they cohabited or were living apart from their relative with dementia. Some of the major problems highlighted included having to deal with their

relative's needs for around-the-clock assistance with basic ADLs (such as washing, grooming, toileting, and eating) and IADLs (such as taking medication, cooking, shopping for groceries, and house-cleaning), safety monitoring inside and outside the home, and managing physically violent or agitated behaviours (see Chapter 5). The next section will highlight the key reasons forwarded by them as to why they discontinued home care and placed their relatives in SCUs.

6.2.1 Inappropriateness of informal care

When questioned in-depth about the main reasons why their relative had been placed in the SCU, most participants stated that in their view home care was no longer viable. They talked at length about the physical features of the domestic dwelling where their relative was being cared for and about issues such as stairs that could no longer be negotiated, bedrooms no longer accessible, bathrooms that were so small that the person became agitated and resistant to showering and toileting, and other such features which had the potential to result in accidents or falls.

The inappropriateness of normal domestic homes not adapted for a PwD and the way in which people's safety needs were compromised were well illustrated in several of the narratives:

> "The major reason [for SCU placement] was fear about the stairs. That was the big one. We, we would have worked with it, we would have gotten carers in, we would have done anything. It was three flights of stairs in a big old Victorian-style house. (...). And also we don't have the facilities, you know, we've, it's a big old house with the world's smallest bathroom, barely room for two of us in it, and dealing with, with the, uh, diaper changes." (Mrs. Breslin, niece caregiver, aged 43 years)

> "That's another thing we weren't happy about: the way her house is laid out. She lived in the downstairs of it. Now it's, it was newly built. (...). There are two bedrooms upstairs. But she never actually slept upstairs. She had her sitting room, kitchen, bathroom and

bedroom all in one area downstairs. So we would have to sleep upstairs. And she could be gone out the door and nobody would know." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

"His bed was upstairs all the time. And he didn't want to move down, uhm, and I can remember a few times, uh, uhm, Mum would lock the back door, uhm, if she went out somewhere and he'd get out through a window. He still wouldn't hold on, like, you know, and we were afraid as well that some night he could think he was on the ground floor and go through the window upstairs." (Mr. Donohue, nephew caregiver, aged 56 years)

"At home Daddy had an open fire as well, and a range, and it was dangerous for Mummy, you know. You couldn't, you just couldn't, you had to watch her all the time." (Mrs. Forbes, daughter caregiver, aged 50 years)

"He could slip on the [bathroom] floor and break his hip or something (...) falling on the floor and hurting himself." (Mrs. Conor, wife caregiver, aged 57 years)

The data here provide powerful examples of some of the real challenges caring for people with severe dementia at home poses and how an environment not adapted for dementia care could be hazardous.

6.2.2 Inappropriateness of nursing home and hospital environment

However, it was not just domestic dwellings that by virtue of not being adapted for dementia put the health and well-being of both PwDs and FCs at risk. As shown in the previous chapter, there were two cases where the PwD had already been admitted to a hospital or nursing home before the SCU admission[8] and both caregivers were very dissatisfied with the care received by their relatives in both these settings. Both caregivers

[8] Mrs. Kiely was in a general nursing home for six months before moving to the SCU. Ms Sheehan was in an acute hospital coronary care ward for two months prior to her SCU placement.

interviewed associated the poor care practices observed (use of physical restraints, neglect, inappropriate activities and poor commitment) with the absence of specialist dementia training of staff. They both complained that these respective settings' physical and psychosocial environments were not customised to adequately manage their relative's complex needs. For example, Mr. Kiely whose wife had been admitted to a nursing home prior to SCU placement (see Table 2) complained that staff lacked a basic understanding of dementia-related challenging behaviours such as wandering, restlessness, and disorientation; that they were incapable of knowing how to engage PwDs in meaningful activities; and that they provided a very rushed approach to care. They argued that in these settings the focus was on monitoring rather than on stimulating and promoting autonomy. In his words:

> "While she was in the nursing home, she was very active. She was walking a lot and going into the kitchen which they didn't like her to do within the nursing home. So they put, they restrained her. (...). They just couldn't manage. I don't know why we were in. They did have patients before that with something similar (...) but they just, they just can't cope with somebody that's walking around the place and I mean I-I don't think she was really that bad. (...). They didn't have the time when she was in the nursing home (...) it's just not the same [as SCU B]. They don't have, they are not caring the same as they do here. (...). They just actually sat with the patients. (...). They just sat there and that was it. And they didn't have the same care, uh, they did their nails and they did a little bit of exercise and the, uh, the karaoke and that but that was it. (...). There's quite a big, there was quite a big staff there. But they did what they had to do, and that was it. I mean they didn't give any special care. They didn't, they sat, and as I've already said it before, they sat with the patients and that was it." (Mr. Kiely, husband caregiver, aged 76 years)

Ms McCourt, whose mother had been hospitalized prior to her SCU placement, expressed similar concerns saying that her mother had spent most of the time alone in a private bedroom on a CCU. During the interview, she complained in particular about the fact that hospital staff were not trained to deal with dementia and adhered to traditional care routines typical of a busy hospital setting. She was of the view that the care provided

failed to consider her mother's individual complex care needs. She was particularly critical of the fact that following an incident when her mother left the hospital premises unbeknown to staff, the hospital then "specialed" her and regularly reminded her that if her mother tried to escape again they would not be held responsible[9]:

> "The staff in [name of city-based hospital] wasn't really trained to deal with this. But at the same time and - and I know, I know that they are busy, you know, I really know that they are busy and they had cardiac patients and that. But I, I think they more or less left my mother to her own devices, you know, and they were, there wasn't much hands-on. In the end, actually, they had to assign a one-to-one personal assistant to sit beside the bed if we weren't there to sit beside the bed to make sure that she didn't leave the hospital. But they'd ring me and said that they weren't really responsible if she did get out. They were not taking, they were telling us that they weren't responsible, you know. So it was, uh, very worrying (...). She was there for the two months and they weren't equipped really to deal with her." (Ms McCourt, daughter caregiver, aged 52 years)

6.2.3 Positive experiences of SCU residential respite care

As mentioned in Chapter 5, the majority of these FCs had used residential respite care in the facilities where SCU LTC admission took place. Interviews revealed that their experiences of residential respite were very positive and for most were a key reason why placement in the same setting was made. During their interviews, all FCs described at length their satisfaction with the SCU; it was safe, homely, highly specialized, and well suited to their relatives' care needs. Some FCs added that in their views the SCU was the only place able to manage their relative's complex challenging behaviours and unique care needs.

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[9] Her mother managed to leave the hospital premises and get to her apartment where Ms McCourt found her sitting in her bed. Ms Sheehan was subsequently brought back to the hospital.

All nine FCs viewed the home-like and safe physical environment, its person-centered needs-based approach to care, and the level of specialisation of staff as distinct aspects that made SCUs a superior care setting.

In response to a general question asked about the differences they perceived between the former setting and the SCU, the lady who cared for both her own mother who had dementia and her aunt made the point that there was a lot more freedom in the SCU:

> "In our house there has to be schedules, things have to happen at a certain time. Here they don't. Here, if she doesn't like getting up at the crack of dawn she doesn't have to and there is nobody going to nag her into. I mean they cajole and they talk her into it. But there isn't this dead-line that I'd be having to deal with, you know. I have to get the lunch made at a certain time. I have to get that sort of thing." (Mrs. Breslin, niece caregiver, aged 43 years)

Mrs. Breslin continued to talk about the specialised physical environment and the trained staff. Her comments were reiterated by others:

> "First of all is the physical environment. Second of all the staff here are trained and we are not. Tha-that's a huge, that has to be a huge factor in it, and they're, not everybody is suited by personality or temperament to dealing with people with dementia, and these people are." (Mrs. Breslin, niece caregiver, aged 43 years)

A wife caregiver particularly liked the domestic homely environment, as evidenced by her statement which resounded with most FCs:

> "Here it's like, it's as if he has a home, which is very good. They've everything, [a] garden. There's everything here for them, everything. For the windows they can close the handle and the lights and they can live a life [sighs, laughs]." (Mrs. Conor, wife caregiver, aged 57 years)

A daughter caregiver – Ms McCourt – made a particular point of the specialist type of care which was radically different from the care her mother had received in the hospital. Her point of view was by no means exceptional but reiterated by several others:

> "It's specialist care here, specialist for dementia." (Ms McCourt, daughter caregiver, aged 52 years)

Ironically, it seems that respite care – a service designed to prolong community care - might have actually contributed to the breakdown of care provided by FCs during the time leading up to placement. Although FCs were not asked specific questions about their use of residential respite care, clearly data revealed how becoming familiar with the unit's enhanced physical features and the quality of care on offer might have made FCs more conscious of the inappropriateness of the home environment (i. e. domestic dwelling). In addition, experiencing the type of care on offer through SCU respite services might have reminded people of the standard of care they would want for their relative and might subsequently have led FCs to expedite the SCU LTC placement. Being aware of one's shortcomings as an informal caregiver and recognising the unit's 'superior' standard of care might thus have contributed to the breakdown of care provided by FCs.

6.2.4 Other decision factors

The literature shows that the decision to place a relative with dementia in LTC is triggered by a multitude of interacting factors including the individual's loss of cognitive functioning, physical functional abilities, and behavioral changes (Bramble, Moyle, & McAllister, 2009; Caron, Ducharme, & Griffith, 2006). Certainly most FCs in this thesis - when asked to talk about the reasons for placing their relative in SCU LTC - referred to myriad different factors. Reasons included an inability to cope with the physical and emotional strain of providing around-the-clock care to the person and their inability to manage the person's challenging behaviors including dangerous behaviour (such as inflicting self-harm, sustaining falls, resistance to care, and incontinence). Attempting to manage these

behaviors and care needs was very difficult and caused several caregivers to decide to discontinue home care:

> "We really, I mean, we were exhausted. She was falling, she wasn't safe." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)
>
> "He couldn't get the care at home. It's beginning to sink in now at this stage how much care Kieran needs." (Mrs. Conor, wife caregiver, aged 57 years)

There were two participants who although not ostensibly FCs were directly involved in their relative's placement (a daughter, a nephew). Both stated how they feared for the primary caregiver's (a father, a sister-in-law) physical and mental well-being should home care continue. In both cases, these concerns were viewed as key decision factors:

> "Daddy [who was aged 80 years] had reached the end for himself. He wasn't able to take care of her any longer. (...). Daddy wasn't able to just take of her, because it was seven days, seven nights." (Mrs. Forbes, daughter caregiver, aged 50 years)

The nephew carer made a similar point and talked about the strain dementia care imposed on his 78-year old mother. Mr. Donohue's commentary particularly well illustrated the impact dementia care has on the family system:

> "There was a fair bit of stress and strain in my Mum, like, you know. Mum's gone seventy-eight years of age now, like. So, you know. So, like, you, she's no longer able, you know, to look after him, really, like you know. So that would be why he came in first, really, like, as she kind of felt, you know, no longer capable of looking after him properly." (Mr. Donohue, nephew caregiver, aged 56 years)

In summary, the data show that a variety of interrelated factors were at play in causing FCs to discontinue home care. One main reason identified by most was the inappropriateness of the home care setting. Another was the severity of dementia-related challenging behaviours which at times put carers' own health and safety at risk. A third main reason identified by most FCs was their positive experiences of using respite care in

the same SCU in the period leading up to LTC placement. A fourth reason was the impact dementia care had on other ageing family members. It seems therefore that several different factors caused FCs to decide to discontinue home care and place their relatives in SCU LTC.

6.2.5 Making the placement decision

During the interviews, FCs were questioned in-depth about how and by whom the decision to place their relatives was made. In the next section findings will be presented on who was involved in the decision-making process and on how FCs responded to the actual SCU LTC bed offer. In addition, data will be presented on the tensions and emotional conflicts of FCs surrounding their admission decision. These conflicts centered on relinquishing their own care-giving role and accepting their relative's need for specialised LTC.

6.2.5.1 Inclusion of other family members

The literature shows how decision-making regarding LTC is a challenging dynamic process that occurs over a period of time (Caron, Ducharme, & Griffith, 2006). In line with the literature, FCs participating in this research reported that the decision to place their relative in specialist long-stay care was emotionally taxing and associated with paradoxical feelings such as acceptance of the inevitability of the PwD's SCU LTC placement; sadness about losing the PwD to institutional life; yet feelings of relief and happiness about the decision, which were also discernible in FCs' narratives. The decision was generally made in conjunction with other family members and over time. The family members involved in the decision-making with the FC were in most cases next of kin who were involved in the PwD's care and included FCs' adult siblings, siblings-in-law and spouses:

> "We [Mrs. Forbes, her three brothers, and her sister] knew Mummy could no longer be taken care at her home, and we were happy that we had done all we could do." (Mrs. Forbes, daughter caregiver, aged 50 years)

"It was very simple process. We [Mrs. McNamara, her husband, and her sister-in-law] talked about it and we said, 'look she is going to get worse and if a bed ever comes up we'll accept it.' (...). That was the decision. It's hard, and it's hard for them to see her here, uhm, but they are both very happy that she's here." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years)

"There's four boys in the family and a [the PwD's] husband. I'm a daughter-in-law. But we, the daughters-in-law are very involved to look after them. (...). I think it was when we had her for the six weeks we had to sit down as family and say, you know, she really does need long-term. (...). It just came towards that she just needed [the SCU] for her sake, uh, uh, she needed it, and you had to do what was best for Isobel as well, you know. We'd be sad and the whole lot but we're very happy now." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)

There was only one very unusual case where a spouse was reluctant to place her husband into the SCU but felt pressurised by her children and finally succumbed:

"The family were very, uhm, they were very, uhm, what's the word for it, pushing me [laughs]." (Mrs. Conor, wife caregiver, aged 57 years)

6.2.5.2 Exclusion of PwDs

When questioned about whether their relative with dementia may have been involved in the actual decision-making, all of the nine FCs reported that he/she was not involved. The reasons for this were the severity of the dementia and lack of insight associated:

Researcher: "And how was, uhm, Maureen involved into the decision-making?"

Mrs. Philbin: "No, not at all! Poor Granny! Since a long time ago Granny has no concept of, of money, of time, of where she is. (...). You could not involve Granny. Poor Granny was so far gone in her head that you couldn't involve her in anything."

(Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

6.2.5.3 Accepting the bed

As mentioned (see Chapter 5) all but one of these FCs had their relatives wait-listed for the SCU yet findings show that when the offer of a bed was made this tended to happen unexpectedly and decisions had to be made virtually overnight. All nine FCs said they felt fully supported and encouraged by their family members to accept the LTC bed once it became available. Most reported that they themselves had to finally decide about their relative's placement once they were formally offered the bed. Most added that they were required to make the decision very fast. A few said that they accepted the bed on the spot without consulting other family members. For instance, one daughter-in-law said:

> "The decision was, was made very quickly, and we didn't have to. I didn't have to think about it 'cause I knew my husband would say yes. I didn't have to ring him or anything. I knew he'd say 'take it'. And when I'd rang him - after the Clinical Nurse Specialist rang me I rang him - and he says 'what did you say to him?' I said 'I accepted it'. And he says 'great'. He says 'that's perfect'. He says 'you did fine'. I rang then my mother-in-law's daughter and she said 'I hope you accepted it' [laughs]. I said 'I did' [laughs]." (Mrs. McNamara, daughter-in-law, aged 51 years)

Other FCs felt that having to decide so quickly left them without time for consulting with other family members at this stage. They believed they had to accept the bed on the spot since they were aware that a bed was a scarce commodity and was seldom allocated:

> "We kind of said, you know, if she's ever offered full-time we would take it. We kind of, it was kind of, say that, uh, you know, I said 'No, off chance. Off. We won't be offered a spot. If we ever are we can't turn this down.'" (Mrs. McNamara, daughter-in-law caregiver, aged 51 years)
>
> "Well, I suppose we were so lucky to get a bed. They are like gold dust. So I couldn't refuse it." (Mrs. Conor, wife caregiver, 57 years)

A few claimed the final placement decision was made very quickly and felt rushed and under huge pressure to make the first decision despite the fact that most caregivers were

hugely over-extended and appealing for more help when the bed offer was finally made. For instance, one daughter-in-law stated that the family was given one day to make the final decision:

> "The Unit Manager phoned and she said 'I have a bed but I need to know by tomorrow'. And that was the Monday before. She needed to know by the Tuesday, and I had to phone my husband and say 'look we are going to have to make a decision.'" (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

One third expressed their surprise about the suddenness with which they were actually offered a LTC bed by the SCU. Some carers had expected much longer waiting periods before being offered a LTC bed:

> "I didn't think it would come so quick. Out of the blue, like." (Mrs. Conor, wife caregiver, aged 57 years)
>
> "We never envisaged that she was going to get it that quick. That's to be totally honest, we didn't, we didn't... we didn't think she was going to get it." (Mrs. McNamara, daughter-in-law caregiver, aged 53 years)
>
> "As I said the way it happened was good. But in another way it was just so quick, you know. One minute she's on for a week and then she is not coming back." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

6.2.5.4 Emotional conflicts

Numerous studies have been published demonstrating that the decision to place a relative with dementia into LTC is one of the most difficult emotional experiences a FC ever has to undergo (Bramble, Moyle, & McAllister, 2009; Butcher et al., 2001; Caron, Ducharme, & Griffith, 2006; Dellasega & Nolan, 1997; Ducharme, Couture, & Lamontagne, 2012; Kellett, 1999). Butcher and colleagues in their study of placing a PwD into SCU LTC care found that FCs struggled with grave feelings of guilt and anguish about the impending

placement (2001, pp. 475-476). Others have referred to this decision as the greatest nadir in life (Caron, Ducharme, & Griffith, 2006).

In this thesis, participants vividly described the emotional conflicts surrounding admission decision and procedures. Their accounts show how decision-making was not done lightly and was an emotionally taxing and paradoxical process for families. About one third said that they found the decision-making "hard" and two others described it as "a big decision" and "a huge step". These statements appear to indicate considerable levels of stress and fear associated with deciding to place a relative with dementia into skilled LTC. Several FCs, however, also indicated positive feelings about the placement decision; in particular, feelings of relief and happiness.

Analysis revealed that in general mixed emotions were how most FCs responded to the placement decision. On the one hand they were saddened about letting go of a loved one and relinquishing the caregiver role to professionals but on the other hand understood and accepted the need for specialised LTC. Mixed reactions were particularly evident in the spouse caregiver interviews. The two spouses felt particularly torn between acknowledging their inability to continue to care whilst accepting their partners' need for professional care and dealing with their own desire to continue living with their spouses:

> "I keep saying to myself why can't he be at home instead of being down here? But then I suppose if I was older, there's fifteen or thirteen years between him and me and, like, if I got older then I was, wasn't able to physically mind him, you know. Which I suppose there comes a time when you can't do any more. And it's great [here in the SCU] because you know the doctor will go around and see them and examine them and check out that everything is in order with my husband." (Mrs. Conor, wife caregiver, aged 57 years)

Other FCs also talked about their complex emotional reactions - feeling guilty but confident they made the right decision and feeling saddened but relieved:

> "There's a huge relief grained with, you know, with sadness. But it was a huge relief, too. It really was. I'd say it's a very strange mix of emotions." (Mrs. Breslin, niece caregiver, aged 43 years)
>
> "I felt guilty, too, because she'd been so much a part of my life, too, you know, that it was, it was hard. But we know that it was the best decision." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

Three carers reported they felt confident and at ease about making the decision. These carers who had been living apart from the PwD during the time leading up to SCU placement said that the decision had been easy and was in their relative's best interests because the specialist setting would provide a better level of care and would optimally meet their relatives' unique and complex needs. One of these carers who worked full-time said:

> "We both [Ms McCourt and her brother] agreed straight off that this is what she needed or what, where she would get the best care. Because even though I live on my own I can't care for her the way she needs to be cared for. 'Cause I work full-time. I've two dogs and the dogs would be gone missing on my mother's word if she was out in my house. My brother has three young children, and he works full-time. His wife works. So for her to get proper care, maybe it sounds a bit selfish as well, but I don't think I could have handled it. I really don't think I could handle it. And my brother and I are both in agreement with that." (Ms McCourt, daughter caregiver, aged 52 years)

It might be argued that because these carers lived apart they were not as 'engulfed' in the care role (Twigg & Atkin, 1994) and thus were better able to accept the fact that professional care was in both the person's and the primary caregiver's best interests (Nuffield Council on Bioethics, 2009).

6.2.5.5 Communicating news of the placement to PwDs

During their interviews, FCs also talked about how they communicated the news of the SCU bed vacancy to their relatives. Data analysis shows that in all cases, FCs failed to honestly inform their relative about the impending transfer. Instead they tended to avoid giving any information or gave misleading information and told half-truths about the actual length of stay, the actual destination, and reasons for the SCU stay. The next section highlights communication strategies used by them and reports on reasons why such strategies were used.

6.2.5.5.1 Avoiding truth-telling

When asked about how information about the permanent placement was communicated to the PwD, FCs described ways in which they conveyed news of the impending LTC admission to the person. The following two commentaries were reiterated by others:

> "I didn't tell him anything more than I had to, you know [laughs]. I think to be talking about it and the more you say to him, like, I think, the more confused he is likely to get, like. So I kept it to a minimum, you know. Just 'you, you have to stay in here, Walter, for a while'." (Mr. Donohue, nephew caregiver, aged 56 years)

> "I always described it as going on holiday, a little bit of a break, somewhere with no stairs. That was the major selling point." (Mrs. Breslin, niece caregiver, aged 43 years)

In one extreme case, the carer resorted to transferring her relative without giving any information:

> "I just didn't say anything, I just brought her in, you know, uhm, and just left her." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

6.2.5.5.2 Attempting truth-telling

Only two FCs (both daughters-in-law) strove to tell the truth about the admission by initiating a conversation about the impending transfer a few days prior to the actual

physical relocation; informing their mothers-in-law that they would stay in the SCU for an unlimited length of time; and explaining to them that they would stay in a dementia-specific unit because of safety and care needs. In their own words:

> "We laid out the facts, the bare facts, you know, that she wasn't able to cope on her own, that she s-, wa-, you know. We asked her, was she afraid? And that was the biggest thing when we asked her, was she afraid? She said she was. So we kind of said 'Look, to stop this fear and not have you being afraid, we think you should go in full-time.'" (Mrs. McNamara, daughter-in-law caregiver, aged 51 years)
>
> "You would have said to her 'Look, you are coming in here and th-, you are going to be very well looked after but we'll be out' and you would discuss that with her. But that's just for your own sake. But she knows that she would forget. She wouldn't know two minutes later what we had spoken to her. But it would have been said to her, you know, that she was coming in here and it was for her, for her, her good." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)

Despite their honest attempts at disclosing the truth, however, both carers' statements indicate that they failed to explicitly address the true reason for the transfer ("because of your dementia-related care needs") but like the other carers resorted to using "euphemising" language ("because of your fear", "for your good"). It may thus be concluded that no FC gave truthful information about all aspects of the upcoming relocation to the PwD – i. e. moving to a specialist dementia care unit where the PwD would remain for an unlimited period of time because of his/her complex care needs.

6.2.5.5.3 Reasons for not telling the truth

Reasons why FCs resorted to lying or avoiding informing their relative were because of their perception of the severity of the dementia and consequently the futility in imparting such news to a person who lacked insight or would forget anyway (Ducharme, Couture, & Lamontagne, 2012). Carers claimed that their relative no longer understood abstract concepts, such as "nursing home" or specific place names, and that they would no longer

be capable of registering and remembering any form of environmental change. They also believed that truth-telling might distress them:

> "She just doesn't, doesn't even remember what happened yesterday. So coming from there [the generic nursing home], she doesn't even remember where she was. (...). She has no memory of what happened a week ago. She thinks they asked her one week, she said. She thinks she's only in here a week. So she has no perception of days or time remembrance or about whatever." (Mr. Kiely, husband caregiver, aged 76 years)
>
> "I don't think she would have understood, and her experience of going up to the home, the county home would have been a different thing than it is now. So to, to try and explain if we use the term 'the county home' or [name of geriatric hospital to which SCU A is attached], that sort of thing, she would have harked back to the old days, nearly workhouse times, it would have that connotation, you know. So I think we would just have made her more stressed out." (Mrs. Breslin, niece caregiver, aged 43 years)

In one unusual case a daughter-in-law who essentially abandoned her relative, giving her no information at all (see page 187), stated that had she attempted to be upfront with her mother-in-law, the latter might have refused to move and may have become physically aggressive towards her:

> "I thought if I started trying to explain 'Well, I'm bringing you in here and you're going to stay here', number one she probably wouldn't come with me, or she could turn around and hit me or something." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years)

Four FCs said that in conveying news of the permanent bed they used the same approach as they were accustomed to using when communicating news of short-term respite care:

> "I was talking to Mummy as I normally do coming in [for respite care], because I would show her the fields and I'd show her, 'cause she had great interest in cattle, 'cause farming, and she'd look at the fields and we're chatting about all the lovely houses, 'cause it was a nice day. And we, she-she, that's what we did all the time. So we didn't change that, that conversation." (Mrs. Forbes, daughter caregiver, aged 50 years)

"I said 'You need to bring a few things with you, Walter, for, for a few days', and it's the way it went on anyway in the early stages, you know, and when he was coming in permanently it was much the same, like, you know. We just kind of prepared the same way, and, you know, as if he was coming in, like, for maybe a week." Mr. Donohue, nephew caregiver, aged 56 years

6.2.5.5.4 Accepting the news

When caregivers were questioned in-depth about how their relative reacted to news of the transfer, most said they showed no signs of distress and appeared to accept the impending changes to their living situation. For instance, Mr. Donohue who kept information disclosed to a minimum said:

"He seemed, uh, happy enough, like. He accepted it anyway, like, you know. I hadn't any problems, like, uh, persuading him to come in, no." (Mr. Donohue, nephew caregiver, aged 56 years)

Similarly, Mrs. Ryan who was more upfront stated:

"So we were just literally talking about where she was going to, what was there. 'The nurses very nice and staff very nice, and are going to meet nice, you are going to get new friends over there, you're going to meet new people', and, uhm, she was quite content now with that." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)

6.2.5.5.5 Ethical dilemma

Carers claimed they strove as best as they could to communicate the news about the permanent bed in a way that was meaningful, not potentially stressful, and cognisant of their relative's CI. By doing so, however, all FCs appeared aware of the fact that they used ethically questionable communication modes. Two of these carers talked about the dilemmas they experienced. For example, a daughter expressed feelings of guilt and self-reproach about not telling her mother the full truth about the SCU LTC transfer:

"Maybe I wasn't, I should have been more honest with her. I don't know." (Ms McCourt, daughter caregiver, aged 52 years)

"That was really all you could say to her, you know. It's very, very difficult when, when she's not, uhm, you know, when she's not really with it all the time." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years)

6.2.6 Section summary

So far the chapter has shown the various factors that influenced the decision of FCs to admit their relative into specialised LTC. Most FCs viewed SCUs as safe settings which offered a level of care which was superior to home care and better suited to the complex needs their loved ones now experienced. Most carers made the decision to place for a variety of reasons including the high level of care which was required, the inappropriateness of home care arrangements, positive experiences with respite and the adverse impact co dementia care was having on other family members.

The chapter has also given new insights into how FCs decided about their relative's SCU LTC placement. In all cases, other family members participated in the decision-making whilst the person was not included. Once offered a SCU LTC bed, FCs accepted it instantly, fearing that by delaying the decision they would lose their entitlement. A few FCs also said that they were given very short notice to accept or decline the bed offer (deadlines ranged between one and three days). Making decisions to admit their relatives into SCUs caused considerable emotional conflicts for FCs who were torn between wanting to provide the best quality of care to their relative and feeling that this should be done by them and not others, yet being unable to deliver this care themselves.

This section also shed light on how FCs communicated news of the admission to their relative. FCs were not honest. Most tended to provide minimal or wrong information, half-

truths, and in one case they moved their relative without giving any information. Most FCs were of the view that their relative was no longer able to understand. They also feared that the truth about SCU LTC placement might cause their relative distress.

Communicating information about the move into a specialist LTC setting thus posed a serious ethical dilemma to FCs. This dilemma had some repercussions on SCU staff members who were later faced with the task of helping to settle new residents into the SCU. The next section of this chapter reports data collected from SCU professional caregivers about their experiences of admitting residents into care.

6.3 Experiences of FGs

We have seen how FCs coped during this time, and why and how they made decisions about placement and broke the news about the transfer to their relative. As mentioned in Chapter 4, FGs were held with SCU staff members in three different SCUs. The next section presents data generated from these three FGs on SCU staff members' experiences of admitting new PwDs into LTC. The section commences with a profile of FG participants' socio-demographic and occupational background. This will be followed by data which highlight the admission policies and assessment protocols used by FG participants. Data will also be presented on how decisions to admit new PwDs were made, and what emotional consequences these decisions entailed for SCU staff.

6.3.1 Socio-demographic and occupational profile of FGs

This section provides basic information on the socio-demographic and occupational background of the staff who participated in the three FGs (see Appendix R). Five participants belonged to SCU A (FG A), four to SCU B (FG B), and three to SCU C (FG C). The mean age of the twelve participants was 37 years (range 22-53). Ten were women (four Health Care Assistants, two Nurses, a Multi Task Attendant; a Clinical Nurse

Specialist, a Clinical Nurse Manager, a Unit Manager) and two men (a Clinical Nurse Specialist, a Nurse). Eight of the twelve FG participants were front-line staff providing hands-on care and/or involved in decision-making about new admissions. Four were Health Care Assistants, three Staff Nurses, and one was a Multi Task Attendant (her tasks included caring, catering, and housekeeping). Four were senior staff members; two were Clinical Nurse Specialists (SCU A, SCU B), one was a Clinical Nurse Manager (SCU A), and one was a Unit Manager (SCU C).

With only one exception, all FG participants worked full-time and each had been working an average of six years as a formal caregiver to PwDs (range 2-18). Each FG participant had been working as a SCU staff member an average of only two years (range 8 months - 4 years). Thus, working as a SCU team member appeared to be a relatively new experience for FG participants. This was particularly true for staff members of SCU B who in comparison to the FGs held at SCU A and SCU C, respectively, had only been working for eight months (one year in the case of the Clinical Nurse Specialist) as part of the SCU team.

Most FG participants were women and worked as full-time front-line staff members. In addition, FG participants had on average been working for more than five years as formal caregivers to PwDs and thus appeared to be experienced in caring for PwDs.

6.3.2 Admission policies

In the next section data collected from FGs about admission policies used by the three SCUs will be presented. Admission policies dealt with organisational aspects of the admission process that exerted a major influence on decision making and outcomes. These aspects included admission criteria, waiting lists, and emergency admissions.

6.3.2.1 Admission criteria

Questions were asked about how in general SCU admissions were organised in each of the three units. Findings presented below relate to each individual SCU. Differences were evident across these units and will be highlighted.

FG A revealed how SCU A was HSE-funded and used three strict admission criteria. In response to a general question asked about what happened next once a LTC bed became available, the Clinical Nurse Specialist said that to qualify for placement a person needed to i) have a primary diagnosis of AD or other dementia subtype, ii) display one or more dementia-related challenging behaviors unable to be managed in an alternative setting, and iii) be able to mobilise independently:

> "We have three strict criteria for people who are admitted here. They must have had a primary diagnosis of dementia, they must be independently mobile, and they must have had what is perceived as challenging behavior." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)

Data about admission policies for SCU B was obtained not through the FG but via a document sent to me by the Clinical Nurse Specialist. Reviewing this document revealed that two admission criteria were used. These were i) a primary diagnosis of AD or other dementia subtype, and ii) one or more dementia-related behavioral and/or psychological problems that could no longer be managed in the community:

> "The nature of SCU B is to provide support to residents with Dementia and their families at a stage of the dementia where the resident is demonstrating behavioral and/ or psychological disturbance and the family is experiencing difficulty in coping with the current behavior of the resident as a result" (Procedure for Admission to [name of SCU B], 2011, p. 4-5)[10]

In the third SCU (privately funded SCU C) the sole criterion used for LTC placement was that the person would have a diagnosis of AD or any related dementia subtype. This

[10] This document will not be referenced for reasons of confidentiality.

information was obtained during an informal conversation with the Unit Manager, which served the purpose of clarifying the data collected so far and was held after the data collection had been completed in SCU C.

6.3.2.2 Waiting lists

Wait-listing for LTC beds was also a central part of the admission process for all three units and this topic was examined in depth in the respective FGs. In further response to a question asked about what happened next once a LTC bed became available, those in charge in all three units said that positioning on waiting lists (which they each used) guided decisions about who to admit:

> "At the moment we have a waiting list. So if a bed becomes available we would notify the relatives whoever was first on the list. And we'd just notify the relatives, tell them there's a bed becoming available, and we just ask them if they were still interested and that we'd tell them the day it would be available for them." (Mrs. Corbett, Unit Manager of SCU C)

> "We would have a waiting list for, for residential beds in SCU A. So we just look at the, the waiting list and decide. (...). If it's a waiting list situation we'll look at who's next on the waiting list." (Ms Devers, Clinical Nurse Manager of SCU A)

In addition, the manager of SCU B talked about how residential respite care acted as an entrée into LTC placement:

> "If someone comes for respite, and if their needs change and they need continuing care that can be done - if there's a vacancy. If there's not they can go on a waiting list. And when a bed becomes available then we will discuss whether they, they will meet the needs to move on from a respite bed to a continuing care bed." (Mr. Navid, Clinical Nurse Specialist of SCU B)

6.3.2.3 Emergency admissions

However, the process of admitting new residents into SCUs was not quite as straightforward as this and involved more than wait-listing and the use of respite care as the data show. Analysis of transcripts revealed that sometimes people not wait-listed had priority if deemed to need "emergency" placement. These "emergencies" were reported to be rare and usually occurred when family care-giving arrangements broke down due to caregiver exhaustion, illness, death, or lack of community-based supports. In these rare cases, as emphasised by senior staff members of all three units, the person would get immediate prioritised placement without being first wait-listed. In these cases where emergency placement was sought, SCU staff was required to assess other factors:

> "It sometimes can be family members, something would happen, the family members would get into touch with us about an emergency. (...). I'm just thinking of specifically of a lady we had in last year, and her husband collapsed one morning. So he was the main carer. He collapsed. She had to be admitted here in an emergency." (Mrs. Corbett, Unit Manager of SCU C)
>
> "If it's a crisis [for example, the FC becoming ill], [if] we assess it as a crisis, then they will be in despite the waiting list." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)

FG findings show how "emergency" admissions were also made from nursing homes and acute hospitals if a SCU bed became available. Staff reported how these cases took priority over and above regularly wait-listed persons. For example, if staff from acute hospitals or nursing homes sought emergency placements, these requests were given top priority over cases already wait-listed. In fact, this was how two PwDs in this thesis gained access to SCUs.

Where admissions were of an "emergency" nature and in the context of one of the HSE units, it was stated during the FG that these new admissions were sent to the general hospital first for assessment. Assessment was aimed at observing the person's coping responses and judging his/her eligibility for specialist long-stay care. This observational

assessment was conducted outside SCU A in order to find out if the PwD could perhaps be cared for by a generic setting:

> "If that person could really only be cared for in SCU A. Is there somebody then that maybe could be tried on another ward? But what we generally do there is, you would do it [admitting the PwD to a generic ward] on a couple of days' trial. You would try somebody outside, for a couple of days to see how they get on. If they don't cope then they would obviously still have that bed. That bed would still be there as in SCU A." (Ms Devers, Clinical Nurse Manager of SCU A)

This was not the case in the context of the other two SCUs where admissions occurred directly into the units and assessments were not undertaken at the adjoining hospital and nursing home, respectively.

6.3.3 Decision-making as a complex and challenging experience

The SCU staff members involved in the FGs were also asked additional questions about placement protocols, new admissions and what it was like dealing with admissions and discharges when working in SCUs. The next section will report on these topics.

6.3.3.1 Multitude of decision factors

The previous section demonstrated how all three FGs used admission criteria and wait-listed but also gave priority to "emergency" admissions. Further data analysis revealed that in addition, other decision factors were also considered by all three SCUs. In further discussing what happened once a LTC bed became available, staff members in charge at HSE-funded SCU A reported that apart from wait-listing (i. e. length of time spent on the waiting list) other issues such as i) challenging behaviours, ii) coping resources, and iii) the general suitability of the person in the context of other residents were also seriously considered. According to senior staff at this unit, consideration of this constellation of reasons often resulted in prioritised admissions:

"But it's not just who's next on the waiting list. [It's] who's on the waiting list that has the most needs at that particular time. (...).The, the person's priority from a needs' perspective or the time while he was on the waiting list guide us. Then we've to, it would be Ms Devers and myself and Ms Gallagher, and Mr. Singh, we generally decide then who would be the most appropriate for the next admission. (...). If there's a, like Ms Devers said, a crisis in the community it does put pressure on us to, uh, to look at the current group of ten residents we have." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)

"Sometimes the person that actually comes in, their needs may not be any more or any less than the person that was above them or below them on the list but that family's ability to cope would be what'll determine." (Ms Devers, Clinical Nurse Manager of SCU A)

Similarly, at SCU B a nurse participant talked about the level of distress FCs were under prior to their relative's SCU placement. Although this was not identified as a main factor in the decision-making process, her statement indicated that SCU staff certainly considered care-giving burden as an issue of some importance resulting in the need for SCU LTC placement, and that SCU staff therefore recognised factors other than the PwD's wait-list status:

"We have to remember that when they're coming from home, uh, which is generally, you know, often the case from outside, like, you know, it could be down to, maybe perhaps, one other carer being the majority stakeholder in looking after them, you know, which could be very taxing. " (Mrs. Kissane, Staff Nurse of SCU B)

In examining this unit's written policy it was noted that what was important was to "determine the resident most in need" of being placed (Procedure for Admission to [name of SCU B], 2011, p. 6). This statement also appears to indicate some level of need assessment that goes beyond merely considering a person's wait-list status. In SCU C, however, a person's wait-listing status appeared to remain the most important factor in deciding about new admissions.

6.3.3.2 Multitude of voices in the decision process

The issue of who was involved in decisions about new admissions was discussed during each of the three FGs. In the two public SCUs, decision-making appeared to be democratic with all SCU team members (managerial and junior) involved in the process:

> "It would be our Clinical Nurse Manager, myself, and our Health Care Assistants, and our Staff Nurse, we generally decide then who would be most appropriate for the next admission." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)
>
> "It's feedback to the team [after the assessment of a LTC candidate has been completed], the team which includes the GP, the staff here, uh, the management and, uh, the team in the community as well. We have a discussion of who are [new residents] with, with our staff [that is] here." (Mr. Navid, Clinical Nurse Specialist of SCU B)

However, in the private unit, findings revealed how new admissions were mainly decided upon and managed by the Unit Manager, the Matron, and the proprietor of SCU C. Accordingly, the policy adopted at this SCU was that front-line staff members were excluded from being actively involved in the decision-making process but were informed by senior staff about all new admissions:

> "The decision would be made to admit, you know, that somebody wanted to come in and the families would be in discussion either with me or with the Matron, usually with the Matron before coming in. (...). They [the SCU team members] would be informed beforehand if there was somebody being admitted and that the decision was made." (Mrs. Corbett, Unit Manager of SCU C)

The fact that in two of the three SCUs, a number of staff members were involved in the decision process further highlights the complexity of deciding about a new admission to LTC. In both HSE units several individual staff members' opinions on new admissions had to be considered; often individual preferences had to be moderated and synthesised into a group decision.

Making complex decisions about appropriate admissions had the potential to be enormously stressful for SCU staff. As a starting point not all staff members would always agree on who a bed should be offered to. This could lead to serious conflicts among staff members. In cases where junior staff members were excluded from the decision process (as in SCU C) staff might feel undervalued in terms of their professional skills and this might in turn affect the quality of care.

6.3.3.3 Emotional challenges associated with deciding about a new admission

For staff employed in the three SCUs, admitting new people was also very difficult. During the FGs the twelve participants described in much detail the stressful aspects of admitting new PwDs to the SCUs where they were employed. Analysis of data revealed how this stress was associated with their having to cope i) with FCs' and PwDs' own reactions to admission; ii) with the loss including deaths of well-known residents thereby freeing up the new SCU bed; iii) with dealing with consequences of having to inform others that they were not successful in getting the bed; iv) with adapting to individual needs of admitted PwDs; and v) having few psychosocial supports during this stressful time. These findings were based on narratives that were elicited by questions asked about participants' personal experiences of admitting new PwDs and questions asked about the supports that were in place for SCU staff.

6.3.4.3.1 Coping with FCs' reactions to being refused admission

All three units were located in rural areas. Accordingly, when a resident died or was discharged, news of a bed vacancy was circulated very quickly. This put SCU staff under pressure with families and service providers lobbying for the bed. Indeed, when asked in-depth questions about their experiences of admitting new residents, staff in SCU A explained that due to the very high demand for beds they had to regularly refuse placements even when FCs were acutely distressed and wanted immediate help. These staff members stated that in such cases, FCs were often unaware of the strict criteria and procedures used. Participants added that they had to often educate families about these

admission procedures, such as wait-listing prospective residents, conducting assessments and prioritising cases; and ensuring that the potential resident could benefit from this specialised setting:

> "We have had situations [laughs] where somebody has, uhm, deteriorated and you know maybe we are talking to a particular family about somebody moving out, and we have had phone calls from families in the community who are obviously buddies with this other family, to say 'oh, well, uh, you know, uh, we're just wondering is there any bed coming up' and then you'd say 'well, you know, it's a waiting list', and they will basically say 'well, I heard that so and so is moving', you know. So that desperation and that word of mouth, and the desperation that some families are in." (Ms Devers, Clinical Nurse Manager of SCU A)
>
> "They [FCs] say, that's the quality, that's the standard they want for their relative, and they won't settle for anything else. And again that probably puts pressure on, on you also, this kind of trying from the admission process's point of view. We are trying to say 'well, look, but you your daddy or your dad probably doesn't need that level of support we have to offer. He can be looked after in other areas.' And they don't want to hear it that often. But they want to bring him in here." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)

FG findings showed how staff from SCU A claimed that refusing admissions where family members were in acute distress and needed immediate placement for their relative was very difficult for staff. Indeed, during one of FGs a staff member recalled an extreme case where FCs offered to actually buy a LTC bed, or fought with senior HSPs, such as the Director of Nursing or PHNs, whom they held responsible for the denied placement:

> **Clinical Nurse Specialist**: "There's always times we'd rang families to say, that, you know, here is what we've got. We have just one bed, and they just start fighting, uh, at the Public Health Nurse. (...). We had a couple of occasions, like, where people get very cross. And, you know, they go to the Director of Nursing and then go to anybody else."
> **Clinical Nurse Manager**: "Or they've offered to buy a bed. They've offered physically..."
> **Health Care Assistant**: "Yeah, they do."

Clinical Nurse Manager: "...if I would a buy a bed, can you leave that in there extra, and that Mummy or Daddy or whoever can stay? You know. People, it can bring them in lots of different emotions." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A; Ms Devers, Clinical Nurse Manager of SCU A; Ms Gallagher, Health Care Assistant of SCU A)

This commentary reflects a rather naïve belief that SCU beds could be purchased or that staff could be manipulated into deciding in favour of their relative.

6.3.4.3.2 Coping with FCs' reactions to admission

Apart from having to relate to families who were refused beds, staff also talked about having to deal with distressed family members who were coming to terms with placing their relatives in SCUs. The latter was cited by most staff members during the FGs as highly stressful. They spoke about family members' mixed reactions to the news of a bed vacancy; many felt guilty and yet relieved. Most participants in the FGs (both management and junior staff) talked at length about what it was like for them having to deal with mixed emotions whilst having to 'conceal' or disguise their own mixed emotions including sadness and upset. This often placed additional strain on staff members who were sometimes also worried about whether they had made the right decisions:

"Sometimes you would [get upset] but I suppose we sort of mask it or we work around that, especially if the carers are getting upset and if we were adding to that we'd just sort of withdraw ourselves from the situation." (Mrs. Corbett, Unit Manager of SCU C)

"We are trying to make this a very positive experience for the families. (...). We have to try and sort of upscale that and try and hurl that around and make it more of a positive experience. (...). When you're emotionally attached you can't care. It drags you down into that to a certain degree. You have just to keep it of course to yourself and perform your professional duties and make them as good as it is possible for them and certainly for the family." (Mrs. Kissane, Staff Nurse of SCU B)

"It's heartbreaking, you know, when you have the process of admission. When you think how the relatives find it difficult to let go... when they come here on the admission day. You can sense their feeling of uncertainty and guilt of leaving someone behind. So you feel quite similar... So it's something new, you know, 'have they made the right decision? Am I doing', the relatives would be saying to themselves 'am I doing the right thing?'" (Mr. Navid, Clinical Nurse Specialist of SCU B)

In one particular case a staff member talked about feeling 'doubly' challenged by having to deal with both the issues confronting FCs about to place their relative with dementia; along with dealing with other family members whose relative was about to be discharged from the SCU. She said that admitting a new PwD was inevitably linked to discharging a well-known resident from the SCU, and that both processes were extremely stressful for both groups of FCs and very stressful for staff. She talked about relatives' emotional reactions including extreme distress, resentfulness towards staff, and a refusal to maintain ongoing contact with the unit. This hostility was directed towards her as a staff member and was very distressing and difficult to manage:

"Like I often say I made two people cry. Two families cried today, you'd ring the family to say, look we have to move your Mum or Dad out and they get quite upset, and then you'd ring the other families who are looking for a bed and you'd say, we have a bed for your Mum or Dad or husband or wife, and then they get upset. So it's quite traumatic, psychologically traumatic, every single time." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)

She also described how some families, even after their relative was moved to another setting, maintained contact with SCU staff whereas others were reluctant to visit and resented staff for discharging their relatives to hospital or other nursing homes. This tended to reinforce staff members' own misgivings and guilt:

"When the patients are transferred from here they're in a very late stage of their dementia and they are not always as aware of the physical environment and the people around. The families are, and they have gotten used to this area, and then it's very different. They're

> kind of more visitors... Some of those families are great. They'd always come in and they'd visit in other parts of the hospital. Other families are almost hurt. They cannot bear to come in, and they don't come in because they kind of almost say, you took him out, and it's... terribly hard." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)

6.3.4.3.3 Coping with PwDs' reactions to admission

Another challenge facing staff was that of new residents initially failing to settle in. In response to questions asked about their own experiences of admitting PwDs, staff members of SCU A described feelings of distress experienced when new PwDs failed to settle in some time after placement. Whilst this was reported to happen only in a small minority of cases, nonetheless it caused SCU staff much distress. One Clinical Nurse Manager talked at length about how staff felt traumatised when residents failed to settle in. It was as if staff felt they had personally failed:

> "We had people that never settled, and that was extremely traumatic. Only a few that I can think of that nearly pined away, and it was very traumatic for everybody but you will never going to obtain what that person wanted. They were looking for that whole thing of home which was when they were a very young child, and their mother and their father and you always, even now you would try and give that support and that psychological support, you will never go in there to provide that thing that they wanted, and that was very traumatic, very, very difficult." (Ms. Devers, Clinical Nurse Manager of SCU A)

Other staff talked about people newly admitted who felt disoriented; abandoned; and wanted to go home almost immediately upon arrival. Many new residents on admission were not aware of the fact that they were going to be staying in the SCU permanently. In the words of one Clinical Nurse Specialist:

> "When you look at people's facial expression, being left here. And the constant asking 'oh, where am I? Where am I? Where's my wife? How long am I here for?'" (Mr. Navid, Clinical Nurse Specialist of SCU B)

Two participants (both from SCU C) stated that in cases where the new resident had been told lies about the placement and told that he/she would eventually be discharged home, staff were confronted with the residents' confusion, distress, and fear about being permanently kept in the SCU. Being responsible for 'telling the truth' to the PwD and helping this person come to terms with their changed living situation was very stressful for staff:

> "I've seen people coming in and, and maybe the family would have told them lies about coming in. So, you know, they were just going for a drive and they would be visiting someone and, you know, when they arrive here they'd say 'we're coming here for a visit' and then they'd just sneak off without telling them or something like that, you know. But usually we tell them, like, tell the truth anyway. (...). It's a while since we'd have that (...). It used to happen now and again with, say, respite or that, you know, and the family members would tell them lies to get them here and then when they were here you had to tell lies to, to get them in, and usually they would be very upset, very angry when that would happen." (Mrs. Corbett, Unit Manager of SCU C)

It seems that in some cases staff felt that they had no option but to corroborate with families and continue these charades and telling lies about the true nature of the placement as is exemplified in the following case where the PwD was told an overt lie:

> **Researcher**: "And when that happens that they are here for long-term care and they are getting unsettled and want to leave (...) what do you tell them about being here?"
>
> **Mrs. Quigley**: "It depends on the person. I would try and distract them. I'd very often say 'we're gonna have some tea or else and then we'll see how you feel'. You might use delaying tactics and things like that. But really if the family hasn't explained that they are here for long-term care it's, it's too upsetting and it's too agitating for the resident for you to turn around and say that they are going to be staying here. Normally, just delay them, delay them and say 'it's late now, there's bed here, will you stay with us tonight?' and 'sure you will if you, if you want to head off in the morning.'" (Mrs. Quigley, Staff Nurse of SCU C)

The data suggest that telling lies or misleading information about the permanent placement at times made the professional caregivers' work even more difficult as staff were keenly aware of the fact that colluding in FCs' lies and ploys was an unethical practice. At the same time, however, data suggest that staff's colluding in such lies and ploys and continuing to give misleading information to PwDs may spare both staff members and PwDs distress, thereby making staff's own work more manageable.

6.3.4.3.4 Coping with the loss of PwDs who were discharged from the SCU

As mentioned earlier, new admissions generally meant the death of a former resident or a discharge of a resident to an alternate care facility. During the FGs, several staff members talked about how upsetting and distressing it was for them to lose a well-known resident because of discharge from the SCU or death. The data suggest how staff often became much attached to the residents and were themselves affected by their deaths and discharge:

> "The admission process comes as a result of somebody transferring out of here to another unit or somebody dying, and one is as traumatic almost as the other." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)
>
> "It still hurts. We still miss him [a resident who had only recently been discharged from the unit]." (Ms. Gallagher, Health Care Assistant of SCU A)
>
> "A few years back we had a young man here. He was about, I think, he was about sixty-ish and his parents were still alive when he died. He had a very aggressive form of dementia and he died before his parents. I found that upsetting. His parents were in their eighties. It was really, really sad." (Mrs. Corbett, Unit Manager of SCU C)

Admissions and discharges occurred so rapidly that it made it all the more difficult for staff to come to terms with losses associated:

> "Like, one could be moved out today and in a day or two's time someone else has moved in, and it's kind of like feeling 'cheers there he is, he is gone'. And then he's gone out and

> someone else is here, coming to his place." (Ms. Gallagher, Health Care Assistant of SCU A)

During one FG (SCU A), several staff members complained at length about the absence of dedicated end-of-life care resources in the unit. This meant that staff was obliged to discharge residents dying with dementia to other facilities and they felt saddened and guilty about this. They said that for the family, this transfer of residents with dementia at end of life from familiar supportive environments to new settings was very difficult. A Clinical Nurse Specialist gave a chilling account of how distressed and powerless she and her colleagues felt because of this inhumane policy:

> "They get referred to another ward, and there is nothing we can do about it. (...). That is so hard for us. It really is. It's almost as if we are doing it. But it's actually the organisational structure. It's causing that to happen. But obviously we're going to get the grief from the families when they are about to be retransferred, and they are afraid, they are nervous." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)

This policy of moving people with end-stage dementia who needed palliative care out of the unit was also in evidence in one of the other two units (Unit B). In contrast to both public units that relocated PwDs with terminal-stage dementia to other settings, the private SCU allowed residents to die in place.

6.3.4.3.5 Adapting to individual needs of admitted PwDs

Staff also talked about the different reactions of residents newly admitted and some were positive and others not so positive:

> "Some will walk in the door as if they had lived here all their life while others won't talk. Others will react quite differently" (Mrs. Kissane, Staff Nurse of SCU B)

Getting to know the resident as a person and accommodating their needs seemed a priority:

"I mean we tend to fit their routine rather than the other way 'round. So I think it always have an impact, yeah. You're trying to find out about the new resident and adapt yourself to them as best as you can." (Mrs. Quigley, Staff Nurse of SCU C)

However, this could place strain on staff members, illustrated by the following comment:

"it is a huge effort on the staff's part, you know. You really have to give up yourself, don't you, to accommodate to everybody." (Mrs. Kissane, Staff Nurse of SCU B)

During the FGs, some staff talked about the concerns they had that newly admitted residents would upset the status quo and disrupt other long-standing residents.

6.3.4.3.6 Dealing with lack of psychosocial supports

Overall, the data show that admitting new residents was also a stressful time for SCU staff. When asked during FGs specific questions about the type of support available to them during admissions all staff claimed that little support was available to help them cope with the distress experienced. It seems too that any support available tended to be practical rather than emotional:

"If there is any query or if you are not sure about something you can always fall back on the management here or on the referrer or on the GP, Public Health Nurse. So you'll fall back on that if you feel that you need more support, there is something not clear, there is something not right, you know." (Mr. Navid, Clinical Nurse Specialist of SCU B)

"I mean the Director of Nursing is excellent. She'd always have a soft spot for SCU A. She always appreciates the work that staff does here and she is good at reminding ourselves about that appreciation." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)

In one unit the Clinical Nurse Specialist complained about the fact that at this critical juncture no clinical supervision was available to him or the other staff. He considered that

this type of support should be available because it was important as were the opportunities to learn from practice:

> "I think to have a clinical supervision is very important to have but there's nothing, no structure in place for that. I think the benefit for the staff to have a clinical supervision where they have the opportunity to look back at the experience and look back at the support in place when they've dealt with an admission, for example, with transfer, and then they can have opportunity to feed back and discuss ways of improving. It's like a reflective practice." (Mr. Navid, Clinical Nurse Specialist of SCU B)

It seems that senior staff went to great lengths to support junior staff during new challenging admissions. Supports offered by them included being available, and approachable, and encouraging front-line staff members to discuss with them the difficulties they encountered:

> "You know you'd always have the support from our Clinical Nurse Specialist, in fairness I have to say" (Mrs. Kissane, Staff Nurse of SCU B)
>
> "I suppose again from a support perspective you did ask earlier for what sorts of support. It's great to know that if any of us can pick up the phone if you're stuck here, to ring our Clinical Nurse Manager if she is at home or if I was somewhere else." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)

Whilst senior staff attempted to support junior staff members during and surrounding new admissions, the data showed that senior staff did not receive any psychosocial and practical supports themselves. In one unit, senior staff involved in new admissions stated that they often provided support way beyond the call of duty and were available to assist staff even on their days off. Some of these senior staff encouraged front-line staff to ring them at anytime if problems were encountered or if advice was needed. Other senior staff claimed they often volunteered to contact the staff on duty in order to get updates about a new resident's settling-in progress and they would remain very involved with new

admissions particularly where problems arose and even when they were officially "off duty":

> "Especially if there is somebody who is coming in who is not settled. If the Clinical Nurse Manager is on her day off she'll ring in to see how we're getting on. If I'm on my day off I'll ring the Clinical Nurse Manager to see how she is settling in." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)

Having responsibility for supporting SCU staff during this phase meant that management staff had considerable difficulties with detaching themselves from the SCU environment as well as from their work experiences. Two senior staff members explained the way in which work issues permeated their home lives:

> "Yeah, you go home and you do it. You switch off and then you do still click in. And the next day you phone up and you say 'well, what's the story?' You do take a certain amount of it home with you, don't you?" (Ms. Devers, Clinical Nurse Manager of SCU A)
>
> "There is that element of it's difficult to move away. It is just, I'm not sure, well, half of me doesn't want to move but the other half wants out on a traumatic time I'd say, yeah." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)

The enormity of the responsibilities involved in supporting staff was often taken home and discussed with other family members after hours. Caring for some of these professional staff clearly did not stop once they went "off duty":

> "Then from a support point of view you tend to go home and keep your partners or husbands or whoever at home up past the night because you are thinking there so much, you know, it's hard to say. It's hard to say." (Mrs. Flaherty, Clinical Nurse Specialist of SCU A)

6.3.5 Section summary

The FGs conducted at the three SCU sites have yielded new insights into the complex challenges SCU staff confront when deciding about new admissions. SCU staff members were guided in their decision-making about who to admit by internal policies reflecting admission criteria. In all three units, residents needed to have a primary diagnosis of dementia and in the two HSE units new residents also had to have challenging behaviors that could not be managed in any other setting. One of the units also required new residents to be able to mobilise independently.

All three SCUs also wait-listed people assessed as being eligible but data showed that for the public units a person's wait-list status was only one of several factors used to determine priority. Both HSE units considered alternative decision factors, such as carer stress, family coping resources, and the needs of other PwDs already residing in the SCU. Other data, however, suggest that family members were not aware that these other factors played a role in determining new admissions.

Data show how all three units also had to accommodate "emergency" admissions and this policy needed a different and more flexible approach. PwDs in need of emergency placement needed to be prioritised, and criteria other than the person's wait-list status had to be considered; for example, pressures to free hospital beds, inappropriateness of other facilities (nursing homes) and the unavailability of community support.

SCU staff in all three units described how they arrived at decisions about admitting new residents. In both public units this process was democratic and involved both junior and senior staff. In contrast, at the private unit this decision was made by senior staff members who later informed junior staff about who would be admitted. Deciding about new admissions was emotionally challenging for SCU staff. FG participants reported that they regularly had to deal with the despair and distress of families who were refused admission. Given they often personally knew these families through offering them respite

care services, this was often very difficult for them. In addition, every new admission meant the death or the discharge of a well-known resident. In both cases families were traumatised and very upset; SCU staff had to deal with these distressing reactions on a regular basis. Losing a well-known resident through death or discharge from the SCU was a particularly distressful experience for staff members, leaving them feeling bereft and guilty.

FG participants also talked about the stress of dealing with new residents who failed to settle into their new environment. This was often the case for residents who had not been told the truth about their long-term stay by FCs. Adapting to the individual and complex needs of a new person was also very stressful for SCU staff. These experiences of SCU staff were aggravated by the fact that little dedicated psychosocial support was available to them. This was particularly true for senior staff members who went out of their way to support junior staff but did not receive any psychosocial support for themselves.

Chapter 7: Immediate and longer-term adaptation to SCUs

7.1 Introduction

Chapter 6 dealt with FCs' experience of the time around placement; how, why and by whom the decision was made, and how information about the transfer to the SCU was conveyed to these men and women most of whom had severe dementia. The chapter also reported on how paid care staff decided about new admissions, what admission criteria were used, and how they coped with new SCU admissions including emergency admissions. This chapter discusses the FCs' perceptions of their relatives' adaptation both in the short term and longer term to the SCU placement and their, the carers', own reactions to the changes the placement meant for them. Wherever possible the respective views of PwDs who were interviewed and who had undergone the transition will be drawn on to illustrate how they were adjusting.

The data presented in this chapter is based on in-depth interviews with the nine FCs within four weeks of the placement and six months later, and on interviews conducted with eight PwDs at phase one and six at phase two. Following data analysis, and given the fact that no major difference was found in data collected during the two phases, findings relating to both points in time will be presented interchangeably throughout the chapter. Since the information collected from these men and women with dementia is most important but very limited and since it was at times very difficult to interpret, the chapter opens with a brief overview of this interview data and then progresses to discussing FC's perceptions of their own and their relative's adjustment during a six-month period following SCU placement.

7.2 Interviews with PwD

As mentioned coding and interpreting the interview data collected from PwDs was no easy task. Often the information collected was disjointed and made no real sense. This is not surprising as several of these participants had an advanced dementia and were significantly disorientated in time. Others were difficult to interview since they had hearing difficulties or did not understand the simple questions posed and gave answers that were irrelevant to the topic under study.

Some of these men and women with probably severe dementia (see Table 2) were living in the past. They thought they were children again referring to their "Mummies and Daddies". Others had returned to their early adult lives believing that they were young parents and that they were rearing their families. One man who gave a lengthy interview seemed preoccupied with ageing and possibly with dying. Sadly by phase two, he had actually died. At phase one he talked at length about being a sheep farmer and spent a lot of time reminiscing about former days, referring to the sky and the roads and outdoor life and walking following sheep and sleeping rough on the roads:

> "I remember when I was a young fellow walking from the North towards... with sheep ... they were all together and I kept walking after them. I walked along the road now and all at the wild. I waked up in the morning and off I started again. I've never seen sheep like them since or before." (Mr. Donohue, aged 86 years, interviewed at one month post-admission in SCU A; MMSE score: 15)

Whilst this man appeared relatively reconciled to being placed in the SCU stating at one point "I'll be here for some more time, I won't... I didn't hear about dying or something", the qualitative data emerging from the interview with him contrasts sharply with that of another male resident whose interview was dominated by repeated reminders of how unsettled and unhappy he was since being moved into the SCU and culminated in an appeal from him to be taken home: "No, I don't like it at all in this place...I don't like it... I

don't like it... I wanna get out". This case was unusual as in all other cases, the residents interviewed appeared to be settling in well to their new environment and by phase two several had made new friends and seemed very content.

There was one other very unusual case where the resident Mrs. McNamara appeared to be completely at ease with the placement commenting "I think it was a wise idea" and appeared to have a lot of insight into her condition: "Well, those other people have the same ailments – something not the exact same as mine but something similar". At phase one, this lady talked about the SCU being "very friendly", "I have no dislike whatsoever", "I'm quite happy here", "it suits me fine", and "I get along quite well... I have plenty in there". At phase two she seemed even more content and made a point of saying that being around people she already knew from that part of the country made adjustment there easier for her. She said:

> "Well, we know of some of them who are neighbours of ours that are here. There's some of them we know, like, and some of them we know long." (Mrs. McNamara, aged 80 years, interviewed at six months post-admission in SCU B; MMSE score: 22)

This same lady particularly liked having her own private bedroom which she repeatedly referred to as her "hutch". She liked the fact that the SCU afforded her privacy, choice, and autonomy and made several references to the activities run by the SCU, even showing awareness of the health benefits of the exercise programme. Despite her relatively content disposition, she did during the phase two interview allude to loneliness and sadness and the need to remain stimulated and occupied when she said:

> "There may be days it hits you, you know, and you'll just feel if there maybe over a long spot that you hadn't anybody with you talking to anybody, and it's Sunday, it hits you then I'm on me own. (...). The worst thing sometimes is that, that the time seems long, that there's nothing to put in the time." (Mrs. McNamara, aged 80 years, interviewed at six months post-admission in SCU B; MMSE score: 22)

These interviews, however, were unusual. Most of the men and women interviewed were not very forthcoming and tended to answer the questions posed generally with monosyllabic replies or with statements about matters irrelevant to the questions being explored (see Chapter 4).

However, I felt that the data suggested that by phase two most of these people were well adjusted to their new surroundings. In my view this point was supported by commentaries such as "it's like being at home (...) there's no pressure on you" (Mrs. Kiely, aged 81 years, interviewed at phase two in SCU B). Several had made new friends and each appeared (in direct response to questions asked about activities) to enjoy the activity programme the respective SCU had on offer. Reference was frequently made during interviews to the excellence of the staff and to the importance of having regular visitors and of residents' remaining socially engaged. For instance, two ladies spoke about their nearest and dearest visiting them regularly. Their commentaries suggested that they very much enjoyed their FCs' visiting, which was evidently important to them and meant their remaining connected with their next of kin:

> "They come to see me every week-, uh, end. It's mainly the lads coming down and down to see me and then you go for a walk." (Mrs. Philbin, aged 85 years, interviewed at six months post-admission in SCU C; no MMSE score available from SCU records)
>
> **Mrs. Kiely**: "Oh, they didn't, they didn't mind coming over here, you know, uhum."
> **Researcher**: "So are you spending then, with your husband, you are spending then the afternoon [with him]?"
> **Mrs. Kiely**: "Yeah, I was spending it with you [to her husband] yesterday afternoon and yesterday we dined. Are we going out to dinner, are we now? Are you taking me out to dinner?" (Mrs. Kiely, aged 81 years, interviewed at six months post-admission in SCU B; MMSE score: 12)

So did these residents' views about life and adjustment to life in SCUs concur with the views of their FCs?

7.3 PwDs' blossoming in the new environment

Chapters 4 and 5 showed how stressed the nine FCs were and how desperate they were to obtain the SCU LTC bed for their relative due to the very high level of care warranted, the safety concerns and other challenging behaviours. Chapter 5 also showed that some of these FCs had competing demands on their time. Several had multiple carer roles and four out of nine also worked in the labour market. In the two cases where the PwD was already in care prior to SCU placement these carers were also very distressed since they knew that the care being provided (in one case in a hospital and in the other in a general nursing home) was sub-optimal.

So how did these caregivers feel once their carer role was relinquished? How did they believe their relatives were adapting to the new care environment? What was it like for these family members adjusting to new roles and responsibilities? The next section will report on these findings. It commences by highlighting - through the eyes of FCs - their perceptions of the immediate and longer-term responses of their relatives to their SCU LTC placement.

7.3.1 A gradual settling-in

At baseline all of the nine FCs interviewed stated that their relative had on arrival settled into the specialist environment without showing any adverse reactions such as distress, fear or anger. Interestingly, six months later the same FCs reported that their relatives continued to settle in; by and large they were adapting well and were continuing to show no adverse reactions. During their interviews all nine FCs stated that their relative was in better form and appeared more relaxed than before.

Carers' perceptions of their relatives' adjustment were generally supported by the views of these newly admitted residents who when asked about the SCU and how they felt, overall

tended to be relatively content with the transfer. Most considered the place homely and very much enjoyed the access to the multi-sensory garden:

> "I like this place (...) something nice to have along the line, you know, and in the flowers". (Mr. Donohue, aged 86 years, interviewed at one month post-admission in SCU A; MMSE score: 15)
>
> "The garden is great. Great to watch it grow, see the little birds. (...). I had a lovely garden." (Mrs. Kiely, aged 81 years, interviewed at one month post-admission in SCU B; no MMSE score available from SCU records)
>
> "I like it alright." (Mrs. Magill, aged 77 years, interviewed at six months post-admission in SCU C; no MMSE score available from SCU records)

Whilst prior experience using residential respite services at these same facilities might help explain the very smooth transition most people had (six out of nine were already familiar with the setting and with the staff through respite care) it is noteworthy that even in the two cases where no respite had been used at the facility, these two PwDs also settled in well to the new facility and showed no adverse reactions at admission or at phase two six months later.

Open-ended questions were asked of FCs about what factors in their view may have helped explain the smooth transition and adaptation of these nine people to the SCUs. Some carers (like Mr. Kiely) talked about the fact that their relatives' level of CI was so advanced that they possibly were not aware of the changed environment, and thus were not affected by the SCU transfer. A husband – whose commentary was reiterated by most FCs - stated:

> "It made no difference. I mean it would have made no difference to Deidre, you know. It's exactly the same as if we weren't doing it. It was like walking into another room. There was no problems at all, none of whatsoever there is." (Mr. Kiely, husband caregiver, aged 76 years; statement made at one month post-admission)

> "She's looking well, she's eating well, she's put on weight, uh, there's nothing that has much changed since, since then [admission and first interview]." (Mr. Kiely, husband caregiver, aged 76 years; statement made at six months post-admission)

Several said that the skills and expertise of SCU staff and their excellence in offering reassurance to their relatives after placement was another important factor that helped the transition remain minimally disruptive. Others commented that using SCUs' respite care services prior to placement clearly facilitated the gradual settling of their relative into the new surroundings because he/she had already been familiar with the unit's surroundings, SCU staff members, and physical transfer routines prior to LTC placement:

> "Auntie Aoife went through the transfer very gradually. She had been in that unit for respite several times. We knew the staff. We knew the physical environment. We knew the ethos of the place. So it wasn't like auntie Aoife was living with us on Tuesday and she was living in some cold, strange place on Wednesday. And the gradualness of that transition I think was very important." (Mrs. Breslin, niece caregiver, aged 43 years; statement made at six months post-admission)

In response to a series of questions asked of FCs about their views on any changes (positive or negative) noted in their relative since placement, most spoke about specific improvements observed although some also spoke about further deterioration including new dependencies and problems. The next section presents data on FCs' observations of both improvements and disimprovements noted in their relatives following the SCU transfer.

7.3.2 Regaining skills

It is interesting that all of the FCs interviewed stated that their relatives had acquired new skills or had regained former skills since placement. Most reported that their relatives were now more alert, socialising more with other residents, and were more stimulated by

interacting with other residents and staff on a regular basis. Most also claimed that their relatives were more physically active than before.

7.3.2.1 Social engagement and interaction with fellow residents

One merit of the SCU was that for the PwD there was constant company; people to talk to and interact with, whereas prior to placement some PwDs (N = 4) had been more solitary. The advantages of having company and stimulation were highlighted by one of the FCs:

> "She has company, constantly, which is great because at home she'd have had her little ladies, home helps, and she'd have had me once or twice, three times a day, whatever was needed but she has constant stimulation now." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years; statement made at six months post-admission)

Narratives such as these reflect the way in which FCs were satisfied with their relative's improved levels of socialising and were happy that their physical and psychosocial needs were being better met now than before. They also attributed such improvements to staff training and expertise and to the purpose-built environment which encouraged engagement and interaction. Indeed, in two cases – and six months following the placement - PwDs had regained skills to the extent that they now had very close friendships established with fellow residents, and were at follow-up spending a lot of time together. In both cases, these friendships were not established immediately after admission but during the follow-up period, exemplifying the fact that establishing relationships with others is a gradual process that takes time. FCs' perceptions of their relative now socialising more, enjoying the company of his/her peers, and gradually adapting to the socially stimulating and meaningful environment provided by SCUs since placement were indeed shared by some of the PwDs themselves when they commented on their new surroundings. For example, at phase one Mrs. Philbin was obviously estranged and only getting used to the new facility whereas at follow-up she had made friends and seemed more "at home":

> "There's lots of people coming in. (...). I don't know anybody in here. (...). There's people in here." (Mrs. Philbin, aged 85 years, interviewed at one month post-admission in SCU C; no MMSE score available from SCU records)
>
> "You're meeting people, different people. (...). And there's a round to seeing everybody else. (...). I've made friends. We are all very friendly." (Mrs. Philbin, aged 85 years, interviewed at six months post-admission in SCU C; no MMSE score available from SCU records)

Statements such as these show the benefits new residents derived by virtue of being in the SCU including more social contact, new friendships, and improved well-being. PwDs' statements also showed that adapting to the SCU's social setting is an ongoing process, made easier when residents feel familiar with others and consider they are alike:

> "I like it here. I'm meeting people, all homely people. There are all people like myself." (Mrs. McNamara, aged 80 years, interviewed at one month post-admission in SCU B; MMSE score: 14)

7.3.2.2 More physically active

The majority of FCs also reported that their relatives were more physically active since admission. Their narratives demonstrated that increased activity levels were promoted by staff who went to great lengths to provide meaningful and enjoyable activities tailored to individual needs. Most FCs stated that these improvements were noticeable immediately after placement, and continued during the follow-up period.

In line with previous findings, improved physical activity levels were particularly noted in cases where the PwD had been isolated and left without psychosocial stimulation in previous settings. In one unusual case where the PwD had prior to admission regressed to the point where she was extremely apathetic and had given up all former interests (gardening, reading the news), after placement, she was once again gardening and at

follow-up she was reading newspapers and helping with seasonal activities such as decorating the SCU's Christmas tree. Her daughter-in-law was very proud of her regaining her former skills and commented:

> "Last year Olivia wasn't fit to put up her Christmas tree. So the kids, my daughter put it up for her and Olivia's daughter. But like this year we came in on last winter week, and she was sitting there and she was handing up the decorations to put them on the tree which's a huge thing... A year ago she wasn't capable of doing that." (Mrs. McNamara, daughter-in-law caregiver, aged 76 years; statement made at six months post-admission)

This FC's comments were reiterated by several other carers who were also very satisfied with their relative's improved activity levels.

Carers' comments were also re-echoed in the words of one resident with dementia who seemed very happy with the activity programme available at the SCU where she was living:

> "We have exercises there now after dinner today (...). Arms up, down, and out and out, in and up [laughs], you know, just to keep your muscles, to keep them ailed. (...). Every morning we go, there's mass at ten o'clock or half ten or a quarter to ten (...) and it's great, it's a great relief to be able to get to mass every day." (Mrs. McNamara, mother-in-law, aged 80 years, interviewed at six months post-admission in SCU B; MMSE score: 22)

7.3.2.3 Improved communication skills

Three FCs claimed their relatives' verbal and non-verbal communication had improved since admission and continued to improve at phase two. According to these carers, their relatives could converse better with family members, smile more, maintain better eye contact, and this was very gratifying for them. Interestingly, the same three FCs claimed that in the month following the admission their relatives' medication had been changed.

They attributed the change in medication to improvements in levels of alertness and responsiveness.

A niece caregiver, who described interactions with her aunt as being tense and stressful for all prior to placement, noted instant improvements in her aunt's verbal and non-verbal skills after placement. She claimed her aunt was now more aware of her surroundings and more interested in their conversation than before. These changes continued during the follow-up period:

> "Dad and I came up on Wednesday for the first time (...). The two of us came in, uh, big smile, she turned and looked at me and said 'That's [name of Mr. Breslin, her brother and Mrs. Breslin's father]. How did you get here? Look, the two came to see me', you know. This was, this was very positive, and she had a big smile, she was engaged, she was looking around at everybody else and everything that was going on." (Mrs. Breslin, niece caregiver, aged 43 years; statement made at one month post-admission)
>
> "For the last few visits now she's been interacting a lot more and making eye contact. (...). She also asked after her brother and sisters the last day I was up for the first time in ages, in absolute ages. It was great." (Mrs. Breslin, niece caregiver, aged 43 years; statement at six months post-admission)

Changes such as these helped carers cope with the placement and made visiting more rewarding since the PwD could now engage in more meaningful conversations, thereby witnessing her blossoming back to her former personality.

Apart from caregivers assuming that improved communication was precipitated by medication changes, they also thought that changes were promoted by staff which had expertise in initiating interactions among residents in facilities which afforded ongoing opportunities for socialising and interacting. For some, improvements in communication may also have triggered off more fulfilling relationships since FCs were now relieved from the unbearable levels of tension and conflict they experienced in former relationships.

7.3.2.4 Fewer challenging behaviours

Three FCs whose relatives had been physically aggressive prior to placement (see Chapter 5) said they no longer exhibited such challenging behaviours immediately after placement and continued exhibiting no signs of aggression at phase two. All three FCs claimed that in hindsight, this aggression was probably an indicator of their distress and discomfort triggered by an inappropriate home environment. The three FCs commented that in their view the specialist approach to care provided by SCUs was the key to eliminating their relative's challenging behaviours including physical aggression.

Several FCs talked about how proficient paid care staff was at managing dementia-related challenging behaviours. One carer talked about the fact that prior to placement her relative used to become verbally aggressive when she attempted to groom, toilet, and shower her which meant that she often looked dirty or unkempt. After placement, however, she said her aunt always looked well-looked-after. She no longer exhibited these behaviours, was in better mood, and appeared well-groomed. This carer indicated that such changes in her aunt's behaviour continued throughout the follow-up period:

> "She is cleaner and she has that lovely cared-for look. That was something I couldn't do, and it's so nice to come in and she always in clean clothes, you know, smells as fresh as a daisy, her hair is brushed." (Mrs. Breslin, niece caregiver, aged 43 years; statement made at one month post-admission)
>
> "Her emotional needs are taken care of, her physical and medical needs are constantly monitored." (Mrs. Breslin, niece caregiver, aged 43 years; statement made at six months post-admission)

There was one very unusual case where a daughter reported that her mother immediately following admission was prone to behaving aggressively towards other residents and staff. The carer said that in the early days following admission her mother hit, scratched, and shoved these people around and took ownership of dolls and teddy bears. She claimed that these behaviours caused much distress and reflected in her view a type of protest on

the part of her mother against the move into the SCU. She made a point of saying however that this behaviour had stopped completely by phase two, and six months after admission her mother appeared well-adjusted to the new setting:

> "The other day she attacked a lady in there and marked her. (...). The first week, ten days I think she had her first instance where she I think attacked one of the care staff or the nurses, I'm not sure about which, and scratched their face. And I think there were a few instances of that. (...). Then the other day she attacked a lady who comes in here for respite." (Ms McCourt, daughter caregiver, aged 52 years; statement made at one month post-admission)
>
> "There's very little aggression there now. The odd times she'd get a bit stroppy, you know, but nothing like she was." (Ms McCourt, daughter caregiver, aged 52 years; statement made at six months post-admission)

Apart from attributing a decrease in aggression to staff skill and expertise, two other FCs believed that reducing the use of PwD's psychotropic medication may have resulted in a reduction in aggressive or agitated behaviour in their relatives.

'Blossoming' for PwDs in their new environment after placement did not only mean a regain of skills and improvement in well-being but also meant that some of these residents enjoyed better physical health. Indeed, most FCs talked at length about the positive changes they had noticed in their relative's physical health both immediately after placement and six months later. Their narratives will be presented in the next section.

7.3.3 Improved eating behaviours and weight gain

Six FCs reported that their relatives' eating habits and food intake had improved since placement and four out of the six said that such changes occurred quickly after placement and continued to improve during the follow-up period. In the two other cases the improvements were only noted at follow-up.

Ms Sheehan who prior to placement was a patient in an acute hospital ward had gained weight since SCU admission. Mrs. Kiely who prior to placement had been placed in a generic nursing home where she had been losing weight stopped losing weight after SCU placement; indeed, her weight was stabilised after SCU placement. In both these cases carers reported that prior to placement their relatives had been living in unsuitable facilities and were very distressed. They maintained that in these facilities where staff had no training in dementia (general nursing home and hospital) their relatives had not received proper assistance at meal times, and their eating habits had not been properly monitored.

These two FCs reported that during the six months after placement their relatives gained weight and both reached a healthy weight at phase two. They attributed improvements primarily to the person-centred care administered by staff skilled in dementia care. One of these caregivers said:

> "She did go through a phase where she wouldn't eat. This was until quite recently, uh, maybe two months? But she lost an awful lot of weight and just went from only having a little bit down to virtually eating nothing and the girls handled it with such sensitivity. (...). They never stopped keeping an eye her, and they also kept an eye on her medication. Her meds were changed in recent weeks and she is eating again. So I myself found it very heartening that they didn't, they never stopped seeing the person. It never just became 'that's, uh, the next phase of dementia'. It was always 'maybe it isn't, maybe we could change something'. So I found that, I found that wonderful, very heartening." (Mrs. Breslin, niece caregiver, aged 43 years; statement made at six months post-admission)

Others stated that enhanced care practices including monitoring residents' food intake and eating patterns, respecting individual food/eating preferences, providing individualised assistance with meals, and regularly weighing residents resulted in noticeable improvements.

As mentioned earlier, many residents with dementia were unable to volunteer much information due to the severity of their dementia. Nonetheless, a few in direct response to questions about meal times and food commented very positively about the meals in the SCUs:

> "I like the food alright. (...). Get sit down there, you can have a good feed or whatever, uhm. So that's one good point anyway, like." (Mr. Donohue, aged 86 years, interviewed at one month post-admission in SCU A)

This gentleman's statement was reiterated by other PwDs interviewed across all three SCUs. It seems that meals served in the SCU's family-like atmosphere and under the supervision of staff provided PwDs with pleasant sensory experiences, resulting in their enjoying eating, having better food intake, and in some cases gaining weight.

7.3.4 Improved mobility

Three FCs said that their relative's mobility had improved since admission. Improvements in motor skills, gait, and independence in walking were noted. In two cases, gains in mobility were noted immediately after admission and in the other case they had occurred by phase two. One carer told the story of her mother-in-law, who following admission underwent a major transformation. She changed from being apathetic and immobile to now being someone who enjoyed walking and even outpaced able-bodied visitors when it came to walking outside the SCU:

> "My husband was in yesterday and I wasn't. And she, she said she'd go for a walk, and, uh, they went up out around the hospital and, you know, I weren't, and she just told him 'You better quicken up', she says, 'I can't walk as slow as that.' I mean two months ago we were linking her, like, on a walk she was slow and we were linking her. Like, it's a, it's a complete change." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years; statement made at six months post-admission)

In another case where the PwD had been in a general nursing home prior to SCU placement and had been physically restrained, her husband reported how immediately following placement she was independent in all her ADLs. She could dress, go to the toilet, walk, and stand up independently. Indeed, he said that she continued to improve after phase one and was even at phase two able to independently perform most complex motor tasks. In the nursing home he said she could do nothing for herself as she was physically restrained. Her husband was most satisfied with the fast and marked recovery his wife made in the SCU. Commenting on this, he exclaimed:

> "I couldn't believe it. The other day I came in she was standing in the kitchen, drinking a cup of tea. Three weeks ago, three weeks ago she couldn't do that. Three weeks ago she couldn't stand up. To remind that for, I call this [SCU B] Lourdes and Fatima." (Mr. Kiely, husband caregiver, aged 76 years; statement made at one month post-admission)

Overall, these findings show that in several cases newly admitted residents regained former skills, enjoyed a healthier diet, were more independent, and blossomed so to speak immediately following SCU admission and indeed subsequently. For FCs witnessing such changes was important and helped them cope better with the SCU LTC transition.

7.3.5 Some disimprovements

Despite these improvements and what most FCs reported as being a smooth and successful transition for their relative into the SCU, some FCs also talked about disimprovements observed both in the short term and longer term in their relative's health and well-being. These disimprovements will be outlined in the following section.

7.3.5.1 Wanting-to-go-home behaviours, withdrawal, and depression

Data were contradictory as, despite all of the carers stating that their relative settled in well with no adverse reactions, there were two cases where the PwD was also described

by the FC as being initially unsettled and showed problematic 'wanting-to-go-home' behaviours.

One of these was Mrs. Kiely, an 81-year old lady, who had been admitted to the SCU from a traditional nursing home. Her husband reported that she found it very difficult to let him go after his visits and tended to get extremely upset, wanting to leave the SCU with him. He also said she used to constantly search for him during times he was not in the SCU. Her gradual adjustment to the new care environment can be seen in his description of the situation at the two points in time. On being asked how she was settling in at the first point in time, he said:

> "All she wants now is me and to go home and that's heart-breaking. (...). She did initially in the nursing home [but after her initial nursing admission she ceased to show these behaviours until first four weeks after SCU placement]. Every time, it was absolutely heart-breaking. She would come to the window and she would wave at me and then I could see her crying. So when she started this now about going home, this is it going to bring it all back to me again." (Mr. Kiely, husband caregiver, aged 76 years; statement made at one month post-admission)

But later (six months after his wife's SCU placement), he claimed:

> "Some days she wants to go home and see her old house and maybe the rest of the time she is quite happy, she's even telling me to go home because it's getting dark or something. But she does certainly have her bad days when she is crying that she wants to go home." (Mr. Kiely, husband caregiver, aged 76 years; statement made at six months post-admission)

Other disimprovements noted only after six months were personality changes such as the person becoming withdrawn. Such changed behaviours caused carers stress as exemplified by this husband caregiver who talked about his wife withdrawing from any physical intimate contact with him:

"She is just getting a little bit shy now with, uh, if I hold her hand. She just took to holding my hand here, and we all thought she, well, that she was holding my hand and then we would give her a hug and a kiss but now she doesn't want to. I don't know what, why that is as it is." (Mr. Kiely, husband caregiver, aged 76 years; statement made at six months post-admission)

In two other cases, the newly admitted residents were treated for depression. One of these ladies, Ms Breslin, at first refused to eat and was severely underweight at the time of admission and the other lady refused to mingle with others and spent much time in bed. At follow-up, however, both ladies appeared to be better adjusted and showed no signs of depression at six months after placement:

"It did seem to, uhm, Ms Devers the ward manager that Aoife was depressed, and they did, uh, trying her on a couple of different meds. (...). They changed her Ofolon med and put her on a different one, and added a dose of anti-depressant and the whole thing seemed to work. Just after that I went up one day and she looked up at me for the first time in ages, and I got a big smile for the first time in ages, and then she started eating." (Mrs. Breslin, niece caregiver, aged 43 years; statement made at six months post-admission)

"She went through a period, alright, yeah, while back that she was staying in bed a lot, you know. She wouldn't get up, like some days she wouldn't get up at all. And then other days maybe she mightn't get up 'till one or two o'clock, uhm, that kind of thing. But I think that has passed as well. She seems to be getting up now eight or nine o'clock or whatever time and she stays up for the day." (Ms McCourt, daughter caregiver, aged 52 years; statement made at six months post-admission)

7.3.5.2 Other disimprovements

Although as shown in section 7.3.4, three FCs claimed their relatives' mobility had improved since SCU admission, there were four other cases where FCs reported a decline in their loved ones' mobility. In one case, mobility disimprovements were such that

at follow-up a walking frame was now needed. Other disimprovements were also reported. One lady had become doubly incontinent and in another case, an 86-year old man developed serious lung problems and subsequently died.

Similarly, even though eating habits had improved (see section 7.3.3), there were four cases where dietary habits had disimproved and in two of these four cases the PwD had lost weight. In these cases, the FCs stated that the staff, aware of this, were now providing full assistance during meal times, giving their relatives fortified food, and carefully monitoring their weight.

Despite being aware of some adverse changes, by and large FCs attributed such deterioration to the progression of the dementia and they were in general pleased with the quality of care on offer. Overall, the narratives of these nine FCs clearly revealed that most FCs believed their relative's health and well-being had improved significantly since the time of admission:

> "If there is [any change since admission] it's probably better changes because she, she's contented." (Mrs. Forbes, daughter caregiver, aged 50 years; statement made at one month post-admission)
>
> "In general she is much better, much better, yeah." (Ms McCourt, daughter caregiver, aged 52 years; statement made at one month post-admission)
>
> "I can see a big improvement like in her care that we weren't able to provide for her. That's why I'm happy." (Mrs. Forbes, daughter caregiver, aged 50 years; statement made at six months post-admission)
>
> "She is very happy, she is well-fed, she's has put on weight, physically she is well and she gets all the attention she needs." (Ms McCourt, daughter caregiver, aged 52 years; statement made at six months post-admission)

7.4 FCs' adapting to new roles

The previous sections have shown some of the improvements and disimprovements noted by caregivers in relation to their relatives' health and well-being following placement in the SCU. FCs welcomed the fact that by and large their relatives appeared to be adapting well to their new surroundings. This appeared to reassure them that they had made the right decision in admitting them. When during the in-depth interviews further questions were asked regarding changes they noted to their own lives following the relinquishing of the care role, several spoke at length about the practical and emotional changes the placement meant for them. They also spoke about the challenges they were coping with adjusting to their changed roles. The next section will present data on these issues.

7.4.1 SCU visits and new evolving roles

Questions were asked of each of the nine participants about what changes had occurred in their own lives since the time their relative was admitted to the SCU. Not surprisingly, and during both interviews, most FCs said that being no longer involved in their relative's daily care and taking on the new role of visiting was the biggest change witnessed. This relinquishing of the full-time care role appeared most difficult for those who had lived with their relative prior to placement. The physical separation created a void in their lives by virtue of no longer being physically engaged in caring tasks and was considered difficult.

The issue of being married yet being virtually widowed and feeling exceptionally lonely as a result of the change in social identity was well illustrated by a spouse who had been so busy with caring prior to the placement that now she felt bereft and had a void in her life:

> "It's hard to get used to the idea [of having Mr. Conor live in a SCU] as well because if you spend your life with somebody, you go everywhere together and, you know, and especially at bank holiday weekends and we used to go for a drive and, you know, every Sunday

nearly, and, uh, it's lonely. This can be lonely." (Mrs. Conor, wife caregiver, aged 57 years; statement made at six months post-admission)

"I feel it's awkward that when you're bereaved and you're sitting there and you don't know what to be doing or saying and, 'cause I wouldn't have the time to be looking at him at home. I'd be running around doing everything, you know." (Mrs. Conor, wife caregiver, aged 57 years; statement made at one month post-admission)

Each of the three SCUs had open door visiting policies, which were welcomed by FCs - enabling them to visit whenever they wished. It meant that carers could see their relatives without making formal appointments with staff. They were also allowed to take their relative out for brief outings such as a drive and get access privileges such as door codes. This freedom to choose when to visit was important for FCs:

"They give you the code of the door and you can come and go whenever you want." (Mrs. Breslin, niece caregiver, aged 43 years; statement made at six months post-admission)

"They have great visiting facilities here and you can come in and be with Mummy whenever you want." (Mrs. Forbes, daughter caregiver, aged 50 years; statement made at six months post-admission)

Apart from day outings, each of the three SCUs encouraged relatives to whenever possible take residents out for brief visits home or even overnights. FCs commented that this freedom to bring relatives back and forth to the community – albeit for very brief stays - was vital for helping to maintain relationships and helping PwDs connect back to the former lives they had had prior to placement. For some taking their relatives home from the SCU for outings and overnights helped allay guilt and made coping all the more bearable:

"I said to them in here, you know 'is it o.k. if I take him out now and again?' And they said 'no problem', you know, that I can take him out for a night or two nights, and bring him back

in." (Mr. Donohue, nephew caregiver, aged 56 years; statement made at one month post-admission)

"That then, you know, uh, was important for me, you know, the fact that we could take him out, you know, because it took the hurt of out of, uh, having him, you know, have him to-to put him in permanent care. So, from that aspect, uh, I'd say that's very important." (Mr. Donohue, nephew caregiver, aged 56 years; statement made at six months post-admission)

For most, the transition from being ensconced in a full-time all-consuming care role to now caring at a distance meant that time spent together was often less task-orientated and more quality-driven. This aspect of caring at a distance was well illustrated by one FC when she said:

"It's getting your head 'round the idea that I'm not the primary carer anymore. But it's meant that any time I do spend with her is much nicer. It's much more relaxed. Well, I'm now on the outside of her care. I'm not the only one doing it, and that-that feels great. That does feel very good." (Mrs. Breslin, niece caregiver, aged 43 years; statement made at six months post-admission)

In response to questions asked about visiting, most FCs claimed they visited once to three times a week. However, in one unusual case, initial visits by a husband carer were up to three times a day. By follow-up, this gentleman had reduced such frequent visiting to once a day. This was the husband who felt guilty having placed his wife in the nursing home prior to the SCU placement where she had been physically restrained. At follow-up he remarked:

"I come in every day. They [the staff] wish that I would come in every second day and not come in every day. But I just feel that I have to. (...). I come in the afternoon and then I'd come in, the next time I'd come in at seven o'clock and I'd stay for an hour, an hour and a half." (Mr. Kiely, husband caregiver, aged 76 years; statement made at six months post-admission)

Visiting was not always easy for family members. More than half (N = 5) talked about their relative no longer recognising them – a phenomenon which was very distressing for them. One of these, a daughter, talked about her mother constantly searching for her first-born child whenever she would visit. The daughter found this upsetting particularly when her mother failed to ask after anyone else. She said:

> "She looks for [name of FC's eldest sister] and no-one, and that's it. No, she never looks for any of her children now. She looks for Mummy alright, and Daddy. I'd say she does. She's gone back a lot." (Mrs. Forbes, daughter caregiver, aged 50 years; statement made at six months post-admission)

Questions were asked of all FCs about the purpose and meaning behind visiting. Responses demonstrated that visiting was deemed very important for most since it meant maintaining relationships. Carers who had young children considered visiting an important mechanism for enabling their children to maintain relationships with grandparents:

> "We still all visit her, well, just from my family. That would be my husband and the kids. We always come in together. So still we are trying to keep the continuity there with the children that Granny, even though she doesn't look at us she's still around and we're still up to see her. (...). We do make a very conscious effort at least once a week the four of us come to visit." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years; statement made at six months post-admission)

Having visitors was also very important for some residents, who during interviews, often talked about their family members, sons, daughters, and grandchildren (see page 216).

Yet some residents despite having regular visits, clearly felt lonely and bored and would have liked to have had more visitors:

> **Mrs. McNamara**: "You have nobody in up here where I am. I have a son married out. (...). He comes in every night to me himself with the little daughter he has. (...). They're regular, he's very good. (...). I miss family friends and neighbours, and relations that always popped in when they're passing to go into town or something. They'd always con-, come in for a

while and sit down for a half hour and chat and they'd talk and have a cup of tea and go off, and you mightn't see them again for a, a week or maybe even a fortnight or something, you know, but you-you always had somebody you knew that would call up, pull up and come in."

Researcher: "Uhum-uhum, uhum. And you don't have this here in this place?"

Mrs. McNamara: "You don't have that here because we're just too many people here." (Mrs. McNamara, aged 80 years, interviewed at six months post-admission in SCU B; MMSE score: 22)

"We have nothing here." (Mrs. Magill, aged 77 years, interviewed at six months post-admission in SCU C; no MMSE score available from SCU records)

The data show that FCs remained involved in caring even at a distance. Regular visiting enabled them to monitor the quality of care provided by staff and discuss with staff any concerns they had about their relatives' care needs and well-being. This regular visiting meant that they could witness first-hand the type of care that their relative was receiving:

"It's over and above what we, what we expected. It really is, you know. It, it really is very, very good. And you feel very comfortable coming down here." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years; statement made at one month post-admission)

"I think it's excellent and, and you can come in at any time, well, not during meals, and you can see for yourself which I like that. So you can see, so I think it's first-class, the care that Mummy is getting." (Mrs. Forbes, daughter caregiver, aged 50 years; statement made at six months post-admission)

Visiting also allowed carers to advocate for their relative's rights and dignity. For example, in one unusual case a daughter carer recounted an incident where she witnessed a nurse behaving aggressively towards her mother wrenching an object from her hand. The incident upset her enormously and after consulting with other family members she decided to complain. Her complaint was handled immediately, and the respective staff

member apologised sincerely. However, this carer's narrative well illustrated how traumatic and upsetting it was for her to witness a relative being subjected to poor care practices and how challenging it was for her to complain about the incident to nursing staff:

> "[After the incident] I went home anyway, and trying to calm down and think about and all that. And, uhm, I told my brother and my daughter and that, and they were appalled as well, you know, I was really, uh, really annoyed. So anyway, I couldn't, I wasn't going to let it go, I just didn't want, uh, you know, report it until I, I'd calmed down. So I came back in anyway the next day and I reported it to, uhm, one of the nurses in there and she spoke to the lady in question and we met, the lady in question who did this to my mother, and myself met that day, and, uh, she apologized profusely. She was really apologetic and all that, so that was that done and dusted, you know, but I couldn't let it go because my mother is so defenceless." (Ms McCourt, daughter caregiver, aged 52 years; statement made at six months post-admission)

The narrative reminds us of how vulnerable PwDs and indeed family members are and how the complaint was ultimately well handled. The FC felt hugely reassured and confident. The account also reminds us of some of the new concerns FCs had to deal with after their relative was placed in the SCU.

7.4.2 Re-establishing FCs' personal life

So far this chapter has reported on some of the changes noted by FCs to the health and well-being of their relatives following SCU placement and what care-giving at a distance meant for these people including how often they visited and how they felt during these visits when their relatives no longer recognised them. However, apart from renegotiating their care-giving roles, all FCs talked at length about the new challenges they confronted re-establishing their personal lives.

Being exempt from hands-on caring and physically separated from their relative meant that most FCs had more time and freedom for themselves. Those who worked in the paid labour market continued to work (N = 4) and those engaged in other caring duties (children and other relative care) said that the placement meant they had more time for such care tasks. Life had moved on since the time they had full-time care roles for their relative with dementia and some who had busy work roles reflected over and even marvelled at how they had managed the full-time dementia carer role for so long:

> "Do you know, we're just so busy, we often say 'how would we have time to look after Granny as well as do everything else', you know? It's, it's just a farm life. It has, oh, everything had to continue as normal, like it used to go on when she was there." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years; statement made at six months post-admission)

One third of the FCs spoke about the new hobbies and personal activities they had adopted since the placement. New interests included taking up regular exercise, having music lessons, and participating in social events such as bingo and nights out with friends. Engaging in such activities had not been possible prior to placement, when their care roles were so extensive. It was as if these carers were given a new lease of life.

A middle-aged spouse carer who was very distressed after having placed her husband resolved to "get on with myself" and reported that she was now going for regular swims. She also described how she had now more time and she had also commenced attending dementia-related seminars which she felt would help her during her visits to her husband. It was reassuring for her through such courses to meet others with similar experiences:

> "I'm doing a course tomorrow. It's great, yeah. It gives you a feeling of that you're helping instead of sitting there looking at him doing nothing. It's great, yeah, because you find out how other people have the same problem. (...). [Prior to Kieran's SCU placement] I went to a couple of their [ASI] meetings but [Pause] I didn't really get anything from. I'd say I just wasn't interested enough; whereas now I'd take more interest 'cause I want to know more

about Alzheimer's." (Mrs. Conor, wife caregiver, aged 57 years; statement made at one month post-admission)

Six months later, this lady still continued to enjoy swimming and had also taken up keyboard lessons.

A younger daughter-in-law carer explained that since placing her mother-in-law she now had more time to spend with her child. During the interview she described how they both went for regular swims and were planning a family holiday. This carer made it very clear that she had neglected her daughter's needs in the past because of the extensive level of care her mother-in-law required. Her comments were reiterated by others:

"I can spend more time with my daughter now. (...). We go both swimming in the mornings now. It'll be all the little things like that, that, you know, we wouldn't have been able to do, uhm, because it would have been on edge all the time and, uhm, we are going to go on holidays now. (...). My daughter needed her child-time, you know. She's only ten, and she needed her time too." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years; statement made at one month post-admission)

As mentioned (see Table 2) four of these women had other caring roles including caring for other sick family members. Six months after the placement two of these women were continuing to look after their relatives, in one case a father-in-law with cardiac problems, and in the other a parent with dementia. Rather than giving them more time for themselves, in both these cases, the placement gave these two women more time for other care roles:

"I have more time for my Mum which without sounding like the biggest carnivore but she is my priority for I have more time to spend with her because she is upstairs and Aoife was downstairs and you couldn't leave Aoife." (Mrs. Breslin, niece caregiver, aged 43 years; statement made at one month post-admission)

> "You have more time for [name of PwD's husband]. When you have two of them at that, you know, age, like. He is eighty-nine, you know." (Mrs Ryan, daughter-in-law caregiver, aged 53 years; statement made at six months post-admission)

Despite adapting to their changed roles, the changes and adaptation were accompanied by complex emotional reactions and the next section will report on FCs' emotional reactions.

7.4.3 Complexities of feelings

FCs reported experiencing myriad emotions when asked about how they felt after they secured the bed in the SCU and after they placed their relative. Both during baseline interviews and later, their narratives reflected complex emotional reactions and some paradoxical feelings. Closer inspection of data showed that whilst all FCs reported complex emotions, spouses and adult daughters seemed distressed by the separation and tended to have more intense and enduring emotional responses.

7.4.3.1 Relief and guilt

All FCs claimed they were relieved at being exempt from their earlier care-giving duties including the around-the-clock practical and emotional aspects of dementia care. At follow-up, each described how they continued to feel relieved. However, for most (N = 7) relief was accompanied by guilt; in some cases they believed that they may have placed their relative prematurely. Closer analysis of data show that feelings of guilt were most pronounced for spouses, one of whom said she felt tortured by the thought of having abandoned her spouse and acting selfishly. Mrs. Conor said:

> "I thought he must think I must have putting him in here to be done with it." (Mrs. Conor, wife caregiver, aged 57 years; statement made at one month post-admission)

Comments such as these seem extraordinary given the high dependency needs of their relatives and the way in which care-giving had dominated their lives.

7.4.3.2 Bereavement, loss, and being alive

All FCs talked about being saddened by the placement and these feelings of sadness for most continued over time. Some – in particular the spouses and adult daughters - mourned the loss of the life they might have shared with the person had he/she not been admitted to the SCU. The two spouses seemed overwhelmed with grief. They now felt intensely lonely and isolated. Both spouses appeared to be particularly distraught by the placement at baseline and their virtual widowhood but their feelings of grief and loss at follow-up were somewhat abated. This slightly changed perspective enabled them to perceive and enjoy their partner's improved well-being at six months after placement:

> "I feel much better, we all do that she is, that she is, uh, that she is so well." (Mr. Kiely, husband caregiver, aged 76 years; statement made at six months post-admission)

7.4.3.3 Uncertainty and security

Despite FCs feeling relieved that their relatives were now safe and receiving professional care, more than half (N = 5) continued to have concerns about the future. These concerns centred around quality of care issues, nursing home discharge policies, and end-of-life care. It seems that several FCs simply did not know what the future held - how long the SCU would continue to care for their relatives and whether or not they would be allowed to die there. These concerns continued to cause them distress but were mitigated by the fact that their loved one was now in a safe and secure environment and receiving quality care. This 'security' of knowing their loved one was in good care also reinforced a sense of confidence about having made the right decision, as exemplified by the following statement:

"It's a big decision to make to put her into long-term but it made the decision much easier by her getting a bed here in SCU A 'cause it's so good." (Mrs. Ryan, daughter-in-law caregiver, aged 53 years; statement made at one month post-admission)

7.5 Reflections on quality of care - Satisfaction and dissatisfaction

All nine FCs viewed the SCU as a more suitable and supportive environment than home. Their perceptions were unequivocal and their positive views about aspects of the SCUs' physical environment and dedication of staff skilled in delivering person-centred dementia care became apparent during both the interviews.

7.5.1 Improved safety

All of the nine FCs referred to the safety features of the SCU environment, the design of which was such that the person was safe i. e. unable to leave ("escape") unaccompanied; was less likely to fall (no stairways to negotiate); and was at a minimal risk of harming themselves or others. Being impressed with safety features of the SCU was understandable, given the enormous safety worries all families had prior to placement:

"That was my particular, uh, thing, uhm. I-I felt Olivia was going to be safe, uh, I felt she was really getting to the stage where she was no longer safe during the day and I couldn't mind her during the day." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years; statement made at one month post-admission)

"The main difference is the safety. She is secure, she can't leave there and wander and fall outside. (...). The main thing I think we're happy with is the safety element of it. We know she is ok, we know she can't get out into the concrete and bang her head." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years; statement made at six months post-admission)

7.5.2 Increased psychosocial stimulation

During both interviews, all FCs reported how much they appreciated the value staff placed on non-pharmacological interventions. Apart from being happy about the fact that their relative now had ongoing stimulation and company, they also talked about the value of safe outdoor multi-sensory gardens and therapies such as dolls, painting and reminiscence. One of the SCUs had a Snoezelen room although no comment was made about this.

Each of the SCUs had carefully developed activity programmes and carers talked about how impressed they were with ongoing opportunities offered to their relatives to engage in meaningful, enjoyable activities. Activities, such as gardening, attending mass, and going on day trips, were actively promoted by SCU staff. Activities also seemed to be tailor-made and individualised and even when routine domestic activities were not enjoyed by some, other activities with a focus on sensory stimulation could be introduced:

> "One thing I noticed that the ladies do was folding laundry. Everybody's sitting around the kitchen table, sorting socks and folding laundry. (...). It's not busy work, it's not pretence, it's something to work, it's a real, it's really socks and they really have to be sorted out. So I noticed that the girls are putting a lot of effort into thinking about that sort of thing, and I'd say Aoife wouldn't do any of that. (...). She [also] always liked music and dancing and that sort of thing. But they get plenty of that up there, more than she would have gotten at home. She always liked being somewhere where there was activity and watching [others]" (Mrs. Breslin, niece caregiver aged, 43 years; statement made at six months post-admission)

In fact, one lady diagnosed with VD when asked about her life now in the SCU said that she enjoyed activities such as dancing and cleaning:

> "Well, it's very good. We'll dance. (...). Now it's going clean thing, clean (...) and put them in and, uhm, that's what we do, we are doing things like that and, uh, it'll bring in fun." (Mrs. Ryan, mother-in-law, aged 81 years, interviewed at six months post-admission in SCU A)

7.5.3 Increased privacy

Carers also talked about the privacy afforded to them during visiting times. All three units had visitor rooms and lounges for residents and visitors. During visits carers had a choice of either seeing their relative away from others (going to own room or private place) in order to have privacy or joining other residents during the visit:

> "We came in on Mother's Day last Sunday, and we took her out of the day room and we brought her down and we sat and talked." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years; statement made at one month post-admission)
>
> "We had her birthday here, and we brought in a cake, and we had about three other ladies that we didn't even know sitting eating cake with us." (Mrs. Philbin, daughter-in-law caregiver, aged 37 years; statement made at six months post-admission)

Privacy was also very important to some of the residents. Mrs. McNamara for example referred to her bedroom as a "hutch" (see page 215). She felt very safe and content (in particular during night-times) in her private bedroom but objected to the fact that her name was over her door. She welcomed other aspects of the physical environment, such as appropriate room temperature, lighting, and ensuite washing/ toileting facilities. Her case poignantly illustrates the importance of respecting and meeting SCU residents' individual privacy needs:

> **Mrs. McNamara**: "I'd go to bed and would have a place here alongside the hospital and it's a hutch, they call it. (...). It's a little house, and there's just one room in it, and it's single-bedded, and everybody owns their own one. I got one when I came in, and that was awful because, you know, my name is over the door and a photograph of me on it. (...). When I go to bed and shut the door there's no one in that room but meself."
>
> **Researcher**: "Do you like that?"
>
> **Mrs. McNamara**: "I do. I love it. It's cosy and it's warm and there's [a] toilet installed in there, electric light and all, so what more could you ask for?" (Mrs. McNamara, mother-in-law, aged 80 years, interviewed at six months post-admission in SCU B; MMSE score: 22)

7.5.4 Person-Centred Care

The quality of care offered to their relatives including its person-centred focus was something remarked upon by all nine FCs. Each said that the quality of care was now markedly better than before as a result of 24-hour-care available from trained staff members and said that their relatives' care was tailored to individual needs, offered choice, and was aimed at reinforcing personhood (see pages 3-4).

During the in-depth interviews carers spoke about the training and professionalism of the SCU staff and their wealth of experience in dementia care:

> "I mean it's a medical condition but it's so much more than that, you know. There are aspects of depression. You need training. You need to learn all of this stuff. It's not a casual thing that you pick up even though, you know, a lot of the staff up there is actually nurses. They still have the training and they still have fifteen, twenty years of looking after people. And that's a brilliant thing in and of itself." (Mrs. Breslin, niece caregiver, aged 43 years; statement made at six months post-admission)
>
> "I think the people that are in there, like, they have, uh, a good understanding of what's going on and, you know, trying to do the best they can." (Mr. Donohue, nephew caregiver, aged 56 years; statement made at six months after placement)

Most believed that SCU staff always attempted to improve care practices and respond to FCs' suggestions on how to enhance care:

> "If there was anything that could be done [better] I, I'd tell the staff up there and we would try to figure out a way of doing it better." (Mrs. Breslin, niece caregiver, aged 43 years; statement made at six months post-admission)

Some residents interviewed alluded to the high quality of care they received when asked to comment on the SCU staff. They were described as very nice and good and made residents feel well cared for:

> "They are very helpful and very nice, they come round, do you see me, do you want anything and, come in to you at night and see you before they go to bed to see if you are alright before they go. You couldn't ask for better." (Mrs. McNamara, aged 80 years, interviewed at six months post-admission in SCU B; MMSE score: 22)

Knowing their relative was being well looked after was very important for FCs and most settled in very well – this was very reassuring for the carers. Whilst in general these FCs were very grateful for the quality of care delivered to their relatives, four carers voiced complaints about poor policies and practices and the next section will report on these issues.

7.5.5 Dissatisfaction with some care practices

7.5.5.1 Noise

It is curious that whilst SCUs are designed to be peaceful environments where attention is paid to the control of unnecessary stimuli, noise was an issue in each of these three units and a disturbance I myself witnessed when attempting to conduct interviews. It was also an irritating aspect of SCUs mentioned by two FCs. In particular, complaints were made about the door alarms used in two SCUs as according to these carers these alarms caused residents distress:

> "The door going out to the main hospital and the door going out here is alarmed and, uhm, if they go out the-the thing goes loud. (...). Olivia hates the noise of the thing. You know she is deaf, she hates the noise of the thing." (Mrs. McNamara, daughter-in-law caregiver, aged 51 years; statement made at six months post-admission)

> "Sometimes, like, when the lock buzzer goes off as well it drives her mad." (Ms McCourt, daughter caregiver, aged 52 years; statement made at six months post-admission)

One FC, a daughter[11], also complained about TV noise. These complaints related to a TV being on in the visitors' lounge near the main entrance and playing ongoing traditional Irish music. The carer said:

> "There is a TV there, and it has all that old Celtic music on at all of the time, and that tin-whistly stuff (...). It drives me [with emphasis] feckin' mad every time I walk there, you know, but she'd walk away from that as well, you know. She'd just change directions from here to down there if she is not in the mood for listening to it, and other times she'd probably try and sing along with it. But sometimes it does irritate her." Ms McCourt, daughter caregiver, aged 52 years; statement made at six months post-admission)

In another case it was a resident with dementia who herself complained about the TV music at the follow-up interview when she said:

> "The loud music is a nuisance. I can't hear another thing. I hate it." (Mrs. Philbin, aged 85 years; statement made at six months post-admission; no MMSE score available from SCU records)

7.5.5.2 Communication problems

Other complaints were made about communication between families and staff, and difficulties experienced by relatives trying to access senior staff. For instance, one of the FCs talked about the fact that when she wished to speak to the Unit Manager about her mother-in-law's welfare, that person was never available. She also complained about the fact that if she spoke to junior staff members about her concerns they did not always pass on her concerns and queries to the person in charge. There was also sometimes confusion about which staff members were responsible for dealing with FCs' concerns. She said:

---

[11] None of the other eight FCs complained about this type of noise (N = 6 in public units, N = 2 in the same private unit).

Mrs. Philbin: "It's just lately we haven't noticed Grainne [Unit Manager] at all. (...). They were getting a beautician and we didn't want to. But you'll find you don't know who to mention it to because you mention to some of them, and they're actually nurses, they're care assistants, you know. So it is, it can be, it depends on the time we visit I suppose. Now if you get them on the phone, you can phone them up, no problem, but when we're in and we're trying to see someone it's hard enough to track them down sometimes. Now having said that, like I said, the care is fantastic. The girls are great, and the lads but it's just to get someone that's senior. If you had a problem it can be hard enough to track them down. (...). Whenever we're in for a visit and we find something on the evening and we go 'oh we must say that to Grainne' and then Grainne is not there or [name of female staff member] is not there or we're kind of watching out for them, you know [laughs]."

Researcher [laughs]: "And is it [requests] passed on?"

Mrs. Philbin: "It can be. Sometimes we've noticed it's not."

(Mrs. Philbin, daughter-in-law caregiver, aged 37 years; statement made at six months post-admission)

7.5.5.3 Other deficiencies in the physical environment

In particular, complaints were made about the private unit, which had a strict policy of restricted access to the residents' day lounge and to residents during meal times. This was annoying for three FCs one of whom also complained about the large number of residents in the day lounge. In addition, a complaint was made by a daughter caregiver about an incident witnessed by her where her mother had been roughly handled (see page 237).

However, concerns were also voiced about public units. The husband carer for example claimed his wife's private bedroom was too far removed from a nurse's station and hence she could not be adequately monitored. Indeed, this lady had two falls in her room while getting up unsupervised during night-times. The other public unit (SCU A) was criticised by one FC for not having pet therapy. In addition, this unit still provided ward-type multi-

bedded rooms which were not in accordance with SCU physical design principles. The physical layout of this unit might have triggered other difficulties; for example, residents taking fellow residents' clothes as reported by a nephew caregiver:

> "There used to be a bit of confusion about his clothes, alright, like, naturally enough, like, you know. And that was just a little minor thing, you know, but how could you, like, I mean, you know, he didn't know what he was doing with his own and he could maybe, uh, you know, ha-have somebody else's clothes." (Mr. Donohue, nephew caregiver, aged 56 years; statement made at six months post-admission)

Some of these identified problems such as excessive noise, bed location, and unavailability of senior staff members could probably have been rectified if FCs had brought their concerns to the attention of managerial staff. However, FCs appeared reticent about voicing concerns and the researcher got the distinct impression that they were frightened of providing any critical commentary. It might also be that FCs did not know how and to whom to complain because of vague or missing complaints policies.

7.6 Chapter summary

This chapter has attempted to report on both PwDs' and their FCs' views on what life was like for them after the PwD was placed in the SCU. Despite two people initially wanting to go home, all FCs described how their relative settled into the new environment immediately, and continued to settle in over a six-month follow-up period without showing any major adverse reactions. Additional data derived from in-depth interviews with some PwDs, although very patchy, appears to support these findings.

Most FCs claimed that their relative's functioning and quality of life improved after admission and in the longer term. They socialised more, were more physically active than before, and in some cases they rekindled former life-style interests. Data obtained from some PwDs showed that they enjoyed the opportunities afforded to them for socialisation

in the SCUs: the constant company of fellow residents, and their participating in a range of meaningful activities such as dancing, going for walks, and physical exercise. In addition, a few PwDs showed some improvement in their verbal and nonverbal communication. Aggression had reduced in three people at four weeks and again at follow-up.

FCs also spoke about some health gains they noted in their relative after placement, such as weight gain, increased food intake and eating behaviours, and improvements in mobility. Despite these improvements, some disimprovements were also noted immediately after placement. Two people for example wanted to go home, three became increasingly withdrawn, and two were depressed. Physical disimprovements at four weeks post-admission and at six months later were also described including mobility problems, incontinence, and eating difficulties.

Overall, however, FCs were unequivocal in their belief that the SCUs offered an improved care environment for their relatives and carers were very pleased with the professionalism of staff and with the improvements witnessed. FCs attributed any disimprovements in their relative's well-being to the progressive nature of dementia and not to the SCUs. Admission to the SCU was shown to benefit not only the PwDs and FCs but sometimes other relatives who had also been disadvantaged by home care.

Regarding the placement, FCs spoke at length about what adapting to their changed roles meant for them. No longer being physically involved in their relative's daily care and taking on the new role of visiting was the biggest change for them. This was particularly true for the two spouses and for those (N = 3) who lived with their relative prior to placement. All FCs expressed satisfaction with the SCUs' open-access visiting policies, which were described as flexible and supporting their need to stay connected with the person although in the private unit some FCs complained about restricted access to the day lounge and to their relatives during meal times. Being able to come and go to visit their relative when they chose was viewed by most as helpful for coping with the guilt,

bereavement, and loss associated with the placement. Visiting also meant being able to spend more quality time with the person as they were now exempt from previous extensive caring duties. Apart from retaining one's personal connection with the person, visiting helped other family members – in particular, grandchildren – stay connected to grandparents. Regular visiting also enabled FCs to monitor their relative's care and well-being and advocate for them if they felt this was needed.

Caring at a distance enabled most of these men and women to re-establish their personal lives and former roles and relationships. Most reported that they now had more time for themselves. However, increased freedom from minding their relative with dementia for some meant continuing to perform work and other care-giving roles they had had prior to placement. A few FCs spoke about new leisure-time activities they could now do on their own or with other family members. Those who cared for young children acknowledged that their children had been neglected due to dementia care. Those still caring for other family members with complex needs (N = 2) said that they were now able to provide better-quality care to other dependent family members.

Carers also spoke about the complex emotional reactions they experienced that accompanied their role transitions. They talked about feelings of relief yet guilt, and sadness and joy. Some felt bereft over the loss of their relative yet they enjoyed their relationship with the person who was still alive. They felt insecure and anxious about the person's future care, yet assured their relative was in better care. Such paradoxical emotions were found to be most intense and enduring for spouses and for adult daughters. By follow-up the data suggest that FCs were better adjusted to the changes the placement had made to their lives, some having taken up new interests and activities.

A major source of satisfaction for all FCs was knowing that staff were skilled in dementia care and offered person-centered and individualised care. FCs associated the unit's person-centered care philosophy with an enhanced quality of care and quality of life for

their relative. They were particularly impressed with staff's level of training and experience in dementia care, which they perceived as being superior to the care provided in previous settings. Person-centered care for FCs meant care that was based on their relative's needs, enabling him/her to make own choices, and maintaining his/her personhood.

Despite their overall satisfaction with the quality of care being provided, in about half of all cases some aspects of SCU care practices were criticised by FCs. These included poor communication patterns including availability and access to senior staff, visitor access restrictions, overcrowding of common day rooms, absence of some therapies (pet), and noise including inadequate TV noise control and alarm bells.

Chapter 8: Key issues in the transition to SCU care for PwDs

8.1 Introduction

This thesis set out to explore the experiences of PwDs, FCs, and SCU staff of admissions to SCU. Unfortunately, due to the severity of their dementia, much of the data collected from residents themselves could not be used. The thesis therefore reports on the in-depth interviews held with FCs at one month after admission and six months later - findings from which are partly augmented by PwDs' own accounts. The thesis also reports on qualitative data collected during FGs with senior and junior SCU staff where efforts were made to explore their views and attitudes to dealing with new admissions. The research was guided by a constructionist perspective, assuming that lived experiences of a phenomenon are being co-constructed by both the individual and members of his/her social world including the researcher, and are shaped by the context within which the person's experiences occur.

In the first part of this discussion chapter, findings relating to the broad areas investigated in the thesis will be discussed against the backdrop of literature on the topic of admitting people with dementia into LTC (both specialist and general). Efforts will be made to identify where thesis findings converge or diverge with those reported in the literature. Efforts will also be made to highlight the new contributions that this thesis makes to the literature. The second part of this chapter will reflect on the methodological challenges encountered during the entire research process and will report on some of the strengths and weaknesses of this thesis.

8.2 Reasons for admission

Findings from this thesis reveal the extreme levels of emotional and physical stress that FCs experienced during the time period leading up to the SCU placement. Detailed descriptions are provided throughout, of the burden of care and of the types of dilemma experienced by FCs as a result of having responsibility for the full-time care of their relative with a moderate or severe dementia. Whether living apart or alongside the PwD did not seem to make a difference to the extreme anxieties and concerns they had. Several talked about having to provide around-the-clock assistance due to safety concerns, and about having to constantly monitor their relative and cope with serious challenging behaviours such as sleep disturbance, dangerous behaviours, aggressiveness, and incontinence. In one case where the PwD lived alone, the FC had to resort to locking her mother-in-law into her home at night (otherwise, because of her disorientation, she might have left the house to wander the streets alone at night). The data show that these FCs received limited support from other relatives or from formal support services.

Apart from looking after their relative with dementia, three had responsibility for other ageing and dependent relatives who also needed much attention. Two others were parents of young children and balanced their caring role with child care. Four carers worked in the labour market and one of these ran her own business whilst caring for both her aunt and her mother both of whom lived with her. These other work and care commitments made having responsibility for the care of a relative with advanced dementia very difficult particularly in the absence of any outside support.

These findings are in accordance with other research findings showing how stressed carers were during the time leading up to placement. Indeed, several felt wholly overwhelmed (Aggarwal et al., 2003; Argyle, Downs, & Tasker, 2010; Butcher et al., 2002; Galvin, Todres, & Richardson, 2005; Kellett, 1999). In particular, like other studies this

thesis showed that carers found coping with dementia-related challenging behaviours particularly stressful (Balestreri, Grossberg, & Grossberg, 2000; Campbell et al., 2008; Dunkin & Anderson-Hanley, 1998; Etters, Goodall, & Harrison, 2008; Fisher & Lieberman, 1999; Gaugler et al., 2007; Gaugler, Krichbaum, & Wyman, 2009; Hope et al., 1998; Luppa et al., 2010; McConaghy & Caltabiano, 2005; Yaffe et al., 2002). Unlike other studies, however, safety concerns were a major issue for several of the FCs in this thesis and the data provide rich and compelling evidence of cases where care-giving continued despite the fact that home care arrangements were inappropriate and actually placed peoples' lives at risk. Similar to other studies (Arksey, 2002; Arksey & Glendinning, 2008; Kroger & Yeandle, 2013; Pavalko & Henderson, 2006), this research shows very clearly the multiple care-giving roles several of these FCs had and the way in which other work and care roles compounded caregiver stress.

8.3 Waiting times

Another source of strain for FCs as revealed in this thesis was dealing with wait-listing protocols. Data show much variability in the length of time peoples' names had been wait-listed for the respective SCU (mean waiting time was eight months; range 2-24). There was a lack of transparency in wait-listing protocols. Most FCs were not aware that time spent on waiting lists was not the sole criterion used for admission and would regularly call the SCU reminding staff about the urgency of their needs. Families needed regular updating on wait-list prioritisations, their relative's waiting list status, and some indication as to when their loved one would eventually be admitted but this information was not easily available. Staff could not accurately predict when a bed would become available and staff were also obliged to give priority to what were deemed "emergency" admissions (transfers from hospitals or other nursing homes where no wait-listing had been used) despite the fact that most SCU staff were acutely aware of the urgency of these particular peoples' needs as they were familiar with them through respite care services. The

literature notes that the lead-up time to LTC placement is often associated with feelings of insecurity and concerns about the prospect of formal HSPs taking over the care role (Argyle, Downs, & Tasker, 2010; Gaugler et al. 2001; Reuss, Dupuis, & Whitfield, 2005; Strang et al., 2006; Zarit & Whitlatch, 1992). This, however, was not a finding in this thesis as these FCs were clearly ready to relinquish care. The fact that these FCs had such a strong preference for specialist care and were not prepared to wait-list their relatives for any other nursing home - a finding in keeping with other studies (Argyle, Downs & Tasker, 2010; Butcher et al., 2001; Leon & Ory, 1999; Tornatore & Grant, 2004) - probably made life more difficult for them and resulted in delays in securing placement.

Findings from this thesis show the important yet ambiguous role that residential respite care played in relation to SCU placement. On the one hand several FCs claimed that residential respite helped them sustain home care for longer - a finding supported by the literature (Adler et al., 1993; Flint, 1995). But on the other hand using respite at the SCUs where the PwD was ultimately placed also appeared to speed up decisions about relinquishing home care, since the experience reassured caregivers of the superior quality of SCU professional care (Jeon, Brodaty, & Chesterton, 2005) and probably made them aware of the enormity and the next-to-impossible challenge of their own individual caring roles. Findings therefore are in line with the literature and show how residential respite care used at the SCU may have helped ensure a smoother transition into permanent care (Brugler, Titus, & Nypaver, 1993; Manion & Rantz, 1995).

Data from this thesis show that carers were receiving very few formal supports from government services whilst endeavouring to provide full-time care at home. They claimed that services like home help care and night-time respite were largely unavailable yet would have been a huge support to them in the time period leading up to placement. This finding is not surprising given what is known in Ireland about the paucity of community services for PwDs living at home and the inequitable distribution of services (McCarron & Lawlor, 2003; O'Shea, 2000). The paucity of services in Ireland can be contrasted with

other countries such as the UK, France, Finland, Sweden, and Australia where PwDs have entitlements to services (Alzheimer Europe, 2013; Moriarty, 1999; Skladzien, Bowditch, & Rees, 2011). Clearly more adequate and realistic community support would have helped reduce the excessive stress experienced by these FCs during the time leading up to admission (Brodaty, Green, & Koschera, 2003; Covinsky et al., 2003; Papastavrou et al., 2007).

Data show that in two cases, PwDs were already in institutional settings (in one case a hospital and in another a general nursing home) immediately prior to SCU admission and in both cases FCs were most dissatisfied but felt unable and unwilling to complain. Their narratives provided vivid accounts of the problems which can arise for PwDs if placed in the wrong environment and where staff lack specialist dementia training. In particular, in both settings staff had a limited understanding of the complex needs of PwDs and were incompetent at managing behaviours such as wandering, aggression and agitation and indeed in one case had to resort to physically restraining the PwD. Narratives reflected how potentially harmful this lack of specialist training was for both the person's and FC's well-being. These findings are in accordance with previous studies. For instance, studies conducted by Dewing (2001) and Cunningham and Archibald (2006) have shown the adverse consequences of insufficient training in terms of both resident and FC well-being (Bauer-Alfredson & Annerstedt, 1994; Myers et al., 2007). Other writers have also highlighted the importance of more specific training in dementia for general staff (Doody et al., 2001, p. 7; Kuske et al., 2007).

To summarise this section, findings show the somewhat intolerable circumstances many of these FCs found themselves in, during the time period leading up to their relatives' placement. Home care for many was extremely difficult, dangerous and adversely affected not only the welfare of FCs but also their extended families. None of these caregivers, however, were prepared to speak out about their circumstances, seek political action

(engage a TD[12]) and refuse to continue to care for their relatives. The data show very clearly how silenced and disadvantaged these FCs were by policies which exploited them by failing to provide an adequate range of dementia-specific community-based support services; deliver support services based on and adaptable to FCs' individual needs; and guarantee fair and needs-based procedures of accessing formal support services including SCUs.

8.4 Making and communicating the decision

This thesis also provides new insights into how families made the decision to place their loved ones into SCUs and how they broke the news of the placement to their relatives. In keeping with international literature (Butcher et al., 2001; Caron, Ducharme, & Griffith, 2006; Park, Butcher, & Maas, 2004; Tilse, 2000) and Irish-based literature (Argyle, Downs, & Tasker, 2010; Ryan & Scullion, 2000b) all of the FCs said that the decision-making process was complex and emotionally charging. Butcher and colleagues (2001) for example examined the experiences of families deciding to place relatives with AD into SCUs and described the decision-making process as being emotionally complex and associated with intense paradoxical feelings of guilt, anguish and despair but also relief and satisfaction about having made the right decision for FCs.

Findings from this thesis show that FCs made the placement decision for a number of interconnected reasons including safety concerns; their inability to manage challenging behaviours, the unsuitability of the care environment (home, generic ward), residential respite care experienced, and the perceived suitability of the SCU environment. These findings are in accordance with other published research on the topic (Cahill, 1997; Hébert et al., 2001; Luppa et al., 2010; McLennon, Habermann, & Lindsey-Davis, 2010; Yaffe et al., 2002). Findings from this thesis show that FCs tended to share making the decision

[12] Teachta Dála, a member of the Lower House of the Irish Parliament

about their relative's LTC placement with other family members (Butcher et al., 2001; Caron, Ducharme, & Griffith, 2006). In fact, in all but one case, relatives were in agreement that placement was needed. This lady lived with her husband and although completely exhausted, she desperately wished to continue caring for him. Although this is one case only, it does suggest that spouse caregivers have greater difficulties relinquishing the care role (Kramer, 2000; Monahan & Hooker, 1995).

In all nine cases, findings showed that the PwD was not involved in the decision-making process. In fact, most FCs reported they deliberately excluded their relative from entering into discussions about the future placement since they believed that he/she would not be able to comprehend such information. Other qualitative studies investigating the placement decision process have also found that PwDs tend to be excluded (Ducharme, Couture, & Lamontagne, 2012; Sandberg, Lundh, & Nolan, 2001; Tilse, 2000).

This thesis also provides new insights into what FCs told their relatives when they were about to move them into the SCUs. Interestingly, no study to date has been undertaken specifically exploring this topic although two studies reported on approaches used by FCs in conveying news to relatives with AD about nursing home placement in general rather than SCU placement (Ducharme, Couture, & Lamontagne, 2012; Golden, 2010). Findings from these two studies were in accordance with findings from this thesis and showed diverse approaches used. For instance, Ducharme, Couture, and Lamontagne (2012, p. 206) reported that in some cases, the person with CI was told directly about the impending transfer and accepted this and in other cases FCs avoided any discussion about the LTC transition with the person lest such discussions caused distress. Ducharme, Couture, and Lamontagne (2012, pp. 206-207) found that FCs avoided discussing the placement with their relative due to his/her level of CI and also because they felt that discussing the placement would upset both their relative and themselves and place further strain on relationships. Other studies have focused on communication patterns between staff and PwDs and between staff and family members *after* LTC

placement (Adams & Gardiner, 2005; Hasselkus, 1997; Reed-Danahay, 2001). As findings from this thesis show, FCs were not generally honest and many failed to fully inform their relative about the impending relocation. Instead, most avoided telling the truth and resorted to half-truths, lies, or gave no information at all. The interviews show that communicating news of the transfer to their relative was a complex task and some FCs afterwards felt guilty about how they handled this aspect of their caring responsibility.

This finding also points to the need for entering into discussions about LTC options at an earlier stage in the course of dementia and when the individual has capacity and can still participate in decision-making. Such early discussions might also enable people to make advanced directives specifying their placement preferences including timing of placement and placement alternatives should SCU care be unavailable; give carers clarity and security about their relative's wishes; and protect individual autonomy and choice in this life-transforming decision process (De Boer et al., 2010; Menne & Whitlatch, 2007).

The data show that the carers in this thesis were forced to make the placement decision very rapidly, often within a day or three, of having received news that a bed was available. It should be pointed out that SCU staff members were fully aware of how distressing it was for FCs having to make rushed decisions about placement. However, they were also under huge pressure since most bed vacancies arose suddenly (because of other residents' sudden deterioration or deaths or discharges), and they were obliged to manage these vacancies quickly, fairly, and within the context of each facility's admission regulations. Several claimed they had to act fast, conscious that were they to delay they might lose the bed. These findings are in accordance with outcomes from other published research. For example, Argyle and colleagues (2010) in their study on the experiences of Irish FCs of admitting their relatives into LTC found that families also had to decide within short periods of time; and some feared losing their place on the waiting list.

8.5 Staff members' experiences of admitting new residents

As far as I am aware, this thesis is the first of its kind to provide insights into SCU staff members' experiences of making decisions and prioritising potential residents for SCU admission. It is also the first qualitative study in Ireland looking at staff members' experiences of admitting new residents with dementia into specialist LTC. Only two Irish studies have been conducted to date on similar topics. One of these explored the experiences of informal (i. e. family) caregivers placing their relatives in a general nursing home and not a SCU (Argyle, Downs, & Tasker, 2010) and the other study explored staff members' own experiences of their being relocated to a new work place – a SCU (Myers et al., 2007). This thesis therefore builds on this Irish literature by specifically honing in on SCUs and reporting on experiences of the transfer from multiple perspectives.

A new insight generated by this thesis is the finding that admitting new residents with dementia into SCUs from the perspective of staff is very stressful. The data show that any new admission inevitably meant losing a well-known resident through either discharge or death. When this happened, word would get out in local communities about the bed vacancy. Families (several of whom were known to staff through respite services) would then often contact the facility appealing for help and reminding the staff about their respective needs. For staff members the time surrounding placement meant their having to deal with i) the distress of families whose relatives were often refused admission; ii) the distress of those families whose relative was about to be admitted and iii) the distress of other family members due to the death or departure of that person (their former resident) to some other facility. From their point of view, they themselves also had to come to terms with the loss of well-known residents either discharged or dead.

Staff members claimed they missed and grieved the loss of a well-known resident and found the time surrounding new admissions very difficult. This grieving process was made worse by the fact that staff often during the same period had to accommodate the

unfamiliar needs of newly admitted residents. It took time getting to know new residents whilst at the same time mourning the departure of another and worrying about the effect the new person might have on other residents. It took time explaining to families whose relatives were wait-listed and who saw their own needs as urgent that someone more deserving than they had been offered the bed.

In some cases staff felt guilty because they were unable to offer the outgoing resident an end-of-life care bed. Few had any dedicated psychosocial support available to help them deal with reported emotional complexities. Senior staff explained that they went to great lengths to try to help junior staff cope emotionally and practically with new admissions. Whilst it might be assumed that dealing with admissions and discharges is part and parcel of working in long-stay care facilities and staff should have been well accustomed to these transfers, there appears to be something unique about SCUs in that staff members' narratives at no stage reflected a sense of their getting 'used to' or 'hardened' to the emotional hardships of admitting and transferring LTC residents. These came across during the FGs as being truly person-centred in their philosophy and each new admission was dealt with on a one-to-one basis. The data, however, provide a very rich description of the complexities of dealing with new admissions from the point of view of SCU staff.

8.6 Connectedness immediately following admission and longer-term adaptation of PwDs

A real merit of the approach used in this thesis is that it provides new insights into how, from the perspective of FCs, PwDs experience the transfer into the SCU and how they adapt to this environment immediately after placement and six months later. Findings show that most PwDs settled in quickly without showing any major adverse reaction. There was only one case where the newly admitted resident became aggressive following admission. This behaviour subsided and by follow-up it was no longer in evidence.

In line with other studies, several factors might explain residents' smooth adaptation to their new surroundings. These include the severity of the dementia, which probably affected their ability to understand what was going on and may indeed have protected them from fears and maladjustment. Other research has shown that level of cognitive functioning in PwDs influences reactions towards placement (Mirotznik & Los Kamp, 2000, p. 532; Orrell & Bebbington, 1995, p. 614). As mentioned earlier, the use of SCU residential respite care services was undoubtedly another important factor contributing to the PwDs' smooth and successful adaptation to the new setting. The majority of PwDs had availed of SCUs' respite care services and were therefore familiar with the physical environment, the staff, and transfer routines (Brodaty & Gresham, 1992, p. 359). However, other authors exploring the benefits of general respite provided by nursing homes reported similar findings (Argyle, Downs, & Tasker, 2010).

Other factors which may explain the smooth and successful transition of these PwDs into SCUs include the person-centred care promoted by SCU staff (Brooker, 2004; McCormack, 2004; Parker, 2001) and in particular their skills and competencies in dealing with the psychosocial needs of PwDs and FCs. Staff members were described as being skilled, sensitive, and acutely aware of the distressing nature of the LTC transfer; findings which are in line with other studies conducted on the topic (Argyle, Downs, & Tasker, 2010; Myers et al., 2007). In summary, it is likely that a myriad of different factors were at play in making the initial placement and adaptation occur so smoothly.

FCs' narratives demonstrate some definite improvements in their relatives' welfare immediately after placement and over a six-month follow-up period. Most now had more social contact, were interacting more with peers, and were more physically active than before. In one unusual case the person rekindled former interests (reading, gardening, and helping with seasonal activities) both immediately after placement and throughout the follow-up period. Interestingly in this case, this lady's MMSE score had increased quite significantly over the follow-up period. In three cases, the person's verbal and nonverbal

communication skills improved immediately after placement and continued to improve over the follow-up period. Other improvements noted by FCs at both phases included fewer challenging behaviours (less aggression, agitation, and resistance to care), improved eating behaviours and better food intake, and improved mobility skills. Improvements noted only at phase two included improved eating behaviours and weight gain, new friendships, and improved mobility. These findings, although based on very small numbers and on qualitative research, support similar outcomes from quantitative studies which have shown some positive outcomes associated with transfers into SCUs on a permanent care basis for PwDs (Annerstedt, Gustafson, & Nilsson, 1993; Cioffi et al., 2007; Day, Carreon, & Stump, 2000; Kutner et al., 1999; Myers et al., 2007; Sloane et al., 1995). Compared with Cioffi's Australian study (Cioffi et al., 2007), where qualitative data was collected at three and six months, findings from this thesis show how people with moderate to severe dementia can form new friendships in SCUs and can actually regain former skills. A shortcoming of several of these other studies, however, is the fact that phase one data was not collected within a few weeks of the transfer but rather at three months after placement.

FCs also identified some disimprovements observed in their relative's well-being and health after placement and during follow-up. Some reported on new challenging behaviours such as wanting to go home, withdrawal, and episodes of depression. Interestingly, however, all of these problems had stopped by follow-up. Physical disimprovements noted at both phases, included decreased mobility and loss of motor skills. One person had become doubly incontinent, another had eating problems and one person had developed a pneumonic illness. Physical changes noted by FCs only at six months after placement and not earlier comprised deteriorating dietary habits, weight loss and in one case reduced mobility to the extent that a walking frame was needed. Whilst it is not surprising given the disease trajectory that some of this sample had deteriorated by follow-up (Brodaty, Draper, & Low, 2003), nonetheless data show that PwDs' overall well-being had improved immediately after placement and most remained content and well-

adapted to the new surroundings at phase two. None of the nine residents had become bed-ridden and each continued to avail of the activities offered by the unit at both points in time.

As can be seen in the last chapter, great efforts were made to incorporate the voice of the PwDs in this thesis. However, as stated, these people had moderate to severe dementia with associated memory, cognitive, and communication problems, which made interviewing them a challenge. However, some were able to comment about aspects of their new environment which they liked and disliked. Their commentaries revealed that four out of eight reported how they were happy with the new environment straight away and felt very content. These positive views were reiterated by all six PwDs interviewed at phase two.

This finding suggests that most had successfully adapted to their new environment and were probably well adjusted to living in the facility by phase two. During both interviews several residents stated that they liked the company of other residents, they liked the food and they enjoyed having visitors. Most PwDs also commented on the various activities they were offered at the SCU, which they enjoyed. Their comments showed that they perceived these activities to be meaningful and to offer choice. Such activities included dancing, singing, going to mass, and going for walks in the garden.

Findings emerging from this thesis are in accordance with Myers et al.'s (2007) study which showed that PwDs after admission to a newly built SCU expressed contentment and satisfaction within the new environment. Myers et al. (2007) further reported that participants perceived their social environment (staff, peers) as being helpful and friendly, and that they were encouraged to engage in meaningful activities such as baking, reading, and going on outings. This finding demonstrates that adapting to an enhanced care environment is a complex and multifaceted experience for PwDs despite their

advanced cognitive and language impairments and needs to be considered in improving present care practices.

8.7 Connectedness immediately following admission and longer-term adaptation of FCs

Findings show that following the placement all FCs were obliged to adapt to new roles, relationships, and responsibilities. Several described in detail the changes they witnessed from being primary caregivers to now caring at a distance. This finding is in line with previous qualitative studies (Butcher et al., 2001; Dupuis & Norris, 2001; Ryan & Scullion, 2000a). New responsibilities taken on by FCs included visiting, liaising with staff regarding their relatives' health and welfare, monitoring quality of care, and advocacy (Butcher et al., 2001; Dupuis & Norris, 2001; Myers et al., 2007; Ryan & Scullion, 2000a).

FCs also spoke about the mixed and paradoxical emotions they experienced immediately following placement and later. Many felt intensely guilty yet relieved; several felt bereaved yet ironically they were still in relationships (with the PwD); a large majority felt a sense of security having acquired a permanent bed for their relative in a reputable facility yet they had uncertainties about the future. Emotional reactions seemed to relate to present, past and future. These findings are in accordance with the literature (Argyle, Downs, & Tasker, 2010; Butcher et al., 2001; Nolan & Dellasega, 2000). For example, Nolan and Dellasega (2000) showed how FCs' role transitions after admitting a relative with dementia into LTC are emotionally complex and challenging. Findings from this thesis show that admitting a relative with dementia into a SCU is a process that brings about new strains and stresses rather than ending existing ones (Gaugler, Pot, & Zarit, 2007; Zarit & Whitlatch, 1992).

The literature refers to spouses becoming quasi-widows after a partner's placement in a nursing home – an experience which is unique to spouses and most difficult to cope with (Kramer, 2000; Sandberg, Lundh, & Nolan, 2001). Whilst there were only two spouses in

this small sample, what is interesting is that in line with the literature both these people (a husband, a wife) appeared to have most difficulties coping with the separation. Compared with other FCs, they appeared most distressed both at the time of the first interview and later. In particular, they struggled with feelings of guilt and grief, and found it most difficult to adapt to living without their respective partners. For one lady, her stress and guilt was probably compounded by the fact that her husband felt unhappy in the SCU and wanted to initially leave.

In comparison with other caregivers, the two daughter caregivers also appeared acutely distressed about the placement decision and were concerned about their relative's future well-being. The literature notes that kinship bonds may carry a stronger obligation to care than obligations arising from other relationships (Tilse, 2000) - although the numbers here are very small these findings may reflect this.

Findings from this thesis showed that overall FCs were better adapted to the placement – both emotionally and physically – at phase two. They were more convinced that their relative was now receiving more appropriate care and that they had made the right decision to place the person into skilled LTC. Most reported that they enjoyed visiting. Three claimed that they had taken up new hobbies, exercise, socialising, and participating in educational events since their relative's placement. These findings are in keeping with existing literature on changes in FCs' personal activities – such as taking up new hobbies, socialising, going on vacations – after their relative's LTC placement (Ducharme et al., 2005; Riddick et al., 1992; Stadnyk, 2006).

8.8 Sources of satisfaction and dissatisfaction

All nine FCs reported they were particularly happy with the safety features of the new environment. They were also by and large satisfied with privacy levels, psychosocial

stimulation, and the holistic person-centred approach to care offered by SCU staff. They believed that the SCU could provide better care than they could and yield a better quality of life to their relatives. They embraced the philosophy of care in evidence. Their general positive views of the SCUs remained consistent throughout the entire post-placement period (phase one, phase two). These features of SCUs constitute essential characteristics of SCU settings and have been well described in the literature (Calkins, 2001; Fleming, Crookes & Sum, 2008; Myers et al., 2007; Van Hoof et al., 2010).

The placement also helped other family members. For example, two ageing husbands, primary caregivers who were not interviewed for this research but nonetheless had been integrally involved in care-giving, were according to their relatives (the FCs interviewed) in much better mood following the placement. Similarly, two daughters-in-law reported that they could now spend more time with their school-going children whom they thought they had neglected due to extensive care-giving demands. They could now take holidays, exercise, and attend social events. Two others said that they were now better able to care for other family members with high dependency needs (a mother with VD, a father-in-law with cardiac problems), resulting in these people being cared for by the FC in a less stressful atmosphere. These findings remind us that dementia is more than a one-person illness (Bonder, 1987) and also remind us about the way FCs who had multiple care roles were often torn between their different family commitments.

The SCU's flexible visiting policy was something family members welcomed and meant that relatives could come and go as they pleased and remain connected into their relatives' everyday lives (Butcher et al., 2001; Van Hoof et al., 2010). Carers also reported that they had established new relationships with SCU staff and with other residents and their FCs. Fostering these relationships was also part of the person-centred approach to care. Relationships were described as supportive and family-like, helping FCs accept the SCU LTC transition better.

Other aspects of the transition that some FCs considered helpful and well-managed included the fact that if they had concerns, in most cases they could easily access staff by phone or in person (Van Hoof et al., 2010). The fact that SCU staff in some cases went to great lengths to meet with families and listen to their queries and requests was very reassuring. These aspects of 'caring for the FC' (catering to their needs for support, enabling them to discontinue caring, and respecting them as partners and experts in their relative's care) are also important components of the person-centred approach (Kellett, 1999; McCormack, 2004; Nolan et al., 2004).

There were, however, some issues that FCs were unhappy about. A major source of sadness for three quarters of the sample was the loss of the relationships they had shared with their relative due to memory and cognitive decline. Carers talked about the type of situations that sometimes arose during visits; when their relatives would after their having gone to the effort of visiting go on a walk about - it was as if they no longer remembered them and could not be bothered talking to them or returning to them. Other distressing incidents included their mistaking grandchildren or relatives for long-deceased siblings or parents, and mistaking fellow residents for spouses. Accounts of such distressing incidents concur with other published literature on the topic (Elmståhl, Ingvad, & Annerstedt, 1998; Keefe & Fancey, 2000, p. 241; Meuser & Marwit, 2001; Ryan & Scullion, 2000a; Schulz et al., 2007, p. 8; Zarit & Whitlatch, 1992).

Interestingly, although SCUs are supposed to provide state-of-the-art care a few respondents expressed dissatisfaction with aspects of the physical and built environment including noise, communication breakdowns, and care standards (lack of attention paid to monitoring their relatives and privacy concerns). These complaints and criticisms must be carefully considered since SCUs are supposedly exemplary in being purpose-built and require being free from disruptive noises, insufficient opportunities for privacy, and other flaws compromising PwDs' well-being and safety (Van Hoof et al., 2010, p. 206).

Findings from this thesis also show some emerging differences between the two public and the one private SCU in terms of accessibility and quality of care. The private unit attracted most critical commentary. FCs reported that this unit restricted family members from visiting during meal times and denied them access to the communal lounge, because of resident privacy issues. They also complained about senior staff not being readily available to meet with relatives and their concerns not being passed on by front-line staff members to the person in charge. This unit was also critiqued for setting up a constantly running and loud TV in a public lounge area. One upsetting incident of potential abusive behaviour was also reported by a daughter caregiver.

In contrast to the private SCU C, where individual beds were available, the physical layout of both public units reflected hospital ward-style elements, such as multi-bedded rooms (SCU A) and shared washing/toileting facilities (SCU A, SCU B). Both public settings had no facilities for end-of-life care. This meant staff had to discharge PwDs with end-stage dementia to generic care settings. Whilst FCs did not specifically complain about this, staff found it very upsetting and some felt guilty about letting go of residents at a time when they were most vulnerable. Whilst the research did not probe into this area several FCs (N = 5) had concerns about whether their relative would be kept in the SCU should his/her care needs change; the length of time their relative would live in the SCU; and the quality of care he/she would receive in the immediate future.

These findings show that all three SCUs, despite being dementia-specific, had design and staffing features which were sub-optimal. Whilst some of these features, in particular noise and poor communication channels, might be easily rectified by SCU staff and the facility management, others may not be as easy to address in the short term. In particular, the practice of discharging PwDs with terminal-stage dementia to other care settings seemed to cause professional caregivers much distress. The issue of having a SCU ethos yet retaining hospital features such as multi-bedded wards and shared washing/toileting facilities in a specialist care environment is also curious. This thesis sheds light on such

critical aspects of SCUs' physical design and care practices in Ireland. Findings show that SCUs are best viewed as care environments that are in transition themselves and may not always be free from inappropriate care practices. They are therefore in need of constant quality monitoring and improvement.

8.9 Methodological measurement issues

Several methodological challenges were encountered when conducting this research. One such challenge was that significant changes had to be made to the initial research design. When the thesis was first being conceptualised I had intended to have as a central focus the individuals' experience of the transfer into SCU LTC as it seems there was a gap in the literature in this area and that no other study of this nature had ever been undertaken. This was considered important as increasingly, research studies in dementia (particularly qualitative research) point to the importance of taking on board the perspective of the individual most affected by dementia, in this case that of the person diagnosed (Argyle, Downs, & Tasker, 2010).

As the preparation for the field work progressed and, as SCUs were contacted, it became apparent that new admissions to SCUs today are usually of people with a more moderate to advanced dementia. Accordingly, most PwD were so severely cognitively impaired that they could no longer cogently respond to the questions asked by myself. It would therefore have been highly unethical to continue asking them questions. Using an unstructured approach to data collection might have been an alternative, possibly allowing for better adaptation to PwDs' cognitive and language skills. For the purpose of this thesis, I chose a semi-structured approach, however, because I considered it most suitable for exploring the multiple facets of the phenomenon of relocating into SCU LTC in a detailed and focused way; eliciting multi-layered, rich and focused narratives from research

participants about their admission experiences; and gaining an in-depth understanding of the complex process of admitting PwDs into SCU LTC.

The original plan was also to try to investigate the experience of the transfer, ideally following up a small group of people being relocated from a more general nursing home to a SCU. However, at the time the research was being conducted it was not possible to find a nursing home that had recently built a new SCU and was transferring a group of residents from one area to another. Hence this approach could not be used. The outcome, therefore, was that SCUs already offering services, willing to participate in the research conducted for this thesis, and able to guarantee some turnover of residents over time were invited to participate. I ultimately sampled three SCUs and three participant groups (see Chapter 4).

For the purpose of this thesis, PwDs' and their caregivers' lived SCU admission experiences were the unit of analysis rather than the three SCUs, which contextualised participants' experiences of partaking in qualitative research as well as relocating and adapting to a SCU. The chosen approach, however, might be criticised for not being a true multiple case study due to the very small number of SCUs (N = 3) and – due to their not being the unit of analysis – the lack of information about their structure, organisation, and care processes including care plans (I did not collect information about these aspects beyond the information given in section 4.3.3.8). A larger number of SCUs might doubtlessly have allowed for a more extensive in-depth exploration of these aspects, and would have been sampled had I had more resources available to conduct the thesis.

Another challenge in conducting this thesis was the fact that I am German and at the time of the research my English was not very fluent. As a result I may not have always understood the subtle nuances or meanings of statements made by participants. It is probable that such communication obstacles were difficult to cope with by PwDs, who in this sample strongly relied on their native language/accent and were no longer themselves

verbally fluent. For instance, they were no longer able to relate to me that they had not understood an interview question or a comment made by myself.

All nine FCs participating in this thesis came from rural backgrounds and had been reared and lived in small rural communities. They had not participated in academic qualitative research before. This may have resulted in their feeling nervous and apprehensive about being interviewed by a university student although none openly said that she/he felt like this. They may have been inhibited telling a stranger about their experiences – and guilty about expressing dissatisfaction. I had to rely on SCU staff to recruit families for the thesis. These were families who had already been under huge pressure, making placement decisions at short notice and placing someone they loved in SCU LTC. Their participation in the thesis meant their having to agree to be interviewed, the first one scheduled at a time when they were under a lot of stress. Although participation was voluntary and required written and verbal consent some may have felt pressurised into agreeing to being interviewed, being so grateful that they finally got a permanent bed for their relatives.

Regarding the FGs, another challenge noted was the dominance of the voice of senior managerial staff over more junior front-line staff. In all three FGs senior staff tended to answer most questions and this made attempting to get a richer and more comprehensive picture of the overall process of admissions more difficult. A second difficulty with FGs was that although efforts were made to conduct these sessions in quiet rooms in order to maintain privacy, minor disruptions caused by non-participating staff members and residents occurred. At the core of every qualitative research lies a unique constellation of contexts and participants (Sandelowski & Barroso, 2007). Findings emerging from these unique constellations might have been entirely different if conducted with a different set of participants, at different times, and in different SCUs. Despite such difficulties, the interviews and the data emerging from the FGs generated compelling and immensely rich

insights into the lived experiences of both families and SCU staff of admitting PwDs into SCU LTC.

The exact research design used in this thesis – to my best knowledge – has not been used by other qualitative authors (Bramble, Moyle, & McAllister, 2009; Butcher et al., 2001; Cioffi et al., 2007; Gutman, 1989; Iwasiw et al., 1996) and certainly not in Irish research studies on similar topics (Argyle, Downs, & Tasker, 2010; Myers et al., 2007). Several of the insights generated from FGs with SCU staff members particularly those pertaining to the stresses and strains they experienced and the types of dilemma they had to confront are also new and have not been reported on previously (Argyle, Downs, & Tasker 2010; Cioffi et al., 2007; Myers et al., 2007).

A major limitation of this thesis' design is that it is small-scale, draws on a biased sample of rural-based FCs, and findings from the thesis cannot be generalised beyond the context of the thesis. In addition, despite my best efforts as mentioned, it proved very difficult to include the voice of PwDs in the research and much of the data collected from them could not be used. However, despite these demerits the approach taken resulted in recruiting a very diverse sample of FCs who differed in terms of gender, age, relationship to the PwD, and other work and care responsibilities.

This chapter has discussed the main findings emerging from this thesis comparing and contrasting them where possible with national and international literature published on the topic. One of the key difficulties involved in conducting this research is that it straddled both community care and residential care and involved both informal and formal caregivers. For this reason I had to draw on different bodies of literature. Despite several limitations, it has been argued that this thesis has made a significant contribution to the literature and has yielded several new insights into the topic of admitting PwDs into SCUs and FCs' accounts of their relatives' adjustment to the SCU facility. In the next chapter the practice, research and policy implications of some of these key findings will be discussed.

Chapter 9: Conclusion – Practice, policy and research issues

9.1 Introduction

This thesis was designed to explore the process of admitting PwDs into SCUs and the experiences of SCUs from the perspectives of FCs, PwDs, and SCU staff themselves. In particular, it investigated what life was like for FCs during the period leading up to their relatives' admission into SCU LTC and what it was like for them both immediately afterwards and more long term. It has also tried to capture the views and experiences of PwDs about the new physical environment, and the views and experiences of staff delivering dementia care in these settings. In this way the thesis has attempted to provide a very comprehensive account of admissions and adjustment to SCUs from multiple perspectives. Chapter 8 highlighted the key findings from the thesis and discussed these findings drawing on the literature reviewed in Chapters 2 and 3. This chapter moves on and attempts to draw together the key findings from this thesis and articulate the implications of these findings in terms of practice, policy, and research.

9.2 Implications for practice

9.2.1 Realistic community support services

Findings from this thesis suggest that FCs looking after their relatives with moderate to severe dementia living in the community and awaiting LTC placement needed much more extensive and suitable support services. It could be argued that these FCs were let down badly by a system and a state which exploited their good will and allowed them to continue caring even in circumstances that to many would seem intolerable. The data show clear evidence of how when service providers were available, support was offered

only on their terms and when they were available rather than on the needs of FCs. Services which would have made a real difference to the lives of these people include home help, in-home respite, overnight respite and day care. A key worker or case manager assigned to families struggling to provide dementia care at home would also have been very valuable. The data also provide evidence of the struggles some family members had trying to secure some basic services; being obliged to repeatedly ring and remind service providers of their urgent needs, some essentially pleading for help and yet in some cases their requests remaining unheard. Given that most of these families were already in touch with service providers (albeit receiving only very limited support) it seems extraordinary that the latter did not take action and allowed some of these clearly unethical caring arrangements to continue. However, it may well be assumed that HSPs working with very limited resources were themselves severely constrained in the types of support they could provide to families and which were essential to facilitating adequate caregiving arrangements for FCs. The research nevertheless shed light on the absence of advocacy roles being adopted by these service providers.

There is also clear evidence emerging from this small-scale study that the HSE and the DoHC need to improve and expand the resourcing of community services for PwDs and their caregivers. The patchy and inadequate support available to people and the lack of information and confusion amongst caregivers as to what formal care was available made it extremely difficult.

Although, as shown in Chapter 2, government policy in Ireland is very much centred on community care, resource allocation is clearly not in the community but rather in residential care. There is a need for a lot more resources to be allocated to community services and for funding to be re-channelled away from residential care to community services. The upcoming dementia strategy should ensure that families caring for their relatives with dementia receive flexible timely services. At-risk groups such as those with multiple carer roles, older spouse carers, carers who themselves do not enjoy good

health, and carers who work and provide extensive dementia care at times running two houses should receive additional supports. Enhanced provision of community services is necessary given our ageing population and given that within the present economic climate waiting lists for LTC for PwDs will probably continue to be lengthy.

9.2.2 Information and updates about wait-listing

Data from this small qualitative thesis show that SCUs are a scarce resource in Ireland and that demand for these services far exceeds supply. This was evident to me when attempting to recruit the sample - repeatedly I was being reminded by Directors of Nursing when phoning potential SCU sites for thesis participation that beds rarely became available and staff was unable to predict when a new resident would be admitted. Sometimes I was advised that this might only happen every twelve months because it all depended on deaths and discharges.

The randomness of bed availability in SCUs was a phenomenon that many of these FCs were neither aware about nor were they aware that SCU staff used several different criteria to admit new residents. FCs for example appeared not to be aware that the transfer of PwDs from hospitals (considered emergency) received priority over and above those (i.e. their relatives) whose names had been wait-listed for considerable periods. Perhaps had they been made more aware of this, they themselves may have used hospital care as an entrée into SCU LTC. The data show that communication about the imminent placement between SCUs and FCs was sub-optimal.

Findings from this thesis would suggest that FCs about to wait-list their relative for LTC, should be given much more honest and detailed information about wait-listing protocols. They should be advised very clearly that time on a wait-list is not the sole criterion used by staff to prioritise beds and that SCUs generally consider a variety of other factors when deciding about new admissions. These complexities can result in another person who was more recently wait-listed being placed ahead of a person wait-listed for a prolonged

period. The HSE and the DoHC need to recognise that FCs need guidance and assistance in navigating the care system when accessing LTC services especially SCUs. Organisations like the ASI and the DSIDC need to develop information kits for families to help support family members through these very difficult periods. In short, there is a need for more transparency and more equity in relation to SCU placements.

9.2.3 More information about pressures of decision

There is also a need as revealed by the data for FCs to be aware that once a bed offer is made, decisions about placement have to be made virtually overnight and certainly within 36 hours of families first being notified. In several cases, the data showed how pressurised FCs felt to accept the bed offer either on the spot or within a few days. Many knew that by declining the bed offer, they might have to wait a very long time again before another bed offer was made. Their feeling under pressure to accept a bed offer might seem ironic given how desperate most were to secure a bed, but the issues of communicating news of the impending admission to other family members, handling the physical transfer themselves (packing and organising admission) and conveying news of the bed offer to their relative all take some time and need to be done as the data show very sensitively. Findings would suggest that FCs who wait-list their relatives should be advised about the fact that when beds become available, decisions need to be made as a matter of urgency.

9.2.4 More information about complex nature of decision-making

This thesis provided new insights into how families make the decision to place a loved one with dementia into SCU LTC. The carers' narratives reveal that the decision about placement was not made easily. It was complex and emotionally taxing, and often resulted in intense feelings of guilt, sadness, and fear. Caregivers felt torn between accepting the need for the bed versus wishing to continue caring for the person. This tension and conflict seemed particularly pronounced in spouse caregivers when news of the bed

availability eventually came. There is a need for a lot more counselling and support of all caregivers who are about to place a relative with dementia in SCU LTC. Spouse caregivers are a particularly vulnerable group who need additional support during this critical period.

9.2.5 Earlier communication of placement and communication training for FCs

Findings from this thesis showed that the placement decision was made and told to the PwD at a very late stage in the course of the dementia, and when most people lacked capacity and could no longer fully participate in or understand the implications of the decision process. Interviews revealed how difficult it was for the FCs breaking news of the SCU transfer to their loved ones. Several resorted to lies and ploys even though they knew this was not ethical. One person actually abandoned her relative and gave no information about why she was being admitted. Most did not know how to better inform them about the move, and wanted to avoid distressing the PwD unduly.

Telling lies or half-truths had repercussions for FCs as several felt enormously guilty afterwards. Carers' lies and misrepresentations about the move also had ramifications for staff members who in some cases as the data from FGs showed were left to deal with this duplicity and deceit. Clearly there is no right or wrong approach and ideally the issue about care options and choice of LTC should be discussed with the individual at a much earlier point in time during the illness trajectory and at a time when they have still some insight and awareness. The data here show that caregivers needed more assistance and advice on how to deal with this very difficult topic.

9.2.6 More psychosocial support for staff

Whilst much is already known about the burden of family caregiving (Dunkin & Anderson-Hanley, 1998; Twigg & Atkin, 1994; World Health Organization, 2012), this thesis generated new insights into the type of stresses and strains SCU staff experience when

being responsible for discharging well-known residents from their care whilst simultaneously admitting new residents. New admissions were associated with complex and intense emotions, and staff employed in all three SCUs found this time period very stressful. They also claimed that dedicated psychosocial supports designed to help them cope with the emotional experiences surrounding admission and discharge of residents were absent. The data show that some brought their anxieties and concerns about their work home with them after hours and that, like the FCs, they gave of themselves over and beyond the call of duty. Senior staff appeared to be particularly poorly supported both clinically and psychologically.

Findings suggest that more counselling and clinical supervision should be made available for individual staff members to better support them with the extremely difficult task (both practically and emotionally) of admitting new LTC residents. In particular, it needs to be remembered that SCU care is different from general nursing home care. SCU staff members often develop very close one-to-one relationships with their residents whom they get to know as people. This means that when a resident dies or needs to be discharged staff members themselves experience quasi-bereavement. This is an issue that gets very limited attention in the literature and was highlighted in this thesis when staff talked about losses associated with admissions due to the discharge of other residents they cared for and cared about. There is a need for support and training to help staff cope with these quasi-bereavement experiences and to avoid staff suffering from excessive strain and burnout.

9.2.7 More psychosocial supports for FCs after placement

FCs also struggled with mixed emotional responses to the placement both immediately afterwards and throughout the follow-up period. They experienced guilt yet relief; like the professional caregivers they felt bereaved yet they were still in relationships (with the PwD); they had a sense of real security given the improved quality of care yet insecurities were rife about the person's future care. Complex emotional reactions were found to be

most intense for spouses and adult daughters. In addition, spouse caregivers seemed to struggle most with adapting to their changed roles and new lifestyles after placement. One of the spouses in this thesis for example who felt very guilty about his wife's overall management became obsessed with visiting, and during the initial transition period reported he visited her three times daily.

More specialist psychosocial supports should be made available to FCs, and in particular spouses who place a loved one with dementia in SCU LTC. Specialist supports such as individual counselling, support groups, Alzheimer Cafés, and in more extreme cases grief therapy should be available. Ideally, these support services would be available throughout the entire caring process (for example, emotional complexities of decision-making) - thereby taking into account the fact that SCU LTC placement is an ongoing process. The data in this thesis showed that whilst the physical burden of caregiving was removed from FCs by virtue of the placement and hence much of the strain of caring, new anxieties and concerns emerged for them after placement which troubled them and made caring at a distance difficult. A case manager, who would work with families from an early stage in the course of the illness through until such time as a person is placed and later, might alleviate some of the burden and strain experienced by caregivers.

9.3 Implications for policy

9.3.1 Funding of SCUs

Findings point to the fact that SCUs are a scarce resource in the care and management of PwDs in Ireland. Findings showed that these families who were in desperate need for more extensive support were placed on long wait-lists despite the fact that service providers were in close contact with them through community and respite care services and knew the level of care that was needed. The scarcity of resources also placed additional strain on staff members who, when a bed became available, were left trying to

prioritise names on wait-lists and make very difficult choices aware that in choosing one particular person, other families would feel very disappointed.

Findings also demonstrate the marked positive difference SCUs made to both FCs' and PwDs' physical health, mental well-being and social lives immediately after placement and in the longer term (see Chapter 7). FCs clearly ascribed their own and their relative's improved quality of life after placement to SCUs' unique features including a purpose-built physical environment and a person-centred needs-based care approach delivered by trained staff, which resulted in a quality of care superior to that provided by unskilled settings. Findings also show how the wider family system (grandchildren, PwDs' spouses, family members with chronic health problems) benefited from the exceptional quality of care PwDs enjoyed in SCUs. FCs spoke about how reassured they were about SCUs' excellent levels of care and how this helped them relinquish their care-giving role, freeing them up to focus on the needs of members of the wider family system who they had neglected over the PwD's extensive care needs.

The data provide much evidence of the need for more SCUs to be funded around the country. It seems morally wrong given the level of care some of these people required that family members were being expected to provide the level of care they did. It also seems wrong to not prioritise SCUs over traditional LTC settings given the positive outcomes SCUs yield to PwDs', FCs' and other family members' health and quality of life. Concerted efforts of service providers working in different care sectors (community, residential) might be necessary to lobby for increased SCU funding and to draw attention to the plights of families caring for a relative with dementia in the community, and their marginalised role in service provision and policy. The media might also take on a stronger role in raising awareness of FCs' care-giving circumstances and bringing their needs into the focus of policy.

More policy support is also needed for accessing SCUs. Benchmarks for the provision of SCU care (for example, a commitment to developing 12,000 new SCU beds in France) are part of national dementia plans in other countries such as the Netherlands, Norway, and Sweden (Cahill, O'Shea, & Pierce, 2012, p. 123). Establishing such benchmarks for the Irish SCU LTC context might help make sufficient numbers of SCUs available throughout the country, reducing lengthy waiting lists. Benchmarking for SCUs might for instance be targeted by the upcoming national dementia strategy. Policy support is also needed for making placement decisions including decision criteria more transparent. In particular, HIQA might take on a stronger role in reinforcing and monitoring the use of decision protocols/policies/guidelines by SCUs.

9.3.2 End-of-life care facilities

In this thesis, two of the three SCUs had no facilities for palliative care and both employed a rather inhumane policy of discharging PwDs with terminal-stage dementia to other settings (usually to hospitals). This practice caused extreme distress for staff who talked about it in the FGs. They felt guilty and believed they had failed these people as residents moving them out of their "homes" so to speak to allow them die in strange and unfamiliar environments. It was also very upsetting for FCs who often (according to staff) resented them for taking this action.

It could be argued that this practice of discharging people dying with dementia from SCUs is discriminatory and is a violation of human rights (Alzheimer Scotland, 2013). In other countries, such as the Netherlands, France, and Australia, SCUs continue to provide end-of-life support to people dying with dementia and indeed palliative care is available (Verbeek, 2011). There is a need for funding to be made available to equip existing SCUs with on-site palliative care facilities and to devise policies making on-site end-of-life care facilities mandatory for future SCUs.

9.3.3 Audit of SCUs and national register

At the time of writing this thesis, there was no comprehensive list of the location and type of care available at SCUs in Ireland. As far as I am aware there is still no list available. FGs revealed that FCs tended to hear about the location of SCUs either by word of mouth or through community-based service providers, rather than their being able to acquire a list from the HSE or ASI. There is a need for a lot more information to be made available to the public about where SCUs are found across Ireland, about how SCU beds can be accessed and about admission and discharge policies. There is a need for HIQA to collect information about SCUs and to use SCU supplementary standards in undertaking inspections. A national register of SCUs would also assist with future service planning.

The absence of a national SCU database led to difficulties for me. As demonstrated in Chapter 2, exact numbers of how many SCUs there are in the country and where they are located were unavailable. This lack of information made recruitment of suitable research sites very difficult (see Chapter 4). Therefore, a national SCU register would also greatly facilitate future SCU-related research activities in Ireland.

9.3.4 SCU quality of care monitoring

In Chapter 7, qualitative data was shown which was quite critical of some of the professional practice observed in SCUs. Criticisms centred around the lack of availability of senior staff when FCs needed to discuss issues with them about their relative's welfare, visitor access restrictions, noise, and in one extreme case the rough handling of a resident by a staff member. Although considered the gold standard in dementia care, the data show that these Irish SCUs at times failed to meet some basic standards of truly person-centred care. This meant that at times families felt compromised and were unsure whether to complain or not. There is a need for quality inspections of existing SCUs to safeguard residents against possible poor practices and implement truly person-centred care standards in SCUs. Including the voice of FCs into the inspection process particularly

where people have advanced dementia should be considered in future inspections of SCUs. There is a need for HIQA to become more proactive in this area.

As shown in Chapter 7, the private SCU attracted most critical commentary from FCs. Whilst possibly equipped to provide an appropriate physical setting (SCU C had a Snoezelen room, reminiscence therapy facilities, and private en-suites), private units may not fully adopt a truly person-centred approach to care and be more prone to fall back into traditional ways of caring; in particular, if the facility is centrally managed and provides generic care wards along with a SCU. There might be a particular role for HIQA in monitoring private SCUs in terms of how they implement and provide truly person-centred care for their residents. Public SCUs, on the other hand, appeared to adhere to stricter standards of care provision yet they showed greater flaws in their physical environment than the private SCU. There may thus be a need for refurbishing existing public units and for ensuring that to-be-built public units will incorporate core standards of dementia-specific design. The role of monitoring such environmental modifications in HSE units might also be taken on by HIQA. In general, there is a role for HIQA to become more proactive in making supplementary standards for specialist residential care settings legally binding, and in monitoring the implementation of these standards by SCUs.

9.3.5 Written policies on what constitutes SCUs

As shown (see Chapter 2), universal design standards for SCUs now exist that define the key physical and social characteristics of SCUs and there is a consensus internationally about the features and principles of SCUs (Judd, Marshall, & Phippen, 1999). Findings from this thesis show that all three research sites failed to deliver on such design principles and environmental features. For instance, resident privacy is one of several key design features of SCUs (Van Hoof et al., 2010). It should be implemented by providing residents with private bedrooms complete with ensuites. This thesis has shown that both public units were unable to provide private washing/toileting facilities; one unit also accommodated residents in multi-bedded wards.

SCUs should also be small-scale and domestic and while both of the public units met this criterion and accommodated between six to nine residents, the private unit catered for 37 LTC residents. Given that these particular units agreed to participate in the research and identified themselves as SCUs, there is a need for a written policy document about SCUs in Ireland. The policy document would contain information about the minimum requirements needed to operate as an SCU and would act as guidance to ensure improvements for existing units. The policy once implemented would prevent other facilities from trading as SCUs if they failed to adhere to dementia-friendly design and person-centred care.

9.3.6 Criteria for admission to SCUs

As shown in Chapter 6, the three SCUs differed in their admission criteria. Whilst all three units admitted PwDs with a confirmed dementia diagnosis, both public units required residents to have challenging behaviours that could not be managed elsewhere. In addition, one of the two public units required residents to be able to mobilise independently. It might be important for each SCU to develop a written policy about what criteria govern the admission of LTC residents. Such written policies might enhance transparency and help meet the unit's care goals by ensuring the best possible resident mix. There might again be a stronger role for HIQA in overseeing the development, implementation and adaptation of SCU admission policies including admission criteria across the country.

9.3.7 Dementia training for staff working in hospitals and nursing homes

Chapter 5 showed the fate of two PwDs who had been placed in other institutional care settings immediately prior to the SCU transfer and where incidents of neglect and poor practices were reported. These included insufficient monitoring to the point where one lady escaped from the grounds of the hospital, insufficient monitoring of food intake, a foreign language being spoken by staff in front of residents, and karaoke pop music being

offered as an activity. One of these carers reported how his wife once admitted to a generic nursing home was taken off her anti-dementia drugs and given tranquillisers. The same lady was also subjected to physical restraints and tied to a chair.

During the in-depth interviews, both FCs emphasised that such care practices happened because in their view, staff had a very limited understanding of dementia and were not trained to deal with challenging behaviours.

There is a need for a lot more dementia-specific training amongst hospital staff and for staff employed in general nursing homes. Hospital managers and nursing home boards need to ensure the provision of dementia-specific training and education of their staff so as to foster a quality of care that promotes the dignity and personhood of the individual. For training to be effective, it needs to be embedded in the culture of the respective organisational environment. Modules should encompass education in person-centred care, practical training in managing challenging behaviours, and education about meaningful activities. Given that SCU staff have specific skills in this area, it might be helpful to involve them in the development and provision of such training programmes. One idea might be for staff employed in generic nursing homes and hospitals to have internships-as-observers in SCUs.

9.3.8 Education and training for FCs

As indicated earlier (see section 9.2), FCs might greatly benefit from more education and training in the sensitive area of communicating with a relative with dementia; in particular, how to communicate with a person with advanced dementia, how to communicate with the person about SCU placement, and how to initiate and conduct timely discussions about the highly sensitive topic of SCU LTC placement. There is a need for a stronger role of education and training providers (such as the ASI and the DSIDC) in disseminating information about the afore-mentioned issues, and providing trainings specifically tailored to FCs' needs for improving their communication skills and facilitating discussions around

SCU placement. SCU staff members might be included into the conceptualisation and development of such programmes because they are dealing with the afore-described issues on a regular basis and may therefore be a great source of support and expertise. A commitment to increased funding for the development and implementation of such training and education programmes might also be incorporated into the upcoming national dementia strategy.

9.4 Implications for research

This was a very small-scale exploratory study which captured data at only two points in time but through the perspectives of several different players. Although a variety of different issues were addressed by the research, there are other areas that now lend themselves well to future research. For example, a large-scale quantitative study using a quasi-experimental design and which would be designed to assess the efficacy of SCUs over more traditional long-stay care settings would be very valuable. Primary outcome measures in such a study might include challenging behaviours, quality of life (not overtly addressed in this thesis), morbidity and mortality patterns, use of psychotropic medication, carer mental health measures including carer burden, depression and agitation, staff satisfaction, FC satisfaction and satisfaction with end-of-life care. Such a study could also be used to assess the effectiveness of different partnership (staff/FCs) models in nursing homes versus SCUs. Information could be collected at several points in time such as one month, three months, six months, and 12 months after placement in order to capture long-term changes in these measures.

This thesis did not compare SCUs over more traditional LTC units with regard to admitting PwDs into these settings on a long-stay basis. Chapter 8 highlighted the issues of admitting PwDs into SCUs (as emanating from my thesis) which are similar to those of admitting PwDs into LTC in general, for example nursing homes (as identified in existing

studies on generic LTC placement). Further qualitative research comparing admissions into SCUs versus admissions into generic LTC settings might provide in-depth insights into their similarities (and differences), and might help generate a deeper understanding of the SCU LTC admission process.

There is also a pressing need to explore the experience of transition into SCUs from the perspective of a PwD. One of the key difficulties as this thesis has demonstrated is that often by the time the person is ready to be admitted to a SCU, their dementia is so advanced that they are unable to meaningfully engage in research. The challenge is to develop research tools that would enable these people with more advanced dementia to participate and have their voices heard. Observational studies using tools such as Dementia Care Mapping (DCM) might be one approach which in the future could be used (but which was not used in this thesis because of my lack of experience in DCM, the absence of at least one co-worker necessary to perform valid observations, and time constraints).

The research shed light on some of the choices and dilemmas facing SCU staff and highlighted the challenges they encountered working in these units, receiving limited supports and being employed in conditions which at times were far from ideal. Working in such units was shown to be very stressful when difficult decisions had to be made about admitting and discharging residents. There is a need for more research to be conducted with staff employed in SCUs. There is a need to gain a better understanding of staff satisfaction and conversely staff burnout in professional dementia care. There is a need to find out more about what motivates staff to work in such specialist settings and what factors contribute to their quitting work of this nature.

As stated in Chapter 4, staff members' views about the process of admitting new LTC residents were elicited by conducting FGs. The three FGs were successful in exploring staff's experiences in an in-depth (thorough discussion of key aspects of the admission

process by FG members), multi-layered (multiple perspectives), and efficient way (one-off meeting that allowed for participation of different staff members). However, it may be worthwhile for future research to consider conducting individual in-depth interviews with SCU team members about their views and experiences of admitting PwDs whom they knew well and who participated in the study. This approach might help gain an even deeper understanding of the admission experience from staff's point of view. I chose not to use this approach because all three FGs generated rich and compelling insights into staff's general issues and challenges related to admitting PwDs into SCU LTC; because of staff's burden, and for pragmatic reasons (time constraints).

Findings from this thesis have also highlighted the unique challenges of spouse caregivers undergoing SCU LTC placement of their partner. Although only two spouses (a wife, a husband) participated in this thesis, their narratives powerfully revealed issues pertaining specifically to this caregiver group including intense and persisting feelings of guilt, sadness, and loneliness; a very high level of social isolation, and a particular lack of psychosocial supports tailored to this group. There is a need for more research to be conducted exclusively with spouse caregivers in order to explore their unique challenges and needs associated with their partner's SCU LTC placement. I had enormous difficulty recruiting FCs along with PwDs for this research due to the extremely small number of new SCU LTC admissions (see section 4.3.3.7). For the purpose of this thesis, it was thus not possible to exclusively focus on a sub-sample of FCs, such as spouses.

9.5 Strengths and weaknesses

The aim of exploring the phenomenon of admitting PwDs into SCUs from multiple perspectives (FCs, PwDs, SCU staff) concurs with core assumptions held by social constructionist approaches. Social constructionist approaches assume that multiple realities exist. The diversity of realities was particularly illustrated by both FCs and SCU

staff facing identical challenges (such as deciding about placement, communicating news of the placement to PwDs, and adapting to the admission immediately and in the longer term) yet revealing the differences in their experiences, thereby offering unique insights into the admission process from different actors.

Social constructionists would also argue that expertise of a phenomenon lies with those affected by it. This thesis demonstrated that PwDs, FCs, and SCU staff members were the sole experts of the phenomenon of moving into SCU LTC. Their immensely rich and layered accounts of what it meant to be living with dementia and transferring into SCUs generated new and startling insights into how complex and challenging, yet hidden from the wider system (public, government, health care system) the topic of being admitted into SCU LTC is. This thesis clearly demonstrated the importance of accepting the individual expertise each participant had with the placement experience, thereby recognising and respecting the fact that realities are multiple and individual.

Another core assumption of social constructionism is that individual realities are intertwined. Intertwining of realities means that each actor's realities - or experiences - are co-constructed and contextualised by those of the other actors; and are embedded within and shaped by external contexts. This thesis convincingly showed how individual admission experiences for each participant (PwDs, FCs, SCU staff) were both co-constructed and contextualised by triadic relationships, environments (home, SCUs, other care settings) and higher-order systems (such as the current health and social care system). The thesis has been rich with examples of how these entities interact with each other and over time, and how they shape the individual's experience of being admitted into and settling into SCU care over time. For instance, it was poignantly demonstrated how a person-centred philosophy of care, which is understood as an essential component of the context (SCUs) embedding individuals' admission experiences, played an integral part in constructing and shaping both PwDs' and FCs' admission experiences (see sections 7.5.4 and 8.8). By strictly adapting to these people's needs, advocating for their

personhood, and understanding the complexities of SCU LTC admission from FCs' and PwDs' point of view, proponents of person-centred care (such as SCUs) helped these people adapt and cope with the SCU LTC placement, ultimately improving their quality of life.

For example, PwDs' experiences were shaped and contextualised by their interactions with staff and other residents. FCs' care-giving experiences both prior to and after placement were equally co-constructed by their interactions and relationships with community-based HSPs and staff in SCUs whom they had gotten to know through using their respite care services. Service providers in turn had experiences which were co-constructed with family members and with the PwD. It was also powerfully demonstrated how the lives of FCs were inextricably intertwined with those of their relatives with dementia, whom they cared for along with other family members. Participants' narratives showed the dynamic process in which any actions, decisions, or communications made by them impacted on their relative's welfare, thereby influencing PwD's individual experiences. Conversely, any behaviours, changes, and interactions made by the PwD towards their carer shaped the latter's well-being and influenced their further actions. After the placement, these co-constructive dynamics became even stronger when all three participants, namely, the PwD, FC and staff member interacted within one environment (SCU). Caring for the FCs, therefore, did not stop with placement but rather in keeping Zarit's and Whitlatch's (1992) findings, SCU admission reflected a continuation of the process of co-constructing and intertwining individual realities.

As such, these interpretations align with phenomenological assumptions underlying this thesis (see Chapter 4). In particular, the thesis has highlighted my key role in co-constructing and contextualising participants' admission experiences as I encouraged PwDs, FCs, and staff to reflect on their personal admission experiences, allowing them to express their complex feelings about the topic under study, and report honestly on aspects of the admission process they wished to criticise. By assuming this mediating role

and entering the dementia care triad (PwD, FC, SCU staff), I may have represented a fourth (albeit transient) constituent of the care-giving relationship. This unique situation of participating in research while being in the process of admitting a loved one with dementia into SCU LTC may have influenced participants' admission experiences. Viewing PwDs as well as their informal and formal caregivers as experts of their own experiences was a particularly useful stance that helped me never lose sight of their individual personhood, dignity, and choices.

It was highlighted that triadic relationships, however, were not restricted to a particular PwD, his/her FC and SCU staff. Rather, these triads were inclusive of other people. In particular, other family members were part of the triadic relationship on an ongoing yet 'hidden' basis. For example, children were affected by the PwD's care needs prior to placement, and the same children were brought along to visit their grandparents after SCU placement. Spouses remained involved in their partner's life before and after placement. Other family members were involved in deciding about the PwD's placement and came to visit the person in the SCU. Indeed, data showed how professional staff sometimes involved their own family members in discussions about work issues.

The thesis showed how any given triadic relationship was embedded within higher-order systems. They included the respective immediate care environment (home or generic care unit prior to placement; SCU after placement), formal support services provided to families and their relative with dementia, and government and policy regulations for dementia in Ireland. This thesis elucidated interactions between these entities over time by presenting multiple rich examples of how higher-order systems impacted on triadic relationships and the individual's transition experience, making it positive or detrimental for the respective person.

Overall, the thesis showed that whilst the enhanced purpose-built environment and the person-centred philosophy of care provided by SCUs were positive, helped to establish

supportive triadic relationships, and helped both PwDs and their carers to adapt well to their new living situation, the broader system (i. e. external contexts) entailing governmental and service supports failed these vulnerable triads.

As was also demonstrated in this thesis, placing a focus on actors and their individual experiences, on how they co-construct their relationships, on how their relationships are embedded into higher-order systems, and on how these components interact and affect individual experiences, makes the relationship-centred approach fully compatible with core tenets of social constructionism and phenomenology.

As discussed in Chapter 4, alternate research methods might have provided richer insights into the experiences of PwDs. If the research was to be repeated a key change would be that efforts would be made to recruit people with mild to moderate dementia as far as possible to ensure that their voices would be heard. Also, observation-based methods (for example, participant observation and/or videography) might be better suited than interviews to making efforts to fully include PwDs with advanced dementia (as they had in this research). A more thorough recruitment of research sites might be pursued to ensure that only truly small-scale facilities would be included. Some might argue for example that the 37-bedded unit included in this study was not by definition a SCU.

It might also be conceivable to restrict the research focus to the admission time only (i. e. immediately prior to and after placement) and explore this point in time in more depth. However, this thesis covered a whole range of aspects of the admission process and might thus be more holistic – an aim which this thesis set out to achieve.

In conclusion, the thesis was designed to explore in depth the experiences of PwDs, their FCs, and SCU staff of admitting PwDs into SCUs. In-depth interviews conducted with FCs and PwDs at two points in time (phase one, phase two) and FGs conducted with staff from three different SCUs yielded immensely rich and powerful narratives, which highlighted

the many aspects of the admission process from multiple perspectives. By using this holistic approach, a truly in-depth insight into what moving to SCU LTC means for PwDs, their FCs, and SCU staff was generated. Findings demonstrated the overall positive difference SCUs made to these people's lives both in the short term and in the longer term. This research also revealed the complex and ongoing nature of the admission process itself. Whilst the enhanced care setting clearly helped improve these people's lives and relieved them of the strains and stresses experienced prior to placement, this thesis very clearly showed that SCU placement brought about new challenges for these people some of which it is likely they are continuing to deal with to this day. By generating these multifaceted, in-depth insights into the SCU LTC placement process, this thesis has clearly achieved its goal.

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Appendix A: Information letter for FCs

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School of Social Work and Social Policy

DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE

Relocating to a specialist dementia care unit in Ireland: The experiences and views of people with dementia and their caregivers

You are invited to participate in a study

Dear [*insert FC's name*],

I am a postgraduate student in Social Sciences. I have a background in Psychology, and I have worked in dementia day care settings in Germany. This thesis is about the experiences and views of nursing home residents with dementia, their family caregivers and formal care staff of relocating to a specialist dementia care unit.

Background

More Irish people with dementia will need long-stay care. Some will avail of dementia-specific care settings known as specialist care units (SCUs). SCUs have only recently become a part of the Irish dementia care system. Consequently, there is a lack of knowledge about how people in Ireland access such specialised environments, how they experience the transition to such settings, and how the transfer is managed and communicated. This study will explore these topics in depth.

Information from you will help narrow this gap in knowledge and ultimately improve the quality of life for people with dementia and their caregivers. The thesis is one of the research strands of the Living with Dementia programme, which is based at the School of Social Work and Social Policy at Trinity College Dublin and the Dementia Services and Information Development Centre at St. James's Hospital Dublin. The programme is funded by The Atlantic Philanthropies.

What is required from you

If you decide to participate in the study I will explore with you your experiences and views of the time prior to the move, the actual transfer, and the time following the move to the SCU. Therefore I will conduct two individual interviews with you: The first about 3-4 weeks following the relocation, and the second within 4 to 6 months following the relocation. A time and date will be set convenient to you. The interviews will last between 45 to 60 minutes each, and will be audio-taped for subsequent analysis.

In addition, you will be asked to fill out a socio-demographic questionnaire, which will be handed out to you after having completed the first interview. In this questionnaire you will be asked for some general information about you such as age, gender, education, occupational status, marital status, and your care-giving experiences. This questionnaire will take approximately 10 minutes.

Furthermore, the researcher needs your consent to collecting information on the cognitive status and health status of your relative diagnosed with dementia. Therefore, the researcher will access and take notes on relevant medical notes and nursing files provided by the SCU.

Anonymity, confidentiality, and your safety

Your data (i.e. interview tapes, interview transcripts, socio-demographic questionnaire) will be kept confidentially and coded. Only these codes will be used in subsequent data analysis and publications. Your data will be destroyed entirely after the project has been completed. Parts of the interviews will be cited in anonymised form in the thesis and subsequent publications. Your statements will be freed from any expressions that could enable readers to identify you. Your name will not be identified with any information provided by you. The facility's name will also not be revealed in the thesis and subsequent publications.

Independence of interests

The PhD project is being carried out independently and not aligned to [*insert facility name*] and its policies. Your participation in the study is completely voluntary. You can withdraw your consent to participate in the project at any point in time and without any adverse consequences. This includes refusing to answer any questions you don't like to answer. If you wish to participate in the study please sign the consent forms and return one copy to me.

Thank you very much for your interest in my research project!

With best regards

Andrea

Appendix B: Consent form for FCs

Please tick the boxes as appropriate

1. I have read the information provided.	O ***YES***	O ***NO***
2. I have obtained all details about the study.	O ***YES***	O ***NO***
3. I have based my decision to partake in the study on the information provided.	O ***YES***	O ***NO***
4. I am aware that my participation in the study includes two interviews and one socio-demographic questionnaire.	O ***YES***	O ***NO***
5. I am aware that the interviews will be audio-taped.	O ***YES***	O ***NO***
6. I am also aware that my participation in the study will mean that the researcher can access medical notes and nursing files of my next of kin moving to the dementia specialist care unit.	O ***YES***	O ***NO***
7. I have been informed that I can withdraw my consent to participate in the study at any time and without any adverse consequences.	O ***YES***	O ***NO***
8. I now consent to participate in the study.	O ***YES***	O ***NO***

DATE:_____

PARTICIPANT NAME (PRINT):_____

PARTICIPANT SIGNATURE: _____

Appendix C : Information letter for PwDs

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School of Social Work and Social Policy

DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE
promoting excellence in dementia care

Moving to a specialist dementia care unit in Ireland: The experiences and views of residents and their caregivers

You are invited to participate in a study

Dear [*insert PwD's name*],

I am a postgraduate student in Social Sciences. I have a background in Psychology, and I have worked in dementia day care settings in Germany. This thesis is about relocating to a dementia care unit. I am particularly interested in your experiences of relocating to your new domicile at [*insert facility name*].

Background

More Irish people with dementia will need long-stay care. Some will move to dementia-specific care settings known as specialist care units (SCUs). SCUs have only recently become a part of the Irish dementia care system. At present, only little is known about how people in Ireland experience the move to such settings, how they view the move, and how the move is managed and communicated. This study will explore these topics in depth.

Information from you will help narrow this gap in knowledge and ultimately improve the quality of life for people with dementia and their caregivers. The thesis is one of the research strands of the Living With Dementia programme, which is based at the School of Social Work and Social Policy at Trinity College Dublin and the Dementia Services and Information Development Centre at St. James's Hospital Dublin. The programme is funded by The Atlantic Philanthropies.

What is required from you

I am particularly interested in your experiences of moving from your former setting to your new domicile at [*insert facility name*]. Therefore I will need your help and cooperation in three major areas:

1. First I will need to test your memory and cognitive functioning. I will do this by using the Mini Mental State Exam (MMSE). This test will take 10 to 20 minutes.

2. I will also interview you about your experiences and views of moving to your new home at [*insert facility name*]. A time and date will be set convenient to you. The interview will take up to 30 minutes, and will be audio-taped for future analysis.

I would like to conduct a one-on-one interview with you. This allows you to better express your experiences and views. But you are very welcome to have your next of kin attend the interview if you wish to.

3. I will need your consent to collect information on your cognitive status and health status. Therefore I will read and take notes on your medical notes and nursing files provided by [*insert facility name*].

Anonymity, confidentiality, and your safety

I will keep your original data (i.e. interview tapes, interview transcripts, MMSE result sheets, notes on cognitive and health status) confidentially and coded. I will use the coded data only in subsequent data analysis and publications. I will destroy your original data entirely after the project has been completed. I will cite parts of the interviews anonymously in the thesis and subsequent publications. I will therefore free all your statements from any expressions that could enable readers to identify you. Your name will not be identified with any information provided by you. The facility's name will also not be revealed in the thesis and subsequent publications.

Independence of interests

The PhD project is being carried out independently and not aligned to [*insert facility name*] and its policies. Your participation in the study is completely voluntary. You can withdraw your consent to participate in the project at any point in time and without any adverse consequences. This includes refusing to answer any questions you don't like to answer.

If you wish to participate in the study please sign the consent form and return it to me. The consent form needs also to be signed by your next of kin [*insert family caregiver's name*] in order to protect your rights and your safety as research participant.

Thank you very much for your interest in my research project!

With best regards
Andrea

Appendix D: Consent form for PwDs

Please tick the boxes as appropriate

1. I have read the information provided.	O **YES**	O **NO**
2. I have obtained all details about the study.	O **YES**	O **NO**
3. I have discussed my wish to take part in the study with my next of kin [*insert name*].	O **YES**	O **NO**
4. I have based my decision to partake in the study on the information provided.	O **YES**	O **NO**
5. I am aware that I will have to take part in two cognitive memory tests and two interviews with the researcher.	O **YES**	O **NO**
6. I am aware that the interviews will be audio-taped.	O **YES**	O **NO**
7. I am aware that my participation in this study will mean that the researcher can access my medical notes and nursing files at the nursing home.	O **YES**	O **NO**
8. I am aware that I can withdraw my consent to participate in the study at any time and without any adverse consequences.	O **YES**	O **NO**
9. My next of kin [*insert name*] consents to my participation in the study including two cognitive memory tests and two individual interviews.	O **YES**	O **NO**
10. I now consent to participate in the study.	O **YES**	O **NO**

DATE: _____

PARTICIPANT NAME (PRINT):_____

PARTICIPANT SIGNATURE: _____

NEXT OF KIN NAME (PRINT):_____

NEXT OF KIN SIGNATURE: _____

Appendix E: Information letter for FGs

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School of Social Work and Social Policy

DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE
promoting excellence in dementia care

Relocating to a specialist dementia care unit in Ireland: The experiences and views of people with dementia and their caregivers

You are invited to participate in a research project

Dear Member of the [*insert facility name*] Team,

I am a postgraduate student in Social Sciences. I have a background in Psychology, and I have worked in dementia day care settings in Germany. The study I'm conducting is about the experiences and views of long-stay care residents with dementia, their family caregivers, and formal care staff of relocating to a specialist dementia care unit.

Background
More Irish people with dementia will need long-stay care. Some will avail of dementia-specific care settings known as specialist care units (SCUs). SCUs have only recently become a part of the Irish dementia care system. Consequently, there is a lack of knowledge about how people in Ireland access such specialised environments, how they experience the transition to such settings, and how the transfer is managed and communicated. This study will explore these topics in depth.

Information from you will help narrow this gap in knowledge and ultimately improve the quality of life for people with dementia and their caregivers. The thesis is one of the research strands of the Living With Dementia programme, which is based at the School of Social Work and Social Policy at Trinity College Dublin and the Dementia Services and Information Development Centre at St. James's Hospital Dublin. The programme is funded by The Atlantic Philanthropies.

What is required from you
If you decide to participate in the study I will conduct one focus group with you. The focus group means that you and fellow members of [*insert facility name*] staff will be interviewed collectively about your experiences and views of relocating new residents to [*insert facility name*] and of supporting

them and their relatives before, during, and after the transfer. A time and date will be set convenient to all participants. The focus group will last between 60 to 90 minutes, and will be audio-taped for subsequent analysis.

In addition, you will be asked to fill out a short socio-demographic questionnaire, which will be handed out to you the end of the focus group session. In this questionnaire you will be asked for some general information about you such as age, gender, education, occupational status, and marital status. This questionnaire will take approximately 10 minutes.

Anonymity, confidentiality, and your safety
Your data (i.e. interview tapes, interview transcripts, socio-demographic questionnaire) will be kept confidentially and coded. Only these codes will be used in subsequent data analysis and publications. Your data will be entirely destroyed after the project has been completed. Parts of the interviews will be cited in anonymised form in the thesis and subsequent publications. Your statements will be freed from any expressions that could enable readers to identify you. Your name will not be identified with any information provided by you. The facility's name will also not be revealed in the thesis and subsequent publications.

Independence of interests
The PhD project is being carried out independently and not aligned to [*insert facility name*] and its policies. Your participation in the study is completely voluntary. You can withdraw your consent to participate in the project at any point in time and without any adverse consequences. This includes refusing to answer any questions you don't like to answer. If you wish to participate in the study please sign the consent form and return it to me.

Thank you very much for your interest in my research project!

With best regards

Andrea

Appendix F: Consent form for FGs

Please tick the boxes as appropriate

1. I have read the information provided.	O ***YES***	O ***NO***
2. I have obtained all details about the study.	O ***YES***	O ***NO***
3. I have based my decision to partake in the study on the information provided.	O ***YES***	O ***NO***
4. I am aware that my participation in the study includes one focus group and one socio-demographic questionnaire.	O ***YES***	O ***NO***
5. I am aware that the interview will be audio-taped.	O ***YES***	O ***NO***
6. I am also aware that my participation in the study will mean that the researcher can access medical notes and nursing files of SCU residents participating in the study.	O ***YES***	O ***NO***
7. I have been informed that I can withdraw my consent to participate in the study at any time and without any adverse consequences.	O ***YES***	O ***NO***
8. I now consent to participate in the study.	O ***YES***	O ***NO***

DATE: _____

PARTICIPANT NAME (PRINT): _____

PARTICIPANT SIGNATURE: _____

Appendix G: Information sheet given to SCU staff at first visit to SCU

What Are Your Experiences of Moving to A Specialist Dementia Care Unit?

1. Research Programme
I'm a second-year postgraduate student of Social Sciences. My thesis is part of the Living With Dementia Programme, which is based at the School of Social Work and Social Policy at Trinity College Dublin and the Dementia Services Information and Development Centre at St. James's Hospital Dublin. The programme is funded by The Atlantic Philanthropies. My background is in Psychology, and I have worked as formal caregiver in two dementia day care settings in Germany.

2. Study Background
More Irish people diagnosed with dementia will need specialised long-term care. Some of them will relocate to specialist dementia care units (SCUs). SCUs are becoming a part of the Irish long-term care spectrum. Consequently, there is a lack of knowledge in Ireland about how SCUs are accessed, how and by whom the transfer to a SCU is communicated and managed, and how the transfer is being experienced by people with dementia and their caregivers. The thesis is exploring these topics in-depth.

3. Study Aims
- To provide a comprehensive understanding of the experiences of moving to a specialised care setting.
- To generate new knowledge about the (a) transition process, (b) the physical transfer, and (c) effects of moving to a SCU.
- To provide information about (a) the needs of people with dementia and their caregivers and about (b) best relocation practices.
- To help improve the quality of life of people with dementia and their formal and informal caregivers.

4. Key Research Questions
A. What are the short-term and longer term experiences of residents of moving to a SCU?
B. What are the experiences of residents of living in a SCU in the longer term?
C. What are the experiences of family caregivers of accessing a SCU?
D. What are family caregivers' experiences of communicating and managing the transfer?
E. What are the more long-term experiences of family caregivers of adapting to their relative living in a specialised dementia care unit?
F. What are the experiences of SCU staff of admitting new residents?
G. What are staff's experiences of helping new residents and their family caregivers adapt to the SCU?
H. What can be learnt from participants' experiences with regard to improved SCU relocation practices and policies?

5. Research Plan

Study Design: ➢ Qualitative-exploratory ➢ Supplemented by 3 quantitative measures
Sample to be recruited in your facility: ➢ 3 residents living with dementia who have recently been admitted on a long-stay care basis (3-4 weeks post-admission) ➢ Their family caregivers (N = 3) ➢ 3 -5 members of SCU staff, including one senior staff member (Clinical

Nurse Specialist)
Qualitative Data Collection: ➢ Individual interviews with residents and their relatives. The first interview takes place within 3 -4 weeks following the relocation. The second interview takes place within 4 to 6 months following the relocation (~ 20-60 min., audio-taped). ➢ One Focus Group and 2-4 individual interviews with senior staff (Clinical Nurse Specialist). The Focus Group takes place within 3 -4 weeks after admission of the first resident participating in the study (~ 60-90 min., audio-taped). The individual interviews are conducted with one senior staff member (Clinical Nurse Specialist), and take place within 4 to 6 months following the Focus Group (~ 60 min., audio-taped). Quantitative Data Collection: ➢ Mini Mental State Examination (MMSE) conducted with residents prior to each individual interview (~ 10-15 min.) ➢ Self-administered questionnaire for family caregivers and SCU staff (after first interview / Focus Group, ~ 5-10 min.) ➢ Nursing home record analysis.

6. Inclusion Criteria

A sample size of 8 residents and 8 family caregivers is targeted.
To achieve this goal, 3 more residents and their family caregivers are needed.

Inclusion Criteria for Residents:
➢ Recent admission to the SCU (3-4 weeks post-admission)
➢ Diagnosis of Alzheimer's disease or other dementia subtype
➢ Willing to participate in the study

Inclusion Criteria for Family Caregivers:
➢ Main family caregiver
➢ Consenting to resident's participation in the study
➢ Willing to participate in the study

Inclusion Criteria for SCU Staff:
➢ Working in the SCU on a regular basis
➢ Willing to participate in the study

The selection of research sites for this study has been influenced by international consensus criteria on SCU design as well as by Kitwood's concept of person-centred care.

Inclusion Criteria for SCU as Research Site:
➢ Self-contained – i.e. residents don't share their environment with cognitively intact residents
➢ Dementia-specific approach (staff training, activity programme)
➢ Admitting 3 new residents over the next few months
➢ Long-stay/ permanent care – i.e. no respite admissions

7. Participation in the Study

·The study has been approved by the School's Research Ethics Committee.
·To date, a total of 22 individual interviews and 2 Focus Groups have been completed.

·Participants will receive detailed written information about the study.
·Participants will be given the opportunity to obtain more information and to address any concerns about their participation in the study at any time.
·Informed written and oral consent will be obtained from all participants.
·If participants with a dementia cannot give written consent by themselves but wish to participate in the study, proxy consent of their family caregivers will be obtained.
·The interview will be stopped immediately if the resident expresses any verbal or non-verbal signs of discomfort.
·Family caregivers can attend their relative's interview if they and/or their relatives wish so.
·All interview tapes, transcripts, questionnaires, and result sheets will be kept confidentially and will be entirely destroyed after the study has been completed.
·All data provided by participants will be coded and anonymised. Only the coded and anonymised data will be used in the thesis and subsequent publications.
·For more information please see the attached consent and information letters.

Thank you very much for your time and for your interest in the study! I would be delighted to learn more about your experiences of relocating to (name of SCU).

With best regards,
Andrea

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Appendix H: Interview schedule for FCs – First interview

(*) Replace by person's name
(**) Replace by facility name

1) Tell me about where, and with whom, your *relative* (*) was living before coming to (unit)?

-Former settings? Why?
-Cognitive/ health/ behavioural status?
-Relationships with staff and peers?
-Overall impression of his/her situation?

2) Why was your *relative* brought to (unit) (**)?

-What changes in *relative*?
-Why (unit)?

3) Tell me about how you first made contact with (unit)?

-When first thinking about moving there?
-Information and first contacts?
-First visit of (unit) and impressions?
-Easy or difficult to access?
-On waiting list? Waiting time?
-Listed for other units? Why?

4) Tell me about how you made the decision to bring your *relative* to (unit)?

-When? Who involved? What influenced the decision?
-Feelings and expectations?
-Involvement of *relative* into decision-making and further planning?
-What infos? How was decision communicated? His/her responses?
-Further planning for actual move?

5) Tell me about your own experiences of the relocation, beginning with the last few hours in the old setting.

-Immediate time before move?
-Actual transfer?
-Arriving at (unit)?
-Immediate time after arriving?
-First few hours in (unit)?
-Your overall reaction to move at that stage?
-Your relative's overall reaction to move at that stage?
-What main stages and events, in your view?
-Responses of *relative* to these events?

-Communicating these events to *relative*?
-Communication with staff about move?

6) How, and by whom, were you supported throughout the transfer?

-When?
-Practical/ psychological help?
-Main supporters?
-What support was most important?
-Any prior knowledge/ skills/ experiences? Helpful?
- Specific advice on how to communicate transfer to *relative*?

7) What is your overall reaction now to the move?

-Events since first few hours in the new unit?
-Expectations met vs. not met?

8) What is your *relative's* overall response now to the move?

-To his/her new home?
-What communications about move? / His or her major concerns?
-Progress of settling-in?

9) What are the key changes that your relative's move here has brought about in your life?

-Health and emotional status
-Relief
-View of self
-Care-giving role
-Relationship with *relative*
-Family relationships
-Relationships with staff
-Views of dementia and dementia care
-Visiting *relative*

10) What key changes in your *relative's* life have you noticed since the move?

-Cognitive and health status
-Social well-being
-Quality of life
-Reactions to changes
-Expected changes

11) What does the move mean to you?

-How important for you?
-Meaning of new setting?
-Meaning of *relative's* new living situation?

12) Can you tell me the main differences between this place and the place where your *relative* previously lived?

-Quality of care?
-*Relative's* well-being and functional/social status?
-Physical setting?
-Culture of care?
-Staff levels and relationships?
-Care policies?
-Main benefits?

13) What would have made the move better for you and your *relative*?

14) Is there anything else you would like to say about the relocation here?

15) Is there anything else you would like to tell me about your *relative's* overall care now?

Appendix I: Interview schedule for FCs – Second interview

1. Tell me how have things been for you since your relative moved in here [x] months ago and since our first interview?
-Significant events

2. How do you now feel about your relative being a resident here?

3. Are there any differences now between how you feel and how you felt when we last spoke?

4. What is your overall reaction to the transfer now?
-Emotions:
*Positive
*Negative
*Neutral
*Unsure
-Cognitions:
*Expectations met
*Expectations unmet
-Other reaction(s)

5. What if any key changes has your relative's transfer here brought about to your life now?
-Employment
-Care-giving duties
-Leisure time
-Family/ Personal life
-Other changes since time of first interview
-None

6. What has been the most positive aspect for you now about your relative's transfer here to this Dementia Specialist Care Unit?
-Changes in level of caregiver distress
-Relationship with resident
-New forms of support
-Most pleasant experiences
-Other aspects

7. What has been the least positive aspect for you now about your relative's transfer here to this Dementia Specialist Care Unit?
-Distance to relative
-New care-giving role(s)
-Disapproval of move by other family members
-Regulations
-Funding of resident's care
-Most traumatic experiences
-Other aspects

8. Is there anything that could have been done at the time to make your relative's transfer here easier for you?

9. What is your overall attitude to [*name of Dementia Specialist Care Unit*] now?
-Satisfaction/dissatisfaction with the physical setting
-Satisfaction/dissatisfaction with staff
-Satisfaction/dissatisfaction with philosophy of care
-Satisfaction/dissatisfaction with activity programming
-Other comments

10. Have your views about this Dementia Specialist Care Unit changed since the last time we met?

11. What is it like for you now having your relative living in [*name of Dementia Specialist Care Unit*]?
-Visiting: How do you like it? What do you do during a visit?
-Relationships and communication with
*Staff
*Relative
*Other families and residents
-Other routines
-Used to relative living here
-Not used to relative living here
-Other

12. What are the key advantages for you of having you relative in this Dementia Specialist Care Unit?

13. What are the key disadvantages for you of having your relative in this Dementia Specialist Care Unit?

14. What in your view is the main difference now between [*name of former setting*] and here [*name of Dementia Specialist Care Unit*]?

15. What is your relative's overall reaction now to being transferred from [*name of the former setting*] to here?

16. What if anything has changed in his or her life since the transfer now?
-New health problems since admission
-New challenging behaviours such as agitation, sleep disturbance, repeated questions, paranoia, delusions... since admission
-Other changes since first interview (specific period of time)

17. What do you think now has been the most positive aspect for your relative about the transfer here?

18. What do you think now has been the least positive aspect for your relative about the transfer here?

19. Reflecting back now to the transfer here, could anything else have been done to make the transfer easier for your relative?

20. How do you think your relative has settled in to [*name of Dementia Specialist Care Unit*] now?
-Settled
-Remains unsettled
-Sometimes settled
-Relationship and communication with you
-Relationships and communication with other residents and staff

-New concerns and issues

21. Which if any aspects of your relative's former life are most missed now?

22. What do you think is the most positive aspect of this Dementia Specialist Care Unit now for your relative?
-Modified physical environment
-Being with others
-Continuity between resident's former and present life
-Person-centred care
-Activity programming
-Dementia-specific training of staff
-Safety
-Other aspects

23. What do you think is the most negative aspect of this Dementia Specialist Care Unit now for your relative?
-Problems with physical environment (e.g. noise)
-Loneliness
-Losses
-Lack of choice
-Problems with psycho-social stimulation
-Problems with staff
-Regulations
-Other aspects

24. Are there any changes that could be made here now that might make your relative's quality of life better?
-Physical environment
-Staffing
-Activity programmes
-Daily routines
-Meals
-Religious and spiritual well-being
-Other

25. Is there anything else you want to tell me about your relative's transfer here now?

26. Is there anything else you want to tell me about this Dementia Specialist Care Unit here?

27. Finally is there anything else you want to tell me about your relative's overall care here?

Appendix J: Interview schedule for PwDs – First interview

1. How do you like it here?

2. Tell me about what your life is like here?

Prompts:
- Structure of day
- Activities
- Well-being
- Meeting with others
- Sleeping
- Eating
- Important relationships
- Special occasions (e.g. birthdays)

3. What is it about here that makes you feel good?

Prompts:
-Meals
-Friends
-Relationships with staff
-Family activities and visiting times
-Personal activities and hobbies
-Social activities
-Religious services
-Sleep times
-Physical design

4. What is it about here that makes you feel sad?

5. Tell me about the move here.

6. What did the move here mean to you?

7. What has your family told you about the move?

8. Who helped you with the move?

9. What has changed now in your life since the move here? (Use prompts Q3)

10. What other changes in your life do you expect from being here?

11. Do you think this place is different from other places you know?

12. Can you tell me what these differences are?

Appendix K: Interview schedule for PwDs – Second interview

1. What is it like for you living in this nursing home now?
-Like
-Dislike
-Bored
-Happy
-Sad
-Neutral
-Other

2. Tell me about your everyday life in this nursing home now?
-Daily activities
-Eating
-Sleeping
-Choice
-Other residents
-Staff
-Family visits
-Well-being
-Special occasions (e.g. birthdays)
-Outings

3. Is there anything about being here that makes you feel happy now?
-Meals
-Sleep times
-Friends
-Staff
-Family visits
-Individual activities/ hobbies
-Activities with others
-Religious services
-Physical design
-Other

4. Is there anything about here that makes you feel sad now?
-Seeing other residents very sick
-Deaths of others
-Tragedies
-Confinement
-Monotony/Boredom
-Other

The following questions (Q.5 to Q.15) refer to past and anticipated individual experiences relating to relocating to a dementia care unit. Therefore these questions should only be explored with residents with a moderate dementia (MMSE score ≥ 10).

5. How do you feel about moving from [*name of former setting*] to [*name of Dementia Specialist Care Unit*], this unit?
-Feelings about the move
-What it means to you now
-Changes in your reactions to move, from transfer to present day

6. Has your life changed since moving in here?

-Since first interview (recent significant experiences)
-Meals
-Sleep
-Health
-Friendships (old and new)
-Relationship with staff
-Family visits
-Individual activities/hobbies
-Activities with others (old and new)
-Religious services
-Personal goals
-Well-being
-Other

7. What are the best things about the move here for you?
-Most helpful/ pleasant experiences
-Supports (former and present)

8. What are the worst things about the move here for you?
-Most unhelpful/ traumatic experiences

9. Is there anything that could have been done to make the move to [*name of Dementia Specialist Care Unit*] here better for you now?

10. What do you think of this nursing home now?
-Feelings about this place
-What living here means to you now
-Changes in feelings and ideas about this place since actual move?

11. How is this nursing home different from where you lived immediately before coming here?

12. What do you like most about this place here?

13. What do you like least about this place here?

14. Is there anything that could be done to make your life in this place better?

15. Is there anything else you want to say about the move from your former home to here now?

16. Is there anything else you want to say about your life in this nursing home now?

Appendix L: Interview schedule for FGs

1. Can you tell me once a bed becomes available in FACILITY (*) what happens next before a new resident gets admitted?

-Information about new residents and their circumstances:
Who gets admitted? By whom? When? Kinds of information?
-Contact persons in other facilities/ agencies?
-Experiences of being accessed:
By whom, how, main reasons, why FACILITY?
-First contact with new residents and families?
-Decision process: People involved, communication processes?
-Reactions from residents and families?
-Communication of decision to residents/ families/ staff?
-Specific guidelines and policies at this stage?
-How important in overall care process?

2. Tell me about your own experience of the transfer of new residents to this FACILITY?

-Main stages and events?
-Your key tasks?
-Last few hours in old setting?
-Time immediately before the move?
-Physical transfer?
-Arrival at FACILITY?
-First few hours in FACILITY?
-First few weeks in FACILITY?
-Communication with residents/ relatives/ colleagues?
(immediate and longer-term)?
-Specific guidelines and policies at this stage?
-Your overall reactions? Key experiences? Expectations?
Feelings?
-Short- and long-term reactions of residents/ relatives/
people in the unit?
-Meaning the transfer has for you – personal, professional?
-How important in overall care process (e.g. building
relationships with residents)?
-(also: How important are access and long-term resettlement
in care process?)

3. Tell me about your experience of preparing and supporting

-new residents

-their family caregivers

-residents living in the dementia care unit

-care staff

throughout the transition process?

-Kinds of preparation (pre-move)? Practical & psychological

-When?

-Your overall impressions and experiences in preparing residents and families?

-Reactions of new residents/ relatives/ old residents/ staff?

-Kinds of support (physical transfer & post-move)? Practical & psychological?

-When? (see phases)?

-Your overall impressions and experiences in preparing residents and families?

-Reactions of new residents/ relatives/ old residents/ staff?

-Long-term support?

-Overall: Most important kinds of support?

-Overall: Most important knowledge/ skills/ experiences? Why?

-Specific advice on how to communicate transfer to new residents/ old residents?

-How important in overall care process?

-Specific guidelines or policies on preparation and support?

4. Tell me about the policies that you use in relation to best relocation practices?

-Structure/ Contents/ Development of particular policies?

-For which phase of the transition: Access, Physical transfer, Resettlement?

-Overall experiences and reactions?

-Helpful vs. not helpful (Importance)?

-Meaning (e.g. strong vs. weak impact on care processes)?

-How situated within culture of care (e.g. element of CC?)

5. Tell me about the guidelines that you use for supporting people throughout the transition process?

-Which ones?

-For which phase of the transition: Access, Physical transfer, Resettlement?

-Providers?

-For whom (residents, family caregivers, staff)?

-Your overall experiences?

-Importance?

-Meaning (e.g. strong vs. weak impact on care processes)?

-Within culture of care?

6. Have you had any training in helping residents and family caregivers relocate to a new setting?

-Which specific courses etc.?

-Who of you participated?

-Providers?

-Part of your education/ undergraduate training?

-Prior experiences from other settings?

-Your overall experiences and impressions?

-Could that be a criterion for recruiting new staff?

7. What other supports do you use for relocating new residents to this FACILITY?

-For whom (new and old residents, families, staff)?

-Kinds of support?

-Providers?

-Short term vs. long-term supports (e.g. courses on long-term adaptation processes in people with dementia)?

-Peer support/ Supervision?

-Informal private support?

-Overall experiences?

8. How important is the process of admitting new residents to FACILITY for its culture of care?

-Situatedness within culture of care?

-Role the admission and longer-term resettlement of new

residents plays for FACILITY'S culture of care

-Importance for facility/ culture of care/ residents/ families/ staff?

9. What is from your experience the overall reaction of new residents and their families to this FACILITY?

10. What is your experience of the key changes the move to this FACILITY brings about?

-For new residents?

-For families?

-For old residents?

-For staff?

-Immediate?

-Longer-term?

-What transitions? (Dimensions: Health, emotional status, dementia, view of self, care-giving roles, relationships with colleagues/ families/ residents, quality of life, views on dementia care...?)

-Reactions to change (in residents, families, staff)?

11. Tell me about how new residents adapt to FACILITY?

-Your overall experiences?

-People that adapt successfully vs. people that don't? (Indicators)?

-When is adaptation completed?

-Assessments & Tools?

-Impact on yourself/ families/ other residents?

-Adaptation processes in family caregivers?

12. What are the differences that you see between FACILITY and other care settings with regard to relocating new residents to FACILITY?

13. What in your views should be done differently?

-New support practices?

-Efforts to implement new practices?

-Problems?

14. Is there anything else you would like to say?

Appendix M: Self-administered questionnaire for FCs

In the following short questionnaire you will be asked some questions about yourself and about your experiences as a caregiver to a person living with dementia. Please tick the boxes and fill in the blanks as appropriate. Your participation in this questionnaire is entirely voluntary. All information provided will be kept confidential. You can refuse to answer any questions you don't like to answer without any negative consequences.

1. Name _____

2. Age on your last birthday _____

3. Gender Male O Female O

4. Educational status

Some Primary O
Completed Primary O
Some Secondary O
Completed Secondary O
Tertiary (Not University) O
Other Tertiary & University O
Other (please explain):_____ _____

5. Occupational status

Current job title (please explain):_____
Working part-time outside home O
Working full-time outside home O
Self-employed O
Employed by others O
Unemployed but looking for work O
Unemployed O
Housework O
Other (please explain): _____

6. Marital status

Married O
In a de facto relationship O
Widowed O

Separated O

Divorced O

Single O

Other (please explain):_____

7. Relationship to the person diagnosed with dementia

Wife O

Husband O

Daughter O

Son O

Daughter-in-law O

Sister-in-law O

Friend O

Other (please explain):_____

8. Why are you the primary caregiver?

_____

_____

9. Care-giving experiences

Age of person with dementia on last birthday: _____

Former occupational status of person with dementia:

_____

When was the person's dementia diagnosed? _____

Type of dementia:

Alzheimer's disease O

Vascular dementia O

Mixed dementia O

Lewy Body disease O

Other (please explain) _____

Years of caring for person with dementia in total: _____

-From these: Providing care at his or her home _____

-From these: Providing care at your home _____

-From these: Living in residential care _____

Did you live with the person with dementia before he or she first moved from home into residential care? *Yes* O *No* O

When was the person with dementia first moved from home to a residential care setting?

_____

What was the main reason why he or she first moved from home into residential care?

_____

Where was he or she placed prior to moving to (*name of SCU*)?

Type of facility 1 _____ *Length of stay* _____

Type of facility 2 _____ *Length of stay* _____

Type of facility 3 _____ *Length of stay* _____

Type of facility 4 _____ *Length of stay* _____

Total number of relocations prior to moving to (name of SCU): ____

How much does care in (*name of SCU*) cost? Who pays for this?

Thank you!

Appendix N: Self-administered questionnaire for FGs

In the following short questionnaire you will be asked some questions about yourself and about your experiences as a caregiver to a person living with dementia. Please tick the boxes and fill in the blanks as appropriate. Your participation in this questionnaire is entirely voluntary. All information provided will be kept confidential. You can refuse to answer any questions you don't like to answer without any negative consequences.

1. Name _____

2. Age on your last birthday _____

3. Gender Male O Female O

4. Marital status

Married O
In a de facto relationship O
Widowed O
Separated O
Divorced O
Single O
Other (please explain):_____

5. Educational status

Some Primary O
Completed Primary O
Some Secondary O
Completed Secondary O
Tertiary (Not University) O
Other Tertiary & University O
Other (please explain):_____

6. Occupational status

Current job title (please explain):_____
Working part-time in this position O
Working full-time in this position O

Years of work experience as

-Formal caregiver of older people: _____ _____

-Formal caregiver of people with dementia: _____

-Staff member of this dementia unit: _____

Please indicate the job titles you have had as a formal caregiver of older people before taking up your current position in (*name of SCU*):

_____

_____

Please indicate the job titles you have had as a formal caregiver of people with dementia before taking up your current position in (*name of SCU*):

_____

_____

_____

What dementia-specific education and/or professional training have you completed?

Course Content(s)	Year	Provider

Please indicate your current area(s) of expertise in dementia care:

_____

_____

Thank you!

Appendix O: MMSE form and instructions

TARA CARE CENTRE
DATE: _____
LENGTH OF THE INTERVIEW: _____

RESEARCHER: _____
PARTICIPANT ID NUMBER: _ _ _ _

MINI MENTAL STATE EXAMINATION (MMSE)

Orientation

What is the (year) (season) (date) (day) (month)? 5 ( )

Where are we: (country) (county) (town\ city) (building\ place) (floor)? 5 ( )

Registration

Name three common objects (eg.: apple, table, penny)
Take one second to say each. Then ask the patient to repeat all 3 after you have said them.
Give one point for each correct answer. 3 ( )
Then repeat them until he learns all three.
Count trials and record TRIALS ( )

Attention and calculation

Subtract 7 from 100 and keep subtracting 7 from what's left.
Score 1 point for each correct. Stop after five answers.
(93__ 86__ 79__ 72__ 65__).

5 ( )

Alternatively Spell 'world' backwards. The score is the number of letters in the correct order
(D __ L__ R __ O __ W __)

Recall

Ask for the three objects repeated above.
Give one point for each correct answer 3 ( )

Language

Name a pencil and a watch (two points).

Repeat the following: 'No ifs, ands or buts' (one point).

Follow a three-stage command:
'Take a paper in your right hand, fold it in half and put it on the floor' (three points). 9 ( )

Read and obey the following: Close your eyes (one point).

Write a sentence (one point).

Copy a design (one point).

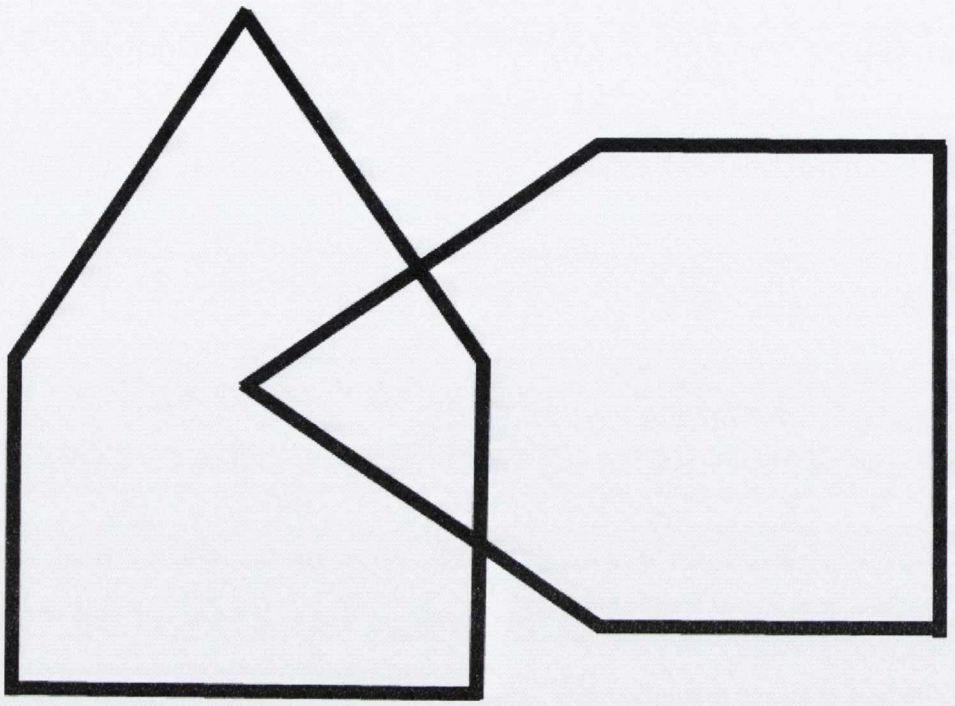
Total score 30 ( )

Patient's level of consciousness: ☐ Alert ☐ Drowsy ☐ Stupor ☐ Coma

Adapted from Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-Mental State." A practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research, 12, 189-198 and Cockrell, J.R. and Folstein, M.F. Mini-Mental State Examination (MMSE). Psychopharm Bull. 1988; 24;689-692. Note: © 1975, 1988 Mini-Mental

MINI MENTAL STATE EXAMINATION
PARTICIPANT ID NUMBER: _ _ _ _ _

RESEARCHER: _____
PARTICIPANT ID NUMBER: _ _ _ _ _



CLOSE YOUR EYES

GENERAL GUIDELINES FOR USING THE MINI MENTAL STATE EXAMINATION

PREPARATION

The items necessary to complete the MMSE are a watch, pencil, eraser and blank piece of paper. A piece of paper with CLOSE YOUR EYES written in large letters and a drawing of two 5 sided figures intersecting to make a 4 sided figure are also required. As with any procedure that requires a person's participation and cooperation it is necessary to ensure that the person is able to perform to the best of their abilities. Before commencing the MMSE enquire as to the use of hearing or visual aides for everyday functioning and ensure that these are available and in good working order. Establish that the person can hear and see you adequately before commencing. Ensure that the location where the MMSE is to be used has good lighting and ventilation to maximise the person's physical comfort. Establish rapport with the person and explain the nature of the questions to come. The MMSE can form part of a larger, comprehensive interview and can be introduced after having asked the person what their concentration and memory are like. The person could be asked if they would mind being asked some questions regarding their memory. Offering the explanation that it is a standard questionnaire that is commonly used as part of a thorough assessment may be useful, to reassure the person that it does not automatically imply that there is concern regarding their memory. The use of the term 'memory test' may prove to raise someone's levels of anxiety and hence influence the score obtained. If there is another person present (relative etc.) it may be necessary to request, in advance, that they allow the person being tested to answer the questions by themselves without prompting. Ensure that any prompts to answers are removed from the area where the test is to be conducted. E.g. calendars etc that would assist with answers related to orientation.

PROCESS

Commence with question 1 and progress through the questions from the beginning to the end. It is important to follow the order as given. A standardized MMSE questionnaire should be used. General guidelines include:

• Record the name of the person performing the test, the client's name and the date the test is performed on the MMSE form being used.

• Record the person's response for each question so that on future testing, direct comparisons can be made and the identical test items repeated.

• Record any factors that may have influenced the testing process. Eg. The person has hearing difficulties or a tremor.

• Ask each question a maximum of three times. If the person does not respond then allocate a score of 0.

• If the person answers incorrectly then allocate a score of 0.

• Accept the answer given. Do not hint, prompt or ask the question again. E.g. if a person responds that the year is 1995, accept that answer and do not ask the question again.

• Do not hint at answers or provide any physical clues such as head shaking, frowning etc.

• Refrain from indicating surprise or disappointment in response to any answers given.

• If the person asks "What did you say?" do not explain or engage in conversation merely repeat the same directions (e.g. What country are we in?) to a maximum of 3 times.

• Questions should be asked in a concise and unambiguous manner. E.g. "what year is it" rather than "could you tell me what year it is?"

• Do not engage in unrelated conversation during the course of the questioning.

• Provide a pencil for the question on naming objects rather than a pen or biro. This reduces the ambiguity with naming this item.

• It is not possible to allocate a ½ point for a near miss answer or to interpret that the person being tested knew the right answer but made a mistake and hence interpret an item as being answered correctly.

• Record not only the score the person obtains, but also how they perform the task. E.g. does the person spend an extended amount of time planning the task/response before attempting it and then being unable to complete it.

• If the person is irritable, agitated, physically unwell, drowsy or in pain it is best to arrange another time to perform the MMSE as any score obtained under these circumstances will not be a true representation of the person's cognitive functioning.

• A score of less than 24/30 or a marked decline from a previous score should prompt consideration of the need for medical review.

• The score obtained from the MMSE does not relate directly to the person's functional abilities. For example, a person with frontal lobe impairment may score within normal range but display marked functional deficits due to problems with planning and/or motivation.

(Compiled by Stephen Merrett. Mental Health Services For Older People,

Country Liaison Service. March 2003)

Appendix P: Self-generated form for SCU medical and nursing records

Date: Facility:
Participant Code:

The following documents are provided by (e*xample: SCU A, name and occupational title of staff member.)*

Document -No./Title -Type of document -Category(*)/Key topics	**Reasons for selecting this document**	**Source/Author**	**Key information**
Example: -1. "Lab report" -Medical report/ record -Physical health/ Cardiac status	*Example: a) Specific info about cardiac disease, b) relevant for understanding of present dementia*	*Example: General Hospital, E./ Cardiac Consultant*	*Example: -Cardiac infarct in 2004 -Significant changes in mobility and cognitive status (MMSE) -Transfer to Geriatric Hospital, M.*

(*) **Key Categories** and suggested sub-categories: (adapted from Bjoervell, Thorell-Ekstrand, & Wredling, 2000)

-Socio-demographic status:
* Age
* Marital status
* Education
* Occupation
* Other biographical information

-Dementia status:
* Diagnosis
* Severity
* Dementia history
* Current Status

-Physical health/ Comorbidities:
* Diagnoses
* Severity
* Health history
* Current Status

-Psychiatric health/ Comorbidities:
* Diagnoses
* Severity
* Health history
* Current Status

-Functional status:
* Weight
* Breathing/Circulation
* Tissues/Skin
* Pain/Wounds
* Nutrition
* Sleep
* Activity
* Mobility
* Perception

-Psychosocial status:
* Emotional status
* Communication
* Relationships
* Spiritual and cultural needs

-Quality of life:
* Physical well-being
* Psychosocial well-being
* Changes

-Additional information:
* Interventions (physical, psychosocial, environmental)
* Medications

Appendix Q: Description of pilot study participants

The pilot sample consisted of a male PwD (Mr. Murray) and his daughter caregiver (Mrs. Giblin). Murray was a 71-year old former mechanic foreman who had been widowed for 13 years. He was diagnosed with AD four years ago. Mr. Murray had spent the 18 months preceding the SCU admission in an acute hospital ward, waiting for a dementia-specific placement. Mr. Murray's MMSE scores were 7 (at phase one) and 4 (at phase two), indicating a severe level of dementia (see section 4.3.5.1.5). Mrs. Giblin was a 47-year old married Health Care Manager, who was working full-time. She stated that she had been Mr. Murray's primary caregiver for the past four years.

The following methods were pilot-tested: i) phase one and phase two interview schedules for PwDs and FCs, ii) the MMSE, iii) the self-administered questionnaire for FCs, and iv) the self-generated form for SCU nursing and medical records. The sequencing of methods was pilot-tested as well (see Diagram 1).

Diagram 1: Pilot-tested research methods and their sequencing

<table>
<tr><td colspan="2">PwD (Mr. Murray)</td><td colspan="2">FC (Mrs. Giblin)</td></tr>
<tr><td>Phase 1</td><td>Phase 2</td><td>Phase 1</td><td>Phase 2</td></tr>
<tr><td>MMSE
↓
Phase one interview schedule for PwDs</td><td>MMSE
↓
Phase two interview schedule for PwDs</td><td>Phase one interview schedule for FCs
↓
Self-administered questionnaire for FCs</td><td>Phase two interview schedule for FCs</td></tr>
<tr><td colspan="4">SCU medical and nursing records analysis (phase 1 and phase 2)</td></tr>
</table>

As can be seen in Diagram 1, both phase one and phase two pilot studies were conducted with the same participants (Mr. Murray, Mrs. Giblin) who were recruited in SCU A. Both Mr. Murray and his daughter took part in the testing of all methods in the intended sequences ('MMSE before interview' for PwDs; 'interview before self-administered questionnaire' for FCs). The MMSE – although piloted at phase one – was administered at phase two as well in order to inform me about what items to choose for Mr. Murray's follow-up interview. The SCU medical and nursing record analysis was conducted after the interviews. The pre-structured form was piloted at phase one and administered at phase two in order to follow up any changes in the PwD's health and care status since first interview.

Before meeting Mr. Murray and his daughter in person, I contacted Mrs. Giblin via telephone and provided her with detailed information about the thesis background, its aims, and about what was expected from both herself as well as her father as research participants. All meetings with Mr. Murray and Mrs. Giblin were held in a separate room across the actual SCU. This room was used for religious services and provided a private and quiet atmosphere. Mrs. Giblin was present during the interview and the MMSE test that was conducted with her father at phase one and at phase two. The phase one pilot study was conducted one week and the phase two pilot study was conducted one month before commencing the respective main study. Both Mrs. Giblin and Mr. Murray were not included into the main sample. Their findings were mainly used to inform me about the changes to be made to research methods and protocols (administration of methods, gaining consent) and were therefore not integrated into findings emerging from the main study.

The following protocol was used to gain their consent to participate in the research conducted for this thesis: I introduced myself and explained the purpose and administration of different research methods to the participants. I informed Mr. Murray that he would have to undergo a memory test - the MMSE - before the interview; this test

would help me make the interview better for him. The interview would help me understand his experiences of coming to this place and would help improve the life of those being in his situation. I informed Mrs. Giblin that she would first be interviewed and then be asked to fill in the self-administered questionnaire. I opted for conducting the interview first in order to establish a rapport with FCs before obtaining intimate personal information from them in written form. I also explained I would analyse Mr. Murray's SCU medical and nursing records in order to improve my understanding of his present situation. I then informed Mrs. Giblin and Mr. Murray about their rights to freedom from harm, withdrawal from the research at any stage and for any reasons, and the confidential treatment of their data. I then encouraged both Mrs. Giblin and Mr. Murray to raise any concerns they might have at this stage.

Following this introduction, I handed out information and consent forms to Mrs. Giblin in order to provide her with additional written information about the study. Following this, I sought and obtained her written consent to her participation in the study. After obtaining her own consent, I also obtained her proxy written consent to her father's participation in the study. Immediately before commencing the data collection, I made efforts to obtain Mr. Murray's assent to partake in the study by asking him if he would like to do the memory test. He verbally consented to partaking in the test and the MMSE was conducted.

The MMSE proved relatively difficult for Mr. Murray; in particular, he had difficulty with items requiring recall and orientation skills. In addition, Mrs. Giblin tried to assist Mr. Murray with the test. After completing the orientation and registration tasks, Mr. Murray began remarking that he didn't need 'this stuff', which I as well as Mrs. Giblin understood as an indication of discomfort. Thus, I decided to omit all further items requiring abstract cognitive skills (attention, calculation, recall) and to proceed with the language items, which Mr. Murray found easier to answer. However, due to Mr. Murray's severity of CI and because he signalled discomfort with the test I decided to abandon the MMSE after completing the 'pencil and watch' task. Mrs. Giblin also wished to bring her father back to

the SCU as she felt he was "a bit upset" and because it was lunchtime. I thanked Mr. Murray for partaking in the study and asked him if I could return for the interview at a later stage. He signalled agreement. After her returning to the interview room, I obtained Mrs. Giblin's verbal consent to participating in the interview including the self-administered questionnaire. I then interviewed Mrs. Giblin about her experiences of making the placement decision and waiting for a SCU bed to become available.

Mrs. Giblin provided an in-depth insight into her experiences of caring for her father at home and the challenges associated with the long wait for SCU placement (Mr. Murray spent one and a half years in an acute hospital). Due to Mrs. Giblin's other commitments, however, I was not able to complete the phase one interview and elicit her views of adapting to her father's SCU placement since admission and the changes the transfer had brought about in her life so far. Mrs. Giblin due to these other commitments was also unable to answer the self-administered questionnaire. We therefore arranged a second meeting in order to complete the interview including the self-administered questionnaire. This meeting was held about four weeks later.

At this second meeting, I again informed both Mrs. Giblin and Mr. Murray about the thesis goals and methods and obtained their assent to participate in the interviews. Mr. Murray was very happy to share his reflections on his rich past when he was a successful boxer and working in different senior-level positions as a farmer and foreman mechanic. Due to his severity of CI, however, he could not comment on the time immediately surrounding the SCU transfer. Despite these limitations, he responded well to the interview situation and did not get upset at any stage.

After completing Mr. Murray's interview I proceeded to interview Mrs. Giblin about her short-term adaptation to having placed her father in SCU A. She again gave a very detailed and reflective account of what life had been like for since placement and the changes brought about in her life by her father's SCU placement. She described the new

living situation as being better than compared to prior to the move. She also talked about her ongoing concerns about having made the right decision and continued to be worried about her father's well-being as she felt he was 'too fit' compared to the other PwDs residing in SCU A.

Mrs. Giblin was very agreeable to answer all questions and did not indicate to feel uncomfortable with any interview item. After completing the phase one pilot interview, I handed out the self-administered questionnaire to Mrs. Giblin and asked her to fill it in. I was present during this task in order to assist Mrs. Giblin with any queries. Mrs. Giblin, however, answered all questionnaire items and did not indicate to feel uncomfortable or have difficulties with any item.

The phase two protocol used to gain consent was equal to that used at phase one. At the second meeting with Mr. Murray and his daughter, which was held about six months after the first meeting, I again introduced the study goals and explained the purpose and administration of instruments. I explained to Mr. Murray that he would have to undergo the MMSE test before being interviewed; Mrs. Giblin would only be interviewed. I informed them about their rights to withdraw from the study for any reasons and to having their data stored safely. I also asked them to raise any concerns they might have. I then handed out phase two information and consent forms to Mrs. Giblin. After having obtained her written consent to her own as well as to her father's participation in the follow-up data collection conducted for this thesis, I sought and obtained Mr. Murray's assent to conducting the MMSE. Subsequently, the MMSE was administered to Mr. Murray. All items except the spelling task ('WORLD backwards') were administered; Mrs. Giblin was not present during the MMSE as she had to meet with SCU staff members. The MMSE test remained difficult for Mr. Murray, who at times indicated that he 'didn't know' when asked questions about his orientation to places and times. Due to Mr. Murray's increased distractibility and because I did not want to unduly distress this gentleman, most MMSE items were not

used. Instead, I used some of test items (such as the watch and pencil question) to initiate a conversation about topics that Mr. Murray enjoyed (cars, watches).

Following the MMSE, I obtained Mr. Murray's assent to interview him about his more long-term experiences of settling into SCU A. Mrs. Giblin was present during this interview. Mr. Murray again focused on his past life and talked about his work as farmer and local politician. Mr. Murray overall responded well to the interview and did not get upset at any stage. After the interview, I thanked Mr. Murray for his participation in the study and he was accompanied back to the unit by his daughter. After Mrs. Giblin's return to the interview room, I sought and obtained her oral consent to conducting the second interview. The follow-up interview focused on her longer-term adaptation experiences and her reflections on the specialised environment. Although being again under time pressure from other commitments, Mrs. Giblin gave again a very detailed and honest insight into what adapting to her father's SCU placement in the longer term meant for her life. She perceived her father's SCU placement as being overall beneficial for her emotional well-being; she now felt convinced she had made the right decision, and continued to emphasise how greatly her own as well as her father's quality of life had improved since placement.

Appendix R: Socio-demographic and occupational profile of FG participants

SCU	N	PARTICI-PANT (PSEUDO-NYM)	AGE (YEARS)	GEN-DER	OCCUPA-TIONAL BACK-GROUND	FULL-TIME (FT)/ PART-TIME (PT)	LENGTH OF TIME WORKING AS CARER TO PWDS (YEARS)	LENGTH OF TIME WORKING AS SCU TEAM MEMBER (YEARS)
A	5	Mrs. Flaherty	49	Female	Clinical Nurse Specialist	FT	4	4
		Ms Devers	41	Female	Clinical Nurse Manager	FT	4	4
		Mr. Singh	33	Male	Staff Nurse	FT	2,5	2,5
		Ms Gallagher	38	Female	Health Care Assistant	FT	5	1,5
		Mrs. Kinsella	35	Female	Health Care Assistant	FT	2,5	2,5

B	4	Mr. Navid	31	Male	Clinical Nurse Specialist	FT	9	1
		Mrs. Kissane	41	Female	Staff Nurse	FT	18	8 months
		Ms Duane	37	Female	Health Care Assistant	FT	2,5	8 months
		Ms Brophy	23	Female	Multi Task Attendant	FT	2	8 months
C	3	Mrs. Corbett	53	Female	Unit Manager	FT	2	2
		Mrs. Quigley	41	Female	Staff Nurse	FT	14	1,5
		Ms Kennedy	22	Female	Health Care Assistant	PT	4	4
MEAN (YEARS)			37				6	2