

**An interpretative phenomenological investigation
of dementia
from the perspective of families and system caregivers:

Stigma, traumatic loss, psychological growth, and
Relational Social Engagement (RSE).**

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Doctor of Philosophy (Psychology-Science)
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Statement of originality

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

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I hereby certify that the work embodied in this thesis has been done in collaboration with other researchers. I have included as part of the thesis a statement clearly outlining the extent of collaboration, with whom and under what circumstances.

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I hereby certify that the work embodied in this thesis contains a published paper/s/scholarly work of which I am a joint author. I have included as part of the thesis a written statement, endorsed by my supervisor, attesting to my contribution to the joint publication/s/scholarly work.

This thesis was completed under the primary supervision of Dr Lynne McCormack PhD, and secondary supervision of Dr Sean Halpin PhD.

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DEDICATION

For Mum and Dad

Without your love, support, belief, and encouragement
this PhD and my career in clinical psychology
would not have been possible.

Publication Status of Chapters

The following manuscripts, developed from the research described in this thesis, are published or in preparation for submission. For all manuscripts, the PhD candidate recruited the participants, collected, and transcribed the data sets. Similarly, for all manuscripts, apart from McCormack, Tillock and Walmsley (2016), the PhD candidate and primary supervisor jointly developed the design, were independent auditors, and co-authors. For McCormack, Tillock and Walmsley, the first and second author conducted the independent auditing. All contributed to authoring.

- Chapter 4** Walmsley, B. D., & McCormack, L. (2016a). Synthesis of meaning: Negative and positive change in family members following the adversity of dementia. *Journal of Humanistic Psychology*, 56(2), 122–143.
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- Chapter 5** Walmsley, B. D., & McCormack, L. (2015a). Stigma, the medical model, and dementia care: Psychological growth in senior carers through moral and professional integrity. *Dementia*, 1–18. Online 12th March 2015:
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Abstract

Scope:

Few studies have investigated distinctive interpersonal characteristics of retained awareness and social engagement observed when individuals at different stages of dementia interact with their family members. Influencing this relational engagement are the subjective interpretations of family caregivers as they experience: (1) the fluctuating psychosocial landscape of dementia pre and post aged-care; (2) perceived psychological consequences of supporting a family member with dementia; (3) the transition to, and navigation of a hierarchical health care system. Additionally, few studies explore the subjective interpretations of health care managers working in dementia including: (1) their perception of their work role; (2) how they interpret the impact of such work on their own psychological wellbeing; and, (3) how they position themselves as witnesses within a health care system that impacts, often authoritatively, on family relationships.

Therefore, this thesis is concerned with the relational, psychosocial, and systemic domains of experiencing dementia. The triad of subjective expertise in experiencing dementia, and the relational and social engagement that occurs within this triad, underpins this research document. It seeks to advance our understanding of relational and social engagement throughout the stages of dementia, and inform models of care for optimising that engagement.

Objectives:

All who experience dementia, either through a diagnosis of dementia, or as a supporting family member or professional caregiver, are vulnerable to psychological distress from chronic and cumulative challenges to their psychological wellbeing. Therefore, this phenomenological interpretative thesis sought the subjective

experiences of dementia from a multi-faceted perspective. It sought observational studies of family communicative-interactions seeking to advance our understanding of family adaptation for interpersonal awareness and engagement throughout the stages of dementia, complemented by the subjective lived experience of supporting family members and health care managers. This research sought both positive and negative interpretations of experiences of dementia and aged care.

Methodology:

Overall, fifty-two participants were involved in this thesis. Video-recordings of family visits, and individual, dyad, and focus group semi-structured interviews provided the thesis data set. Two methodologies were employed, Interpretative Phenomenological Analysis (IPA; Smith, 1996) and Thematic Analysis (Braun & Clarke, 2006).

IPA sought reiterative subjective interpretations of the dementia experience from family and professional caregivers. It informed the semi-structured interviews, transcription, and analysis of collected interview data. IPA is an idiographic, hermeneutic, qualitative approach based on phenomenology and interpretative psychology. It aims to capture the idiosyncratic nature of each participant's narrative and his or her interpreted experiences of rarely researched phenomenon (Smith, 1996). Symbolic interactionism explains the interaction between the researcher and the participant, as it posits that meaning can only be fully understood through the dynamic process of interpretation (Smith, 1996). A double hermeneutic allows both researcher and researched to engage in a reiterative meaning making process of understanding the lived experience.

Thematic Analysis conducted on the video-recorded data collected during family visits sought to break down relational and social engagement patterns that included the

individual with dementia, into interpreted themes by utilising non-obtrusive observation of families engaged in communication. Thematic Analysis goes beyond observable data to describe the phenomenon under investigation and explore latent patterns of meaning. This makes Thematic Analysis suitable for investigations of complex social phenomenology (Fereday & Muir-Cochrane, 2006; Joffe, 2012). From a critical realist perspective, Thematic Analysis maintains a focus on the individual yet also investigates the sociocultural context as it influences individual interactions (Braun & Clarke, 2006; Willig, 2013).

Collectively, superordinate and subordinate themes emerged from all data sets following robust discussion between independent auditors. These provide the results in each relevant chapter.

Results:

Fifty-two participants across seven studies connect the supporting, close-up, and contextual perspectives on relational and social engagement across a *triad of relational and social dementia expertise*. As the overarching phenomenological enquiry of this thesis, it linked the individuals with dementia to their family members and the health care managers who support them. A continuum of positive and negative insider perspectives of relational, psychosocial, and systemic aspects of dementia revealed varying patterns of engagement. They also highlighted the psychosocial struggle, the impact of dementia on psychological wellbeing, and the opportunity for psychological growth in these participants.

The construct *Relational Social Engagement (RSE)* developed from the studies in this thesis represents a complex and accessible set of relational interactions between the person with dementia and their family members, situated in distinctive familial bonds. It is manifest through family interactions, whereby individuals with dementia display

optimal engagement within family groups and can be positive (*in-step*) or negative (*out-of-step*). Family caregivers experience *in-step* interactions as connected, familiar, meaningful, and trusting whereby spontaneous adjustment to developments, opportunities for spontaneous fun, and feeling included and socially supported can occur. Alternatively, *out-of-step* interactions describe feelings of frustration and opposition. When *out-of-step*, shame, blame, guilt, and hypervigilance spill over to interactions in which individuals seek to control, conceal, reject, and escape. As such, *RSE* highlights distinctive familial bonds that offer security and comfort for those with dementia to spontaneously enjoy common ground and express differences within the family group. Although *RSE* can be positive *in-step* or negative *out-of-step*, it occurs more often within family groups during *in-step* interactions.

Conclusions:

This thesis can inform future research, theory, and aged care practice concerning relational and social engagement throughout the stages of dementia. Additionally, it highlights the complex interweave of psychosocial and relational distress experienced by these families as they navigate a western medicalised system of care. However, it also offers insight into the novice and convoluted engagement with a hierarchical model of care and its health care managers that presented the opportunity for the co-existence of traumatic distress and psychological growth.

Central to the outcomes of this thesis and the evidenced negative and positive family communication patterns within the observed interactions, complex levels of awareness were seen to occur in the family members with dementia in this study. Interpreted as *RSE*, and developed throughout the thesis and publications, *RSE* offers a construct for future research hypotheses that offer opportunities to preserve and optimise retained awareness and interpersonal skills in those living with dementia.

For the supporting family members, refusal of shame, rejection of stigma, and meaning brought to relational loss appeared to facilitate hope, and eventual positive redefinitions of relational and social intimacy as the stages of dementia progressed. Although theories of growth posit social support as a necessary condition for growth following adversity, when social support was lacking or even antagonistic for family caregivers, findings of this thesis would suggest that seeking *RSE* with a family member who has dementia stimulates meaning making for psychological growth. Generating renewed moral integrity and authenticity in family caregivers, *RSE* appeared to motivate their advocacy and positive change across other domains in time.

As a qualitative thesis, though these findings cannot be generalised to wider populations, the experience of these participants has provided hypothetical considerations for the researcher to critique. These include positive psychology approaches for living well with dementia and its impacts, and the emergence of qualitative philosophies to inform dementia practice and research. Implications for clinical psychologists seeking to facilitate *RSE* psychological growth in families are discussed at every level of investigation and summarised in Chapter 9.

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Glossary of Terms and Abbreviations

AD	Alzheimer's disease
AIHW	Australian Institute of Health and Welfare
APA	American Psychiatric Association
APOE	Apolipoprotein E
BDNF	Brain-derived neurotrophic factor
BMI	Body Mass Index
BPSD	Behavioural and psychological symptoms of dementia
CDR	Clinical Dementia Rating scale
CVD	Cardio-vascular dementia
DLB	Dementia with Lewy bodies
FTLD	Frontotemporal lobar degeneration
IPA	Interpretive Phenomenological Analysis
NSW	New South Wales
PMD	Person with moderate dementia
PSD	Person with severe dementia
RSE	Relational Social Engagement
TBI	Traumatic brain injury
WHO	World Health Organisation

PREFACE Personal Journey

Chapter introduction

The first step in completing this study called for reflection on living alongside a parent with dementia, for my mum lived with dementia for 10 years, until 2010. Although this personal experience presented biases and preconceptions, it also offered rich insights for analysing the data. However, it was essential as a qualitative researcher to balance personal biases and preconceptions to avoid eclipsing the data (Braun & Clarke, 2006; Smith; 1996), bearing in mind that it is impossible to uncover all biases and preconceptions because reflection necessarily involves subjectivity (Heidegger, 1927/1962). Therefore, this Preface illuminates my personal sense making of living with the impact of dementia.

Finding out

Aged 27 years old, I was living a ‘boy’s own’ overseas adventure, which had included backpacking across Europe through Iran to India and Nepal, travelling across Canada, moving to Bristol in South West England, and then working in London. In the northern hemisphere summer of 2000, a letter arrived from my Dad on the mid-north coast of NSW, Australia:

HOME. 9th August 00.

Dear Bruce. First of all congrats ... Last Sunday Bub and I went out to the pony club - next to the cattle yards about 3km out on Oxley Highway. ...I am very proud of you all. We arranged the genes right. You all got good looks and features from Bub, and all got a good serve of “My Brains” and my “modesty”,

see enclosed LETTER HEAD. ...Your Mum looks as pretty as ever, but no doubt she has ALZHEIMER'S Syndrome. I had to get the spelling from my MEDICAL DICTIONARY – it is not in yours ... All going well we are going down to the 50th YEAR reunion of year 1950 Vet Surgeons. I'll see if I can get some photos for you. Bub and I will be staying at St Andrews College, as will Andrew – to look after us both.

I love you mate.

Dad.

In the months following that letter, I just remember feeling increasingly sad and melancholy, which would remain and fluctuate for the next 10 years. I was also naive about dementia, and how it would impact Mum, Dad, and our family. I knew that it related to progressive memory loss, but I underestimated the extent of this memory loss, and I was unaware of the emotional, social and physical changes related to dementia. The confusing part was that Mum sounded the same on the phone. Both she and Dad said “No need to come home”. I suppose that I was relatively young in my view of the world, and lacked accessible information.

However, concurrent with sadness, I also had a wonderful time for the next 10 months in the UK. Now, I regret not returning home when I heard of Mum's diagnosis. That is when she might have needed me the most. However, I also recognise that our family had three other siblings back home, and that the experiences that I had in the UK were formative ones. On reflection, it was a ‘once in a lifetime experience’ that could not be achieved now. In my own way, I sent Mum a Harrods' bear with a note attached, for her 70th birthday that year.

Returning home

Returning home to Sydney in May 2001, the ocean swells seemed impossibly blue and the sunlight bright. Life in Sydney moved at a slower pace. Meeting up with my sister Margie, we drove five hours north of Sydney to see Mum and Dad in Wauchope. Later, I understood why she had wanted to join me on that first visit home.

When I had last seen Mum in May 1998, and then May 1999, she had been tanned, fit and aged 67 to 68 years of age. Youthful in appearance and outlook, she swam most days at the local Olympic pool. Mum enjoyed the outdoors, in particular beach fishing. She enjoyed weekends away in Sydney, and travelled around the South Pacific and back to Port Moresby where she was born. I remember Mum in the following ways: wearing white shorts, perfume, always lipstick; down to earth; fishing rod in hand, making cakes, gardening, and baby-sitting. Mum was a natural mother, which was often commented on. Though Mum and Dad had a complex marriage and shortcomings like the rest of us, they had five children of whom they were proud. Mum would often say, "Look what I produced!"

As Margie and I entered Mum and Dad's backyard, they were standing under the mulberry tree, which was a giant of a tree from our childhoods. Seeing the changes in Mum, compared to how I remembered her, was a massive shock. She seemed to be 'waiting'. Her hair was missing in clumps, her lipstick uneven, her clothes lopsided, and she walked unsteadily. Mum spoke less confidently and with fewer words. ("Poor Mum!" she would have said about these observations). However, what I also remember was how happy she looked. I remember the smile in her eyes and her embrace. That night, I found her Harrods' bear unopened. Mum had thought it was for me, so she had put it under my bed for safekeeping. Looking back on that day, all those events led me to become more responsible, protective, and involved.

Being with Mum

Although I had a sense of role reversal with Mum, in that I became the ‘parent’ helping with decisions, safety, and involvement in daily life, Mum and I still continued to be together in the same way. I am enormously grateful for this now, because despite dementia and heart break, I had eight-and-a-half more years with Mum, as her son, even as we relied increasingly on formal care.

Of course, my first experience of taking Mum to a care home for respite leave was a horrible one, because she seemed so vulnerable, confused, and alone. I remember Mum describing her room as dark. The lighting seemed fine, but Mum had feared the dark since childhood. Was it her anxiety or vision? Either way, I drove home to get ‘Dad’s lamp’. It was bright and familiar.

This sense of our being there for the other was a consistent dynamic. I remember that when she moved into high-level care within her care home, she turned to me one visit, and said “I wish I could still do something for you, and take you out somewhere”. However, we still did things together. One of my particular memories was of making a drawing of Mum with charcoal (as I was doing art classes in Sydney at the time). She and I did not need to speak, the nurses would drop by to see how it was going, and I think Mum enjoyed doing something together that I enjoyed. We also did day trips together to nearby beaches and valley towns, picnics, cafes, and walks.

However, living a considerable distance away in Sydney was hard. I considered moving home, but I do remember Mum always saying, “You’ve got your own life”. In those years, I bought my first flat, had my first adult relationship, and widened my network of friends. Although I travelled home every six weeks, I regret not phoning her more often. Once when she picked up the phone, I remember her saying “I was just thinking, c’mon Bruce, give me a call!” Over time, her phone conversations reduced to

the ‘important’ words. And when her speech was gone, the nurses told me that her eyes widened when I spoke to her on the phone.

Support along the way

After Dad died in 2003, Mum moved into a care home, where I think she felt lonely and lost for the first six months. That was understandable given she had just lost her husband of 53 years, home of 50 years, and was now living with strangers in a relatively sterile environment. However, the nurses introduced Mum to a similar lady for friendship, and they involved her in daily activities. There were occasional short bus trips. My brother Andy lived nearby, Margie in Newcastle, and I in Sydney. I drove or flew from Sydney every four to six weeks for the next 7 years. Andy and my sister-in-law Carol were wonderful in having me stay, and providing a home away from home. Rarely, sibling differences surfaced over Mum’s care, which highlighted differences in values, goals, personalities, position in the family, life-stage, attachment and relationship with Mum. Overall though, we pitched in and grew closer.

When Mum moved into high-level care, the environment was more hospital-like, with bedrails, linoleum floors, hospital-like food, and medication trolleys. However, Mum’s room probably suited her better because it was light, breezy, and relatively private. It opened onto a veranda with district views. I brought in geraniums for her balcony, and a flowering peace lily for her room. These flowers were familiar and significant in our family, and gave us a point of conversation. There was a photo of a dolphin on her bedroom door. On a corkboard, she had family photos, cards, and drawings. Andy framed a courtship letter from Dad. He also brought in comfortable armchairs. My niece Carlie brought in a blanket from her travels in India.

During Mum’s time in care, she had a consistent set of supportive health care assistants, who looked after Mum and our family in a personal and genuine way. I came

to know them well, and they made a genuine effort to know me. We spoke about home life, our dogs, and we shared a laugh. There was a warm connection. I felt welcome as if it were my own home. I could get extra desserts, milk shakes, and plates for home-cooked food. However, I also experienced some of the health care assistants as authoritarian and abrupt. Mum described them as “having a little bit of power”. One negative interaction became a turning point in advocacy for me, when a care assistant objectified Mum negatively. What shocked me was this assistant’s lack of compassion in light of Mum’s inability to speak or move. I knew Mum did not have long to live, so it struck me as unreasonable, unfair, and unjust. Regardless of that assistant’s frustrations, I regret not defending Mum or reporting that interaction, but I was worried about the repercussions if I did.

Holding on

Despite Mum’s changing abilities, I sometimes found her lucidly aware. She could quickly put me in my place (e.g., “You must never joke about others, for things they cannot help”) or stop me from annoying her with child hood rhymes (e.g., “Oh Bruce, stop it!”). At other times, her awareness fluctuated due to her dwelling in a different time. For example, she once asked which of “the little boys” had just brought her a glass of water. Replying that it was me, she said, “Oh Bruce, he was always the more sensitive one”. I guess she had picked my usual nature, but she did not recognise me as her 35-year-old son. However, it did not upset me because she was happy in my company.

Through my studies in geropsychology in 2009, I began to question medical views of Mum’s level of awareness. As a result, I started to wonder how she experienced the world around her, and whether Mum was in fact more aware than other people assumed. I also noticed ways that care homes could be improved. In particular, having

dedicated staff members or volunteers to spend social-time with residents individually. It struck me how much time Mum, and other residents, spent without company.

Letting go

Mum appeared to live with fewer worries as her dementia progressed. Remarkably, life-long and stress-related conditions normalised. I also saw her as she might have been as a young girl. I remember Andy sending me a photo of Mum around that time, which seemed to capture her distinctive self, even ‘soul’. Two months before Mum died, I made her a bracelet. I remember her looking at it, with the same expression from Christmas’ past: “Oh you shouldn’t have”.

Mum died two days before my 37th birthday (which now reminds me of the value in life, each birthday). However, on that day, I missed getting to her by half an hour. Of all days, there were no flights from Sydney and I became caught in morning traffic. It is one of my greatest disappointments. However, I felt that I had almost reached her. Over time, hearing the experiences of other adult-children caught in similar situations has helped.

Growing into myself

Within the week of Mum dying, I relocated from Sydney to Canberra to start clinical psychology studies. Canberra brought new beginnings. I enjoyed clinical training, making close friends, and living somewhere new. It was a buffer, and a time of raw loss, adaptation, and personal growth. In Canberra, I completed a dementia thesis as part of my clinical studies, and the subsequent manuscript was accepted for publication on the day of my 40th birthday. In a way, pouring myself into my studies helped me redirect my grief. It was something positive that I could do.

Going forward, I am looking forward to connecting people to ideas and stories that help them live well regardless of conditions like dementia. I am also looking forward to making a living from work that I am passionate about, and making a life that I value. My personal experiences and this PhD thesis are part of that journey.

CHAPTER 1 Aims, Objectives, and Thesis Map

1.0 Introduction

This chapter presents the overall purpose and intention of the thesis. It defines the analytic strategy and foci, including the chosen methods for collecting and analysing data. A chapter map seeks to position the chapters relative to each other. This chapter notes that non-stigmatising language is used throughout the thesis, and it provides relational, psychosocial, and systemic considerations regarding the study, in particular that this study fits a western-developed country's view of dementia.

Therefore, Chapter One establishes the structure of this dementia thesis, across three sections:

Section 1: Aims and objectives;

Section 2: Analytic strategy and foci; and

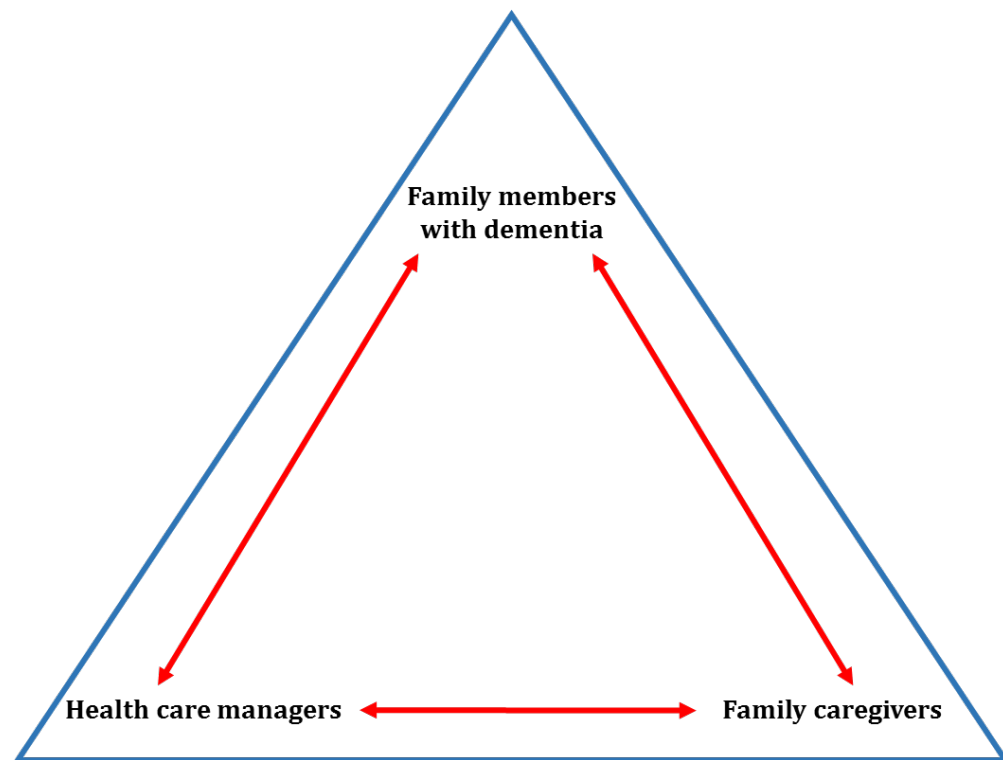
Section 3: Chapter map.

1.1 Aims and objectives

This thesis sought to explore relational, psychosocial, and systemic aspects of dementia, by linking the supporting, close-up, and contextual perspectives of a *triad of relational and social dementia expertise*. This triad included individuals living with dementia, and their supportive health care managers and family members. Moreover, it describes the relational interplay between these three groups of people (See Figure 1).

Figure 1

The triad of relational and social dementia expertise



The premise of this thesis was to investigate this *triad of relational and social dementia expertise* to provide an insider's perspective of living and working with the impacts of dementia. It presents seven studies seeking to explore the supporting, close-up, and contextual perspectives of participants.

Fifty-two participants contributed to the seven studies. Data collection occurred through semi-structured interviews with family members and health care managers, and video recorded observations and analysis of family visits (inclusive of a member with dementia). In detail, the triad and thesis premise included:

- (1) Individual health care managers working in dementia care:
 - a. to explore both positive and negative interpretations of working within a systemic model of care in dementia; and

- b. to seek subjective insights from witnessing the impact of dementia on family relationships;
- (2) Individual family members living with dementia at various stages:
 - a. to observe and describe the unique levels of awareness and patterns of positive and negative interpersonal engagement at different stages of dementia, between those with dementia and their family members;
- (3) Individual family caregivers of a family member with dementia:
 - a. to explore both positive and negative interpreted experience of supporting a family member with dementia prior to and during admission to a hospital or care home within a hierarchical health care system; and
 - b. to seek subjective insights and meaning making of the psychosocial impacts of dementia on the individual family caregiver and family relationships.

1.1.1 Research considerations

This thesis, and its encompassed studies, adopts inclusive, empowering, and non-stigmatising language (see Alzheimer's Australia, Dementia Language Guidelines, n.d.). Where an Australian term differs from those used in the international scientific dementia literature, I have used the international term (e.g., 'care home' instead of 'residential aged care facility'; 'health care assistant' instead of 'assistant in nursing'). When referring to stage theories of dementia and different terms used across the dementia trajectory, terms are used consistently and defined according to the Clinical Dementia Rating (CDR) scale as mild, moderate, severe, or profound (Morris, 1993).

In investigating the health care system, the researcher is mindful that depending on the state of uptake of person-centred care philosophies and multiple other systemic and sociocultural factors, medical model dominance, particularly in western high-income countries, will vary considerably between health care settings. Thus, the

experiences of health care managers, practitioners, and assistants will vary too, depending on their age, length of career, dementia care experiences, and cultural, ethical, spiritual beliefs, in addition to the relationship factors that these studies explore.

Although the medical model is seen as contributing to “diagnostic overshadowing, where all actions and expressions are attributed to the labelled condition” (Downs, Clare, & Mackenzie, 2006, p. 240), dementia-related biological change contributes to physical symptoms that require medical attention (Hughes, 2014). Indeed, individuals respond to anti-dementia medication in the early stages of the dementia trajectory (National Institute for Health and Care Excellence [NICE], 2011). Furthermore, contemporary medical models have emerged to integrate person-centred philosophies consistent with biopsychosocial and holistic views of dementia (Hughes, 2014; World Health Organisation [WHO], 2016). Thus, in a practical sense, a pure medical model of dementia care does not exist, because health care teams cannot ignore the cultural, ethical, spiritual, and relational factors as they impact upon patients/residents and family members.

In this thesis, the complex biopsychosocial interplay between speech and dementia is recognised, but it is particularly concerned with the social cues and stimuli that influenced awareness, communication pathways, and family relationships (Walmsley & McCormack, 2014). In seeking to understand awareness as a phenomenon, the researcher chose a broad conceptual framework to accommodate the dynamic nature of awareness and breadth of awareness expressions (see Section 2.7.1, p. 87, Table 6, pp 96-98: Levels of Awareness framework; Clare, Marková, Roth, & Morris, 2011).

Furthermore, this thesis sought both negative and positive interpretations from participants, because it was recognised that participants might otherwise have only discussed negative experiences, or information that they perceive to be of most interest

to a clinical psychologist. This is because: (1) clinical psychology as a science has traditionally aligned itself with the medical model to investigate abnormal psychology and psychological suffering (Maddux, Snyder, & Lopez, 2004; Seligman, 2002); (2) the illness, pathology, or burnout narrative is still widely accepted as the official way of explaining the reactions and responses of individuals living with dementia and their caregivers; and (3) negative public perceptions of dementia are typical, as the western media still draws attention to the most negative aspects of dementia (Jolley & Benbow, 2000).

Finally, although there is nothing positive about dementia itself, it is the struggle to bring meaning to dementia experiences that can present opportunities for positive change (see chapters 4, 5, 6, and 7). Furthermore, although positive immunological change is possible following traumatic distress (Cruess, Antoni, McGregor, & Kilbourn et al., 2000; Milam, 2004), this thesis is particularly concerned with psychological change following the adversity of dementia (see chapters 4, 5, and 7).

1.2 Analytical strategy

For this thesis, a qualitative investigation was required to understand the lived experiences of individuals with dementia, their family members, and supporting health care managers. This required investigation of interpersonal awareness and engagement observed when individuals at different stages of dementia interact with their family members. It sought insights into how family members and health care managers experienced interpersonal awareness and engagement in those with dementia, and how they made sense of those experiences. Contextually, it sought to understand how a hierarchical health care system influences these individual experiences.

Although complex awareness and engagement has been observed when individuals at the severe stage of dementia engage with other residents (Kontos, 2004),

or researchers “with whom they had developed a person-to-person relationship” (Sabat, 2001, p. 28), it is only recently that similar observations during family interactions have been explored (Walmsley & McCormack, 2014, 2016b; Chapter 6). This represents a significant gap in the research, particularly when: (1) family relationships are unique in their duration and level of intimacy; and (2) the findings on interpersonal awareness and engagement during family interactions are likely to resonate with other families in a similar situation. Of concern, it is estimated that fifty-percent of Australians believe that meaningful conversations are beyond the abilities of individuals who have dementia (Phillipson, Magee, Jones, & Reis et al., 2012). Furthermore, health care assistants engage less, and families visit less often, when a person with dementia is presumed globally unaware because their communication pathways have changed (Boss, 2010; Magai, Cohen, Gomberg, & Malatesta et al., 1996; Norberg, Asplund, Rassmussen, & Nordahl et al., 2001). This is concerning, when isolation and loneliness are risk factors for cognitive decline and maladaptive *behavioural and psychological symptoms of dementia* (referred to as *BPDS*: Bird, Llewellyn-Jones, Korten, & Smithers, 2007; Fratiglioni, Wang, Ericsson, & Maytan et al., 2000; Holwerda, Deeg, Beekman, & van Tilburg et al., 2014; Shankar, Hamer, McMunn, & Steptoe et al., 2013).

Therefore, the analytical strategy of this study seeks the multiple perspectives of individuals who have dementia, their family members, and the health care managers who support them. Multiple data points include video-recorded observations and semi-structured individual, triad, and focus group interviews. Interpretive Phenomenological Analysis (IPA; Smith, 1996) and Thematic Analysis (Braun & Clarke, 2006) seek the insider’s perspective through a process of continual interpretive activity.

Phenomenologically, what participants experience and how they bring meaning to those experiences offers a qualitatively different perspective on a complex and sensitive topic.

1.2.1 Interpretative Phenomenological Analysis

IPA informed the semi-structured interviews, transcription, and analysis of interview data collected from individual, dyad, and focus group interviews. As an idiographic, hermeneutic, and qualitative approach, both phenomenology and interpretative psychology are foundational to IPA. IPA seeks the specific nature of the individual participant's narrative and their interpreted experiences of a complex and poorly understood phenomenon (Smith, 1996). Ideographically, IPA involves an in-depth focus on the specific. IPA can reveal unexpected insights into the quality, texture, and meaning of lived experience without generalising the particular relationship between individuals and their world (Smith, 1996).

Aligned with symbolic interactionism, IPA considers meaning to develop when: (1) people act towards things based on the meanings those things hold for them; and (2) meaning is fluid, interpretable, and derived from social interaction (Mead, 1934; Ashworth, 2000). Symbolic interactionism explains the interaction between the researcher and the participant, as it posits that the dynamic process of interpretation clarifies meaning (Smith, 1996). Interpretation is supported by a double hermeneutic, which allows both researcher and participant to engage in a reiterative meaning making process of understanding the lived experience. As such, the researcher strives to bring meaning to the participant's efforts to comprehend their experiences (Smith & Osborne, 2008).

Although IPA researchers give voice to participants concerns, they also interpret participants' concerns in light of psychological and theoretical knowledge and sociocultural context (Larkin, Watts, & Clifton, 2006; Smith, 2004). With confidence, IPA researchers seek to follow participant stories as they evolve without prematurely redirecting them back to an interview structure or losing a relaxed approach to

interviewing. When the researcher adopts the art of quizzical enquiry, they encourage participants to open up and bring to their consciousness previously invisible concerns (Smith, 1996). This contributes to rich areas of data, encompassing: (1) ambiguities in participant stories; and (2) hot cognitions observable when participants engage in emotionally laden reflection on past life experiences (Willig, 2013). By unravelling each participant's thoughts, words, emotions, and behaviour, the researcher can achieve deeper interpretations. Therefore, researchers using IPA "should practice a disciplined kind of interaction... with their phenomena and informants, and bridle the event so that they do not understand too quickly, too carelessly or slovenly, or in other words, that they do not make definite what is indefinite" (Dahlberg, Dahlberg, & Nystrom, 2008, p. 130).

1.2.2 Thematic Analysis

Thematic Analysis (Braun & Clarke, 2006) offered a flexible analytic method for identifying patterns of meaning in the data set of video-recorded family interactions, and describing the phenomenon under investigation (Joffe, 2012). Unencumbered by double hermeneutic assumptions, Thematic Analysis is well suited to observational studies (Braun & Clarke, 2006; Joffe & Yardley, 2004). During Thematic Analysis, themes contain both manifest and latent content that requires interpretation for a detailed level of meaning (Joffe & Yardley, 2004). Themes can be both deductive (i.e., leveraging existing theory) and inductive (i.e., identified in the data set). However, the researcher needs to strike a balance between existing ideas and novel insights grounded in the data. Theory-led themes allow replication, extension, or refutation of existing studies, whereas data-driven findings can revolutionise knowledge of a phenomenon (Boyatzis, 1998; Harper & Thompson, 2012). As such, Thematic Analysis can provide the reader with a rich

thematic account of the entire data set, or a detailed and nuanced analysis of a particular theme or group of themes (Braun & Clarke, 2006).

Historically, Thematic Analysis stems from content analysis, which is an analytic method for counting the frequency of categories within a data set (Joffe, 2012).

However, contemporary Thematic Analysis goes beyond the analysis of observable data and frequency of codes, to explore more implicit thematic structures and meanings. As a result, it is suitable for investigations of complex social phenomenology (Fereday & Muir-Cochrane, 2006; Joffe, 2012). From a critical realist stance, Thematic Analysis can illuminate complex social phenomenology, in which issues are socially constructed but also grounded in a material basis (Joffe, 2012). Therefore, it maintains a focus on the individual yet also explores the sociocultural context and structural conditions that empower or undermine individual interactions (Braun & Clarke, 2006; Willig, 2013).

1.3 Chapter map

Table 1
Chapter map of this thesis

Chapter	Chapter overview
Chapter 2: Literature review	Chapter 2 offers a critical appraisal of the dementia literature encompassing biopsychosocial and historical issues, current care and treatment, and theories underpinning this thesis.
Chapter 3: Methodology	Chapter 3 provides an in-depth account of how the data were managed and analysed. It explores ontology, epistemology, philosophy, methodology, and method. It closes with a discussion of data quality protocols.
Chapter 4: Pilot study	Complementary to an earlier pilot-study (submitted exclusively for a Master's degree), Chapter 4 presents a later pilot-study (submitted for this PhD) seeking the interpretations of family groups regarding their support of a family member with dementia over a 10-year period.
Chapter 5: Health care managers	Chapter 5 seeks the perspectives of health care managers to understand how they position themselves in the health care system as they witness the impact of dementia on family relationships.
Chapter 6: Family members living with dementia	Chapter 6 investigates the interpersonal characteristics of retained awareness and social engagement observed when individuals with moderate or severe dementia interact with family members. In this chapter, the video recording of family interactions presents a novel research method.
Chapter 7: Family caregivers	Chapter 7 seeks the interpretations of family caregivers as they experience the psychosocial landscape of dementia pre and post aged-care. It investigates the psychosocial impacts of dementia caregiving on these individuals and their family group.
Chapter 8: Critical reflections	Chapter 8 offers a personal and professional reflection on the studies, methodology, contribution to knowledge, and strengths and weaknesses of the studies undertaken.
Chapter 9: Thesis conclusions and implications	Closing the thesis, Chapter 9 presents key research findings, conclusions and opportunities for future studies. The implications for clinical psychologists working in dementia care are discussed throughout.

1.4 Chapter close

To bring positive change to the aged care system and how people with dementia are viewed and treated, we can learn from the everyday lived experiences of those who live with dementia, their family members, and supporting health care staff. Again, this thesis recognises individuality and the value of ideographic phenomenology for contributing to social change. As such, it avoids a top down expert stance and efforts to generalise findings to a wider population. In support of this, Chapter 2 presents a literature review seeking the relational, psychosocial, and systemic aspects of dementia and its impacts.

CHAPTER 2 Literature Review

2.0 Introduction

This chapter presents a critique of the dementia literature across three sections:

- Section 1: A biopsychosocial perspective of dementia, including the impact of dementia on those living with the condition, family members, and health care professionals;
- Section 2: The historical narrative of mental health care, with an emphasis on dementia care in the 21st century. Various models of dementia care are explored, including the contemporary medical model, person-centred, supportive, and recovery models of dementia care; and
- Section 3: The theories related to this thesis to conceptualise the experience of dementia. Although there are many models that talk to the individual experience of dementia, the selected models offered best fit with the thesis topic and received literature support.

Section 1

2.1 Setting the scene

In the past, incurable illnesses commonly caused death prior to an age where individuals might begin to develop dementia. Although dementia is not a normal part of ageing, age is the greatest risk factor for developing the condition (WHO, 2015). As such, global population growth and ageing are contributing to unprecedented levels of dementia prevalence (WHO, 2015). In fact, dementia risk doubles every five years from

0.9% at 65 years of age, to 40.7% for those aged 100 years or older (Corrada, Brookmeyer, Paganini-Hill & Berlau et al., 2010; Jorm & Jolley, 1998). In high-income countries, more people are living beyond 85 years of age and the number of centenarians is increasing (AIHW, 2012; Xu, 2016). As such, peak incidence of dementia occurs between the ages of 80 to 89 years in Europe and North America, between 75 and 84 years of age in Asia, and between 70 and 79 years of age in Africa (WHO, 2015). Though most people with dementia live in low- and middle-income countries, high-income countries have the greatest per capita prevalence (AIHW, 2012; Corrada, Brookmeyer, Berlau, & Paganini-Hill et al., 2008; WHO, 2015). In Australia, more than 342,000 people live with dementia (AIHW, 2012). By 2050, there could be 900,000 Australians living with dementia unless medical or public health breakthroughs occur (AIHW, 2012).

Furthermore, global deaths due to dementia doubled between 1990 and 2010 (Lozano, Naghavi, Foreman, & Lim et al., 2012), such that dementia is the second leading cause of death in Australia behind heart disease (Australian Bureau of Statistics [ABS], 2013), and the leading cause of death for women in England and Wales (Office for National Statistics [ONS], 2014). In the United States, it is the sixth leading cause of death, behind heart disease, cancer, respiratory diseases, unintentional injuries, and cerebrovascular diseases (Alzheimer's Association, 2015). Conversely in Africa, more people die from communicable diseases such as HIV/AIDS, respiratory diseases, diarrheal diseases, or strokes, nutritional factors, and complications relating to maternal and neonatal conditions (WHO, 2012). In South-East Asia, the leading causes of death reflect a mix of those that occur in low- and high-income countries, for example, infectious and parasitic diseases, neonatal conditions, lung cancer, and tuberculosis, diabetes, and cardiovascular and respiratory diseases (WHO, 2012).

In Japan, China, Hong Kong, and Taiwan, rising rates of obesity, hyperglycaemia, hypertension, and hypercholesterolemia are contributing to a dementia incidence that is exceeding forecasts (Sekita, Ninomiya, Tanazaki, & Doi et al., 2010; Wu, Lee, Norton, & Chen et al., 2013). This is because these conditions are cardiovascular risk factors representative of a metabolic syndrome that increases dementia risk (Paturel, 2009, 2013; Muktadar, Testai, & Gorelick, 2012). Metabolic syndrome increases cardiovascular load in later life and contributes to dementia, when for example: (1) heart arrhythmias and vascular damage impede or block cerebral blood-flow; and (2) an accelerated build-up of beta amyloid in the brain and its inefficient clearance contribute to the death of brain cells (de la Torre, 2012; Garcia-Alloza, Gregory, Kuchibhotla, & Fine et al., 2011; Launer, Petrovitch, Ross, & Markesbery et al., 2011; Paturel, 2009, 2013; Tolppanen, Solomon, Soininen, & Kivipelto, 2012; see Table 2, p. 43).

Even now in Australia, two-thirds of middle-aged Australians are overweight or obese yet only 5% see themselves at risk of developing dementia (AIHW, 2012; Smith, Ali, & Quach, 2014; Tolppanen, Ngandu, Kåreholt, & Laatikainen et al., 2014; Xu, Atti, Gatz, & Pedersen et al., 2011). Therefore, cardiovascular risk factors are an important public-health determinant for dementia (de La Torre, 2012), given increasing rates of dementia due to changing population-health risks, increased diagnosis of dementia, and improved epidemiological reporting in low- and middle-income countries (ONS, 2014; Prince, Bryce, Albanese, & Wimo, et al., 2013; WHO, 2015). Indeed, 7% of the world population (44 million people) live with a dementia diagnosis, and globally a dementia diagnosis is purported to occur every four seconds (WHO, 2015). Within the next 33 years, the prevalence of dementia is expected to: (1) double in Western Europe, North America, New Zealand, Australia, and the UK; (2) triple in Asia; and (3) quadruple in Africa and Latin America (WHO, 2015).

However, dementia forecasts can be reduced. For instance, dementia incidence in Australia could fall 11% below 2050 estimates if individual rates of physical inactivity fell 5% every five years (Nepal, Brown, & Ranmuthugala, 2010). Similarly, a 10% reduction in key dementia risks (see Table 4, p. 48) could reduce dementia prevalence in high-income countries by 8.3% within 33 years (Norton, Matthews, Barnes, & Yaffe et al., 2014). These possibilities are already being evidenced in the UK, USA, the Netherlands, Sweden, and Southern Europe, where dementia incidence forecasts heralded in the 1970s are less than anticipated (Christensen, Thinggaard, Oksuzyan, & Steenstrup et al., 2013; Lobo, Saz, Marcos, & Dia et al., 2007; Matthews, Arthur, Barnes, & Bond et al., 2013; Qiu, von Strauss, Bäckman, & Winblad et al., 2013; Rocca, Petersen, Knopman, & Hebert et al., 2011; Satizabal, Beiser, Chouraki, & Chêne et al., 2016; Schrijvers, Verhaaren, Koudstaal, & Hofman et al., 2012). Although this downward trend in dementia incidence can partly be explained by improved cardiovascular health, other explanations remain unknown (Satizabal et al., 2016). Even if medical and public health breakthroughs do occur, millions of individuals worldwide will still live with the impact of dementia (WHO, 2015).

2.2 A complex condition

As a hypernym, dementia describes sets of symptoms for more than 100 chronic conditions that impair brain functioning in a progressive, irreversible, and terminal way (American Psychiatric Association [APA], 2013; Draper, 2011; Prince et al., 2014; Power, 2014). Progressive memory loss is the most common symptom, and Alzheimer's disease (AD) and Cardiovascular Dementia (CVD) are the most common causes (AIHW, 2012; Alzheimer's Association, 2015; APA, 2013). However, half of all people with dementia, especially those in older cohorts, have a mixed type of dementia (See Table 2). Furthermore, an estimated 10% of people with dementia-like symptoms require

differential diagnosis relating to depression, delirium, medication side effects, alcohol misuse, vitamin deficiencies, and thyroid problems (Clarfield, 2003). See tables 2 and 3, on the following pages, for the common causes of dementia and symptom categorisation.

Table 2

Common causes of dementia (AIHW, 2012; Alzheimer's Association, 2015)

Alzheimer's disease (AD)	Affects 60% to 80% of individuals with dementia (50% solely AD). Symptoms: forgetting recent conversations, names, and events, with apathy/low mood leading to impaired judgement/communication, disorientation, confusion, and behavioural change. Eventually AD impairs walking, speaking, and swallowing; Neuropathology: Cumulative build-up of beta amyloid (plaques) outside neurons/twisted strands of protein tau (tangles) inside neurons leading to slow yet consistent impairment. Neurodegeneration starts in the hippocampus (an area of the brain related to memory formation).
Cardiovascular dementia (CVD)	Affects 20% to 30% of those with dementia (1% solely CVD). In older cohorts, 50% of those with AD also have CVD; Early symptoms: impaired decision-making, planning, and organising/judgement rather than memory loss; Neuropathology: Patchy step-wise progression of infarcts/multi-infarcts that disrupt oxygen to specific areas of the brain. Number, size, location of infarcts determines how functioning is affected.
Frontotemporal lobar degeneration (FTLD)	Early symptoms: personality/behavioural change, and impaired speech/comprehension rather than memory loss. More common in younger cohorts. Neuropathology: Neurodegeneration starts in the frontotemporal brain regions, and a spongy cortex develops due to protein build up.
Dementia with Lewy bodies (DLB)	Early symptoms: disturbed sleep, visual hallucinations, slowness, gait imbalance, tremor, rigidity, falls, and often visuospatial-impairment (similar to AD except for significant memory loss); DLB commonly co-exists with AD and sometimes coexists with CVD; Neuropathology: Increasing Lewy bodies (the protein alpha-synuclein) in neurons.
Mixed dementia	Mixed neuropathology: (1) AD/CVD; (2) AD/DLB; and (3) AD, CVD, and DLB in 50% of individuals with dementia.

Table 3

Symptomatic criteria of dementia: Diagnostic and Statistical Manual of Mental Disorders 5th ed. (APA, 2013)

Minor Neurocognitive Disorder	Moderate cognitive decline; Does not interfere with independence; Not due to delirium or another mental disorder; Psychometrically defined as between one and two standard deviations below mean-cognition across complex attention, executive function, learning and memory, language, perceptual-motor, and social cognition (dependent on premorbid functioning and test sensitivity); One or more cognitive domains impaired (for Alzheimer's type).
Major Neurocognitive Disorder	Significant cognitive decline; Interferes with independence; Not due to delirium or another mental disorder; Psychometrically defined as two or three standard deviations below mean-cognition in relation to complex attention, executive function, learning and memory, language, perceptual-motor, and social cognition (dependent on premorbid functioning and test sensitivity); Two or more cognitive domains impaired (for Alzheimer's type).
Severity of symptoms	Mild: Activities of daily living (ADL: e.g., housework, meal preparation, taking medications, shopping, managing money, using communication devices, transportation) preserved; Moderate: Eating, bathing, dressing, toileting, walking, and continence are affected; Severe: Completely dependent.
Behavioural disturbance	Psychosis, mood, and/or agitation.
Probable	Probable neurocognitive disorder (of Alzheimer's type) is distinguished by: (1) presence of Alzheimer's gene (family history/genetic testing); and (2) Minor: impaired 'memory and learning', progressive and gradual decline, no other causes; or (3) Major: impaired 'learning and memory' and one other cognitive domain, progressive and gradual decline, no other causes.

2.2.1 Underlying neuropathology

Around 100 billion neurons connect through 100 hundred trillion synapses to stream information at high-speed in the form of chemicals released from one neuron and detected by another (Alzheimer's Association, 2015). This forms the cellular basis for sensations, thoughts, emotions, and behaviour. Around 300 billion glial cells support this process, by producing brain-derived neurotrophic growth factor (BDNF) to grow new neurons and neural pathways. Such 'brain plasticity' promotes adaptive change in cognition, learning, and memory (Fields, 2009).

However, in dementia, excess plaques (beta amyloid) accumulate around the neurons to disrupt synaptic information flow, and 'tangles' (twisted strands of protein tau) develop inside the neurons to block the flow of BDNF (Alzheimer's Association, 2015). Neurons subsequently die, creating progressive structural and functional disruption (e.g., memory, language, or vision), mental slowing, and confusing reactions and responses (Alzheimer's Association, 2015). It is estimated that neurodegeneration starts 20 years before observable impairments (Reiman, Quiroz, Fleisher, Chen et al., 2012; Villemagne, Burnham, Bourgeat, & Brown et al., 2013). By the time impairments are obvious, the brain is already struggling to accommodate neurodegeneration. By the time obvious confusion appears, significant brain damage has already occurred (Reiman et al., 2012; Villemagne et al., 2013).

2.2.2 Influence of biopsychosocial factors

Except in rare cases caused by known genetic mutations, 1% or fewer of all people carry biological inheritance for Alzheimer's disease (Bekris, Yu, Bird, & Tsuang, 2010; Chow, 2013). However, the Apolipoprotein E (APOE) gene is a recognised risk factor. APOE is a protein that carries cholesterol in the bloodstream, and everyone inherits one form of the gene, APOE - ϵ 2, ϵ 3, or ϵ 4, from each parent. Around 60% of the population

have one or two copies of the 'neutral-risk' APOE ϵ 3 gene, and a further 10% to 20% have one or two copies of the 'protective' APOE ϵ 2 gene (National Institute of Health [NIH], 2011; Raber, Huang, & Ashford, 2004). However, 20% to 30% of the population have one or two copies of APOE ϵ 4, which triples their dementia risk (Holtzman, Herz, & Bu, 2012; Loy, Schofield, Turner, & Kwok, 2014). Moreover, a further 2% have two copies of APOE ϵ 4, which increases their risk of dementia by eight to 12 times (Spinney, 2014).

Although individuals with a first-degree family history of dementia are at an increased genetic risk of developing dementia, environmental and lifestyle factors influence "genetic makeup to eventually allow or deny dementia a foothold" (Chow, 2013, p. 70; Green, Cupples, Go, & Benke et al., 2002; Lautenschlager, Cupples, Rao, & Auerbach et al., 1996; Mayeux, Sano, Chen, & Tatemichi et al., 1991). This appears to explain why 40% to 65% of people with Alzheimer's disease have only one or two copies of the APOE ϵ 4 gene (NIH, 2011). Indeed, neuropathology and lived experiences act upon each other reciprocally to enhance or undermine brain functioning. Therefore, rather than experiencing a permanent state of decay during dementia, the brain continues to problem solve and compensate for structural and functional brain damage (Power, 2014).

Therefore, dementia reflects not only neurodegeneration, but also the individual's response to living with dementia, and their reactions to how others view and treat them (Downs et al., 2006; Sabat, Napolitano, & Fath, 2004; WHO, 2002). Although dementia represents a "shift in the way a person experiences the world around him/her" (Power, 2014, p. 19), individuals living with dementia are often viewed and treated as individuals 'dying' from a terminal disease rather than 'living' with a chronic disability (Taylor, 2011). More so, it would seem that individuals learn what it means to live with

dementia through the messages used to convey or conceal diagnosis, medical descriptions of deficits, and the way in which others interact with them. Over time, these messages start to define their experiences unless they are challenged in their 'undisputed' truth (see Vaihinger 1852–1933).

Table 4

Modifiable risk factors and prevention against dementia (see Appendix 1 for references)

Risk factors	Preventative measures
<ol style="list-style-type: none"> 1. Subjective social isolation and loneliness: Single/widowed/divorced (especially living alone); No social ties; Frequent dissatisfying social ties; No children, or less than weekly contact with satisfying children; Daily to weekly contact with dissatisfying children doubles the risk; 2. Stress: Chronic stress; Caregiver stress; Posttraumatic stress; Death of a child or grand-child; 3. Mood factors: Depression; Low self-esteem; Loss of purpose; External locus of control; 4. Cognitive stimulation: Less formal education; Cognitively unstimulating work; 5. Cardiovascular risk: Alcohol misuse; Sedentary lifestyle; Smoking; Diabetes; Midlife obesity, hypercholesterolemia, and hypertension; 6. Midlife 'binge-drinking' (when at least monthly it triples the risk); 7. Moderate unhealthy-saturated fats in midlife doubles the risk; 8. Repeated traumatic brain injuries (TBI): <ul style="list-style-type: none"> ▪ Mild TBI – blow/jolt to the head, without concussion or hospitalisation (e.g., boxing, rugby codes, combat service); ▪ Moderate TBI (lost consciousness or posttraumatic amnesia for 30 minutes) doubles risk; ▪ Severe TBI (loss of consciousness or posttraumatic amnesia for 24 hours) 4.5 times risk. 9. DDT synthetic pesticide exposure (fruit, vegetables, crops, or fish). 	<ol style="list-style-type: none"> 1. Social factors: Strong social interaction/social network; Emotionally supported, Married and living together; Diverse and 'tribal' social network; Daily-weekly contact with satisfying children or friends; 2. Mood factors: High self-esteem; Life-purpose; Internal locus of control; 3. Bilingualism delays dementia onset by 4.5 years; 4. Cognitive stimulation: More years of formal education; Cognitive activity (reading; puzzles, word games, scrabble; courses; writing); 5. Retiring at an older age; 6. Novelty: Combined and frequent 'novel' cardiovascular/mental/social activities requiring self-initiative; 7. Physical activity (for memory, mental speed, executive function); 8. Nutritional diet and moderate unsaturated fats; 9. A 30-year longitudinal study found midlife people (45-59 years) can reduce dementia risk 60% if they do any four of: <ol style="list-style-type: none"> a) Daily vigorous exercise (e.g., walking 3.2 kilometres [2 miles] per day/riding 16 kilometres [10 miles] per day); b) Healthy diet (three serves fruit/vegetables and less than 13 kilojoules [30 calories] of fat daily); c) Body Mass Index (BMI 18-25); d) Low alcohol intake (less than three units per day); e) Abstinence from smoking.

2.2.3 Functional changes in dementia

2.2.3.1 *Changing levels of awareness*

For people living with dementia, the quality of their day-to-day interactions is supported by their awareness, which contributes to their wellbeing and quality of life (Clare, 2010; Nuffield Council on Bioethics, 2009; Walmsley & McCormack, 2014). However, awareness is one area of functioning that becomes progressively compromised as dementia progresses (Clare, 2010). As a concept, awareness represents a purposeful response to a specific aspect of one's situation, functioning, or performance conveyed through speech, behaviour, and/or emotion (Clare et al., 2011; Planalp, 1999). It is purported to be hierarchical and ranging from the perception of sensory information and simple movement, to the integration of sensory input for goal directed behaviour and complex self-awareness (Stuss, Picton, & Alexander, 2001). Lower levels of awareness involve appraisal and descriptions in the present moment, whereas higher levels of awareness call upon judgements, attributions, comparisons, and temporal reflection (Clare et al., 2011).

Despite the literature on awareness in dementia, no clear relationship has emerged between dementia-related neuropathology and expressed levels of awareness (Clare, 2010). What is known, is that awareness becomes impaired when a person with dementia experiences neural dysfunction, loss of cerebral blood-flow, and disturbed sleep-wake cycles (Edman, Brunovsky, Sjögren, & Wallin, 2003; Woods & Martin, 2007). Furthermore, socioenvironmental

factors such as peripheral noise, nursing activity, and a lack of social stimulation can leave care home residents with dementia appearing withdrawn (Norberg, Melin, & Asplund, 1986). In addition, individuals with dementia may deny or hide their difficulties when their sense of continuity is challenged by memory loss (Clare et al., 2011), which also contributes to an out-of-date sense of identity and personal ability (Klein, Cosmides, & Costabile, 2003; Klein, German, Cosmides, & Gabriel, 2004).

Indeed awareness in relation to dementia is complex, when individuals with extensive impairment reveal few signs of neuropathology post-mortem, and vice versa (Sevush & Leve, 1993; Snowden, Greiner, Mortimer, & Riley et al., 1997). Similarly, cerebral atrophy occurs in most but not all individuals with a dementia diagnosis (Albert, Naeser, Levine, & Garvey, 1984) and awareness levels can improve, decline or stabilise over a 12-month period (McDaniel, Edland, Heyman, & the CERAD clinical investigators, 1995; Weinstein, Friedland, & Wagner, 1994). As a result, awareness in the context of dementia is now widely considered to reflect a dialectical interplay between the biological, psychological, and social aspects of this condition (Clare, 2010; WHO, 2002).

Where awareness has been investigated during the moderate stages of dementia, individuals can recognise themselves (Grewal, 1994), respond meaningfully with emotion (Magai et al. 1996), and display complex awareness encompassing empathy, perspective taking, self-evaluation, relational evaluation, situational and temporal

awareness (Clare, Rowlands, Bruce, & Surr et al., 2008a, 2008b).

Furthermore, in the severe stage of dementia, lucidity and vitality are enhanced when social interactions convey respect, sincerity, intimacy and appropriate playfulness (Götell, Brown, & Ekman, 2007; Normann, Asplund, & Norberg, 1998). In addition, as speech declines, the communicative use of gestures and expressions has been observed instead of speech (Clare et al., 2008a, 2008b; Kontos, 2004, Walmsley & McCormack, 2014).

Even in the profound stage of dementia, when speech is limited or absent, awareness may exist at levels previously unrecognised when social cues support communication pathways (Walmsley & McCormack, 2014). In particular, observed family interactions highlight that the lived experience of family members in this stage of dementia includes striving to retain family membership through communicative interactions (Walmsley & McCormack, 2014). As such, capacities in the emotional and relational domains of life appear to be relatively intact, even in the late stages of dementia (Sabat, 2001; Sabat & Collins, 1999).

2.2.3.2 Alternate perceptions of time

People living with dementia-related memory loss frequently bring meaning to their experiences through earlier life contexts (Clare, 2010; Klein et al., 2003, 2004). Although neuropathology offers a causal explanation for altered perceptions of time, recognition that the 'flow of time' is no longer perceived provides a constitutive understanding (Hughes, 2009). If one considers that time is judged

from an individual and relative perspective, past and present need no longer be seen as distinct entities (Hughes, 2009). Indeed, when dementia interrupts a person's sense of temporal flow, models of time can help explain how people with dementia can dwell in the past but still respond logically to current events.

One such model of time is the 'Axes of Simultaneity and Succession' (Saussure, 1974). According to this model, people understand phenomena from two perspectives: (1) a horizontal A-B axis of simultaneity containing the dyadic relationship between co-existing things fixed-in-time; and (2) a vertical C-D axis of succession upon which only one thing can be considered at a time, but upon which all things are presented with their change across time (Saussure, 1974).

As such, it seems possible that a person living with dementia can tell that one event occurred before another, without knowing when either event occurred (Hughes, 2009). Although change may not be recognised by that person when they see events according to the A-B axis, they might still understand the situation based on similar dyadic events remembered from the past (Hughes, 2009). Furthermore, it may be that their comprehension is supported through some form of emotional recognition that links past with present (Hughes, 2009). For example, although an in-resident father may not recognise his visiting adult-daughter because he remembers her as a six-year old, it may be that her personality triggers his emotional memories to help him link dyadic relationships and make sense of the present situation

(see Feist & Feist, 2008, for a concept of personality as an enduring pattern of traits and characteristics that bring consistency and individuality to a person's behaviour.) As such, the father can still understand and predict according to these dyadic relationships, without understanding when and where each relationship occurred. This is supported by the proposal that people first attempt to understand constitutively by linking dyadic relationships in the *here and now*, before seeking to understand causality through investigation of *past and present* (Saussure, 1974).

2.2.3.3 Changing communication pathways

Arguably, the need to communicate, connect, relate, belong, and express oneself is an inherent human need (Allen & Killick, 2010). We are fundamentally social beings, for our sense of self is retained through autobiographical stories, actions and responses during social situations (Harré, 1983, 1991; Sabat & Collins, 1999). However, one-in-ten Australians would actively seek to avoid interacting with a person who has dementia, despite one-third recognising that individuals with dementia are still enjoyable company (Phillipson et al., 2012).

Nevertheless, families often experience embarrassment when a member with dementia communicates in confusing and unusual ways (Phillipson et al., 2012; Santulli & Blandin, 2015). When family caregivers struggle to explain decisions or reassure, caregiver strain can emerge and give way to shame and anger as repetitive questions

become overwhelming (Sachs, Shega, & Cox-Hayley, 2004; Santulli & Blandin, 2015; Tabak, Ehrenfeld, & Alpert, 1997, see Chapter 4).

For the individual living with dementia, ample research describes their word finding problems, incorrect word association, syntactic errors, and ‘empty speech’ (APA, 2013; Bourgeois, 1991; Whitehouse, 1999). Indeed, people living with dementia effectively describe their own communication experiences as ones of searching “for a word and I can see it walking away from me. It gets littler and littler. It always comes back, but at the wrong time. You can’t be spontaneous” (Snyder, Egan, & Burns, 1995, p. 98) and:

I can’t think of things to say before somebody’s already said it and they’ve superseded what I have to say. The words get tangled very easily and I get frustrated when I can’t think of a word (Henderson, 1998, p. 18).

As dementia progresses, communications changes from a cognitive to emotion foundation (Bryden, 2005; Peterson, 2004; Taylor, 2007), for example:

The locus of my attention is definitely shifting from my head to my heart. I feel and think about feelings more than I think about thinking. Sometimes I am very happy, sometimes I am very sad, and at all times, I am aware of my feelings (Taylor, 2007, p. 128).

Furthermore, non-speech expressions increasingly support and eventually replace speech, as observed during interactions with researchers (Sabat, 2001), other residents who have dementia (Kontos, 2004), and visiting family members (Walmsley &

McCormack, 2014; see Chapter 6). It should be noted however that almost all of a person's communication is non-speech, regardless of dementia. Indeed, it is estimated that up to 93% of communication occurs through non-speech pathways (Mehrabian, Wiener & Morton, 1967; Mehrabian & Ferris, 1967). This includes facial expressions, eye contact, body gestures, posture, and physical proximity, sense of affinity/aversion, rhythm of interaction, tone, pitch and rate of voice, silence, and suppressed behaviour (Mehrabian et al., 1967; Mehrabian & Ferris, 1967).

As dementia progresses and speech declines, social interactions require an 'intentional stance' whereby communication is approached in the belief that the person with dementia is intending to communicate (Dennet, 1987). Furthermore, it requires creativity and willingness to recognise interpret and respond to alternative patterns of communication (Allen & Killick, 2010). Indeed, open, honest, and fulfilling communication can unfold where there is a sense of equality between speakers (Buber 1878–1965). Calling on empathy, or "being sensitive, moment to moment, to the changing felt meanings which flow in this other person", this can contribute to a sense of connectedness (Rogers, 1975, p. 4).

However, empathic connection can "only be done by a person who is secure enough in himself that he knows he will not get lost in what may turn out to be the strange or bizarre world of the other, and can comfortably return to his own world when he wishes" (Rogers, 1975, p. 4). For family members unable to connect through alternate

communication pathways such as emotion, touch, dance, walking, and physical games (McCormack, Tillock, & Walmsley, 2016; Walmsley & McCormack, 2016b), it may be that they miss opportunities for ongoing relational and social connection:

[Individuals with dementia] can connect on both a deeper and a simpler level — heart to heart or soul to soul rather than mind to mind. Those who care for persons with Alzheimer's have the same ability, but may not necessarily realise it. Caregivers too often overlook these powerful, yet subtle connections because they become preoccupied with frustrations of loss and focus on what the person can no longer do (Fazio, 2008, p. 107).

Even in the advanced stages of dementia, individuals can still express themselves communicatively, and share their retained sense of identity in its many forms (Kontos, 2004; Harré, 1991; Sabat & Collins, 1999, Walmsley & McCormack, 2014; chapter 6 of this thesis). For example, researchers have observed expressions of self that encompass: (1) 'self' reflecting one's specific view of the world, attitudes, beliefs, and experiences. This is expressed through first-person pronouns and observed when an individual seeks protection or responds to their name; (2) 'self' comprising one's past and current physical and psychological attributes, and one's beliefs about these. This can be revealed through their reactions and responses; and (3) 'self' representative of one's personas as manifest through others, such as being a parent, or a cared-for person, showing regard, or being protective (Sabat & Collins, 1999). For a person with dementia,

although personalisation of their symptoms can erode their sense of self, sense of self and essential 'personhood' can also be enhanced through affirmation and positive social interactions (Brooker, 2007; Kitwood, 1997; Sabat & Collins, 1999, see Table 5 on the next page).

Positive social interactions are observed when individuals mirror each other's postures and gestures, and complete sentences for each other (Fredrickson, 2001, 2013). It occurs most often when individuals slow down and become present to their bodily sensations, and the actions and reactions unfolding in that moment (Fredrickson, 2001, 2013). Such interactions are foundational upon physical and emotional connection through eye contact, touch, voice, gestures, and postures (Frederickson, 2013). Indeed, eye contact is the "main mode of establishing communicative context between humans" (Farroni, Csibra, Simion, & Johnson, 2002), which in pre-speech infants, for example, allows them to express their emotional needs (Niedenthal, Mermillod, Maringer, & Hess, 2010). Voice also, even if over the telephone, conveys emotional information through its acoustic properties (Bachorowski & Owren, 2008), and smiles trigger neural activity in each interacting person, with a mirroring of neural circuitry helping each person to experience a simulation of the other's emotions (Niedenthal et al., 2010).

Table 5

Person-centred guidelines for social interaction with a person who lives with dementia (Brooker, 2007; Kitwood, 1993, 1997)

'Malignant social psychology'	'Positive person work'
<ol style="list-style-type: none"> 1. Intimidation: Physical threats and coercion; 2. Withholding: Refusing a person's need for attention or contact; 3. Outpacing: Speaking and interacting too quickly for the person to understand or engage; 4. Infantilisation: Patronising the person with dementia; 5. Labelling: Using a negative label to describe the person; 6. Disparagement: Describing the person as incompetent; 7. Accusation: Blaming the person for their behaviour or disability; 8. Treachery: Tricking the person to distract or deceive them; 9. Invalidation: Ignoring the person's viewpoint and experiences; 10. Disempowerment: Blocking the person from using their retained knowledge and skills; 11. Imposition: Overriding and denying the needs of the person; 12. Disruption: Interrupting the person's actions and responses; 13. Objectification: Treating a person as if they were an object; 14. Stigmatisation: Treating a person as if they were alien or outcast; 15. Ignoring: Talking about the person as if they were absent; 16. Banishment: Physically or psychologically excluding the person; 17. Mockery: Making fun of the person at their expense. 	<ol style="list-style-type: none"> 1. Warmth: Genuine affection, care, and concern for the person; 2. Holding: Offering safety, security, and comfort to the person; 3. Relaxed pace: Speaking and interacting with the person in a relaxed way; 4. Respect: Valuing/recognising the person's maturity/life experiences; 5. Acceptance: Unconditional positive regard for the person; 6. Celebration: Supporting and delighting in the skills and achievements of the person with dementia; 7. Acknowledgement: Supporting the person's individuality; 8. Genuineness: Interacting with the person honestly, sensitively; 9. Validation: Recognising/supporting the person's viewpoint; 10. Empowerment: Empowering the person; 11. Facilitation: Supporting the person's needs; 12. Enabling: Recognising/encouraging the person's efforts to engage; 13. Collaboration: Consulting and working with the person; 14. Recognition: Non-judgemental acceptance of individuality; 15. Including: Physically and psychologically including the person; 16. Belonging: Helping the person feel attached to their physical and social environment; 17. Fun: Engaging in a spontaneous, creative, and humorous way.

2.2.4 Stigma versus living well

2.2.4.1. *A stigmatising condition*

Ironically, greater public awareness of dementia has contributed to public fears and misconceptions that stigmatise individuals who live with dementia, and their family members by association (Behuniak, 2011; Goffman, 1963; MacRae, 1999, Werner & Heinik, 2008). Such stigma describes a shamefully different attribute that discredits, devalues, and depersonalises an individual (Goffman, 1963; Link & Phelan, 2001, 2006), and in this context, stigma is maintained by a western media that focuses on dementia and its “most debilitating, demeaning, and despairing features” (Jolley & Benbow, 2000, p. 117). Indeed, people living with dementia describe feeling underestimated in their own abilities and even relational capacity:

“The stigma of dementia is that we have lost our ability to think, to have insight, to make decisions. We are also thought to be already in the last stages, so why bother being in a relationship with us?” (Bryden, 2012, as cited in Power, 2014, p. 85)

Frequently, family and friends stop calling and visiting (Alzheimer’s Association, 2015; Skladzien & Holdsworth, 2013), which undermines their already fragile sense of self:

“After I was diagnosed, my friends stopped coming around to see me. Finally, I called one of them and asked him, “Why don’t you come to see me anymore?” He said, “Richard, I just don’t know what to say.” I said to him, “How about ‘Hello’?” (Richard Taylor, 2011, as cited in Power, 2014)

Even worse, when interactions become superficial and functional, and in extreme cases the source of unwanted humour, it can leave people with dementia feeling a sense of personal shame (Henderson, 1998; Katsuno, 2005; Nuffield Council on Bioethics, 2009; Sapp, 2010; Chapter 5):

“I think for a lot of us the feeling of being cheated, or the feeling of being belittled and somehow made jokes of, I think that’s one of the worst things about Alzheimer’s” (Henderson 1998, p. 37);

However, such experiences speak more of the uncertainty and discomfort experienced by people who are unfamiliar with dementia:

“It’s a strange life when you ‘come out’ - people get embarrassed, lower their voices, and get lost for words” (Terry Pratchett [Author], British Broadcasting Corporation [BBC] News interview, 2008);

Moreover, in using their public profile, such people with dementia can turn their stigmatising experiences into a search for understanding and advocacy:

“It’s a bugger ... It’s just bad luck. You could get rheumatic fever, or lose a leg ... People get all sorts of disadvantage which comes from an illness. Some of them are never the same again. They can’t do stuff they used to, but they don’t become social outcasts or write-offs ... I’ve got no embarrassment about it ... it’s got nothing to do with shame. It’s an illness, which is unpredictable and when it comes you’ve just got to cope with it. And the more research that’s done ... the more it might be, well, not eradicated, but dealt with in better ways ... Because it’s very difficult. It’s like losing your skin or something. But in fact you lose some of your head – your works” (Hazel Hawke [former wife of Australian Prime Minister Bob Hawke], as cited in Pieters-Hawke & Flynn, 2004, Foreword).

Indeed, it is important to remember that despite stigmatising views, individuals with dementia remain: (1) a person despite their impairments; (2) the same person they always were; and (3) equal to those healthy (see person-centred care: Kitwood, 1993, 1997). This reinforces the challenge to interact in ways that support “recognition, respect, and trust” (Kitwood, 1997, p. 8), and when the person with dementia is seen as a ‘person’ first rather than their ‘condition’, stigmatising differences vanish between ‘us’ and ‘them’ and are revealed as a matter of ‘degree’ rather than ‘kind’ (Post, 2006):

“I still would like to be treated like a person, you know, because I’m still a person whether I do it wrong or right ... I want to feel like somebody because a lot of times with this-already with what I have ... I really don’t belong anyplace” (Gisser, 1994, Alzheimer Association, as cited in Wilkinson, 2002).

2.2.4.2 Living well with dementia

A growing body of literature in the positive psychology domain is providing conceptual models and empirical studies for understanding how individuals age well, even when they experience extreme health adversities such as dementia (Stirling, 2010). As a field of science, positive psychology presents studies and theories of positive functioning and wellbeing across personal, interpersonal, systemic, and sociocultural domains (Rusk & Waters, 2013; Seligman, 1975, 2002, 2004). Although positive psychology has been criticised for its denial of suffering, suppression of negativity, false-hope, and victim blaming (Aspinwall & Tedeschi, 2010), for clinical psychologists it represents a shift away from the medical model to explain abnormal psychology (Maddux et al., 2004; Seligman, 2002). As such, clinical psychologists who remain committed to the range of negative and positive aspects of human experience, can come to reject: (1) normal and abnormal behaviour as dichotomous entities; (2) maladjustments as residing within the individual to the exclusion of sociocultural

context; and (3) individuals being viewed and treated as the ‘passive recipients of care’ when pathology is considered to be the root cause of their maladjustments (Maddux et al., 2004).

Therefore, the positive psychology movement has provided clinical psychologists with a body of knowledge and tools regarding the nature and measurement of human strengths and virtues, positivity, and well-being, and the environmental conditions that promote positive subjective experiences (Seligman, 2004). For example, in older people experiencing extreme health adversities, dispositional optimism, and positive expectancy are found to support recovery from surgery and/or survival from illness (Allison, Fung, & Gilain, 2003; Scheier, Matthews, Owens, & Magovern, 1989). Positive expectancy also offsets negative social expectations about older age, which can lead some older individuals to ‘act down’ to negative beliefs and adopt weak social roles (Kitwood, 1997).

Furthermore, positive psychology approaches are helping individuals redefine what it means to live with dementia:

I have been so blessed to decline much more slowly than expected given the degree of brain damage already apparent on scans in 1995. The neurologist is amazed at the level of function, despite the ongoing damage, and declining cognitive ability on testing. But that’s the medical model. I prefer the view of ‘use it or lose it’ and having a positive attitude. As a team with Paul ... I still advocate for people with dementia, but not as often. We still travel, but less frequently... Our youngest daughter is on track for an academic career. ... we have two delightful grandchildren from my eldest daughter ... I never thought it possible that I would live long enough to see all of this. The trauma to my family ... in the few years after diagnosis seems now so long ago. (Christine Bryden, as cited in Bryden, 2016, p. 136).

Thus, the positive psychology movement is redefining dementia for clinical psychologists, to emphasise the retained abilities, assets, and resources of individuals with dementia (Wolverson, Clarke, & Moniz-Cook, 2016). When viewed in this way, individuals are recognised as striving to retain their sense of self, rather than living with “a biological disorder with defined symptoms and stages that leads inexorably to loss of function and end-of-life” (Wolverson et al., 2016; p. 42). For the clinical psychologist adopting this stance, they can support the individual’s positive adjustment to living with dementia and the emergence of personal strengths, regardless of fluctuating and progressive decline (Clarke et al., 2016; Lloyd, Patterson, & Muers, 2016). In support of this more balanced and positive view of dementia, two-thirds of people living with dementia in the UK report living well with their condition despite concurrent experiences of anxiety and depression (Kane & Cook, 2013).

In living with a relative balance between negative and positive experiences, people who have dementia describe a ‘good life’ as one that includes opportunities for: (1) embracing the moment; (2) preserving their sense of identity and selfhood; (3) maintaining important relationships; (4) valuing the good days in comparison to the bad days; (5) retaining a sense of personal agency; and (6) maintaining good health (Diehl, Hay, & Berg, 2011; ESRO, 2014). Comparatively, a recent systematic review found wellbeing to exist across three domains in people with dementia: (1) identity and growth (e.g., gratitude and appreciation, preserving a sense of self, and seeing beyond dementia towards others and spirituality); (2) engagement with life in ageing (e.g., seeking positive enjoyment, enjoying the moment, feeling able, and positive connections with others); and (3) engagement with dementia, such as confronting, accepting, and challenging the condition through humour and hope (Wolverson et al., 2016). For clinical psychologists, this reinforces that people living with dementia are able to use

coping strategies for the active pursuit of wellbeing and positive identity (Clarke & Irwin, 2016).

2.3 Dementia treatments

2.3.1 Pharmacological interventions

As yet, there is no medical cure for dementia. Indeed, between 1998 and 2012, 101 unsuccessful clinical trials were conducted in the search for pharmacological treatments seeking to prevent, slow, or reverse dementia (Rubinstein, Duggan, Van Landingham, & Thompson et al., 2015). However, most pharmaceutical companies have now withdrawn from further trials, due to prohibitive costs (Rosenberg & Petersen, 2015). Nevertheless, a few pharmacological treatments are effective for improving functional ability during the mild and moderate stages of dementia, in some people, for up to 18 months (NICE, 2011). Similarly, new drugs are in-development for people living with the mild stage of Alzheimer's disease, and although even if successful, they are unlikely to halt the decline of dementia completely (Kurz & Perneczky, 2011).

2.3.1.1 *The use of psychotropic medications within care homes*

Most care home residents with dementia have high-level needs for their cognitive, functional, and communication impairments, medical and mood co-morbidities (AIHW, 2012). In particular, an estimated 90% of these residents will experience *BPSD* (behavioural and psychological symptoms of dementia) such as aggression, agitation, and psychotic delusions at some time during the dementia trajectory (Corbett, Smith, Creese, & Ballard, 2012). Subsequent distress places both the individual and others at risk, and typically ends up being treated with psychotropic medications. However, these antidepressants, antipsychotics, and sedatives are inappropriate and often ineffective (Ballard, Orrell, Yong Zhong, & Moniz-Cook et al., 2015; Gitlin, Kales, & Lyketsos, 2012; Lyketsos, Colenda, Beck, Blank et al., 2006; O'Neil, Freeman, & Portland, 2011; Ramadan,

Naughton, & Prior, 2003). Indeed, antipsychotics are only recommended for short-term use and as a second-line option due to their cardiovascular side effects and risk of morbidity (Liperoti, Pedone, & Corsenello, 2008; Serby, Roane, Lantz, & Cohen et al., 2009).

In fact, residents experience positive clinical outcomes when anti-psychotics are discontinued and replaced with psychosocial interventions (Ballard et al., 2015; Ballard, Hanney, Theodoulou, & Douglas et al., 2009). In one such intervention, discontinuing anti-psychotics reduced morbidity by 30% when individualised social interaction was included within the intervention (Ballard et al., 2015). Unfortunately, most Australian care homes do not have enough trained staff, especially when there are no mandatory minimum staff-resident ratios (AIHW, 2012, 2013). Of further concern, clinical psychologists are rarely included within care home interventions, yet can offer enormous value to residents (Bird et al., 2007; Brooker, 2008). Where clinical psychologists have been included, resident outcomes include: (1) a tenfold reduction in the duration of hospital stays; (2) a three-fold reduction in side effects from psychotropic medications; (3) a 50% reduction in visits by general practitioners; and (4) a 75% reduction in visits by geriatricians (Bird et al., 2007).

2.3.2 Psychosocial interventions

Psychosocial interventions seek to preserve and optimise skills at any level of cognitive and functional impairment to achieve or maintain optimal activity, participation, and social engagement (Kurz, Clare, & Lautenschlager, 2013). In effect, this helps individuals rejuvenate their extra time with activity and social engagement (Kurz et al., 2013). For residents experiencing BPSD, individualised psychosocial interventions: (1) present a first-line/long-term treatment option to be provided by health care staff (Gitlin et al., 2012; Lyketsos et al., 2006; O'Neil et al., 2011; Ramadan et

al., 2003); (2) offer a solution when striving to maintain identity in the perceived disorder and restriction of some care homes (Graneheim & Jansson, 2006); and (3) provide meaningful occupation for improved wellbeing, cognitive, physical, and behavioural outcomes (Cohen-Mansfield, Libin, & Marx, 2007; Cohen-Mansfield, Marx, Dakheel-Ali, Reiger et al., 2010).

Interventions adopting psychosocial approaches include cognitive stimulation (Woods, Aguirre, Spector, & Orrell, 2012), reminiscence therapy (Woods, Spector, Jones, & Orrell et al., 2008), cardiovascular exercise (Cheng, Chow, Yu, & Chan et al., 2014; Winchester, Dick, Gillen, & Reed et al., 2013), and group programs involving board games (e.g., Mahjong) which can reduce symptoms of depression (Cheng, Chow, Yu, & Chan, 2012). Indeed, research indicates that psychosocial interventions promote brain plasticity, although the relationship between cortical thickening, neuronal activation, behavioural gains, and the prevention or slowing of cognitive decline remains unclear (Draganski & May, 2008; Erickson, Voss, Prakash, & Basak et al., 2011; Lautenschlager, Cox, & Cyarto, 2012; Valenzuela, Matthews, Brayne, & Ince et al., 2012; van Paasschen, Clare, Woods, & Linden, 2009; Voss, Prakash, Erickson, & Basak et al., 2010).

2.3.2.1 Interventions involving the arts

There is a growing interest in the cognitive and functional benefits of arts interventions for individuals who have dementia. Arts activities stimulate social engagement and memories, sharpen attention, and improve mood (Osman, Tischler, & Schneider, 2014; Young, Camic, & Tischler, 2016; Young, Tischler, Hulbert, & Camic, 2015). In the performing arts space, ethnographic researchers and theatre practitioners recently collaborated in the UK, to address the challenges of dementia care by staging a theatre production to portray a dementia unit from the perspective of the patients, health care staff, and family visitors. This production titled, 'Inside Out of Mind', sought

to positively impact on dementia care and encourage empathy and intuitive listening (Schneider, Lowe, Myers, & Scales et al., 2014). Around 1,300 health care practitioners attended the play and related workshops, and seven performances raised public awareness. In particular, the strength of these performing arts interventions appears to be their potential to “change hearts as well as minds” by presenting audiences with an “effective tool for reflection” (Schneider et al., 2014).

In addition, caregiver singing elicits reciprocal benefits for both residents with dementia and health care assistants (Götell, Brown, & Ekman, 2009), as do individualised ‘music as therapy’ programs delivered by music therapists (Cameron & Sosinowicz, 2014; Han, Kwan, Chen, & Yusoff et al., 2010; Raglio, Bellelli, Traficante, & Gianotti et al., 2010; Sung, Chang, & Lee, 2010; Sung, Lee, Li, & Watson, 2012; Wall & Duffy, 2010). Singing also promotes social inclusion and belonging, and subsequent mood improvements even outlast memory of the activating event (Osman et al., 2014). It may be that such engagement through song and speech combines language and inherent human behaviour to stimulate the brain (Jeffries, Fritz, & Braun, 2003).

Participative arts programs, such as ‘art gallery visits’ are also of benefit to individuals with dementia, caregivers, and intervention facilitators (Camic, Tischler, & Pearman, 2014; MacPherson, Bird, Anderson, & Davis et al., 2009; Young et al., 2015). Similarly, art viewing and related discussion offers opportunities for social inclusion, and engagement, and relational connection within families inclusive of members with dementia (Camic et al., 2014; MacPherson et al., 2009). Furthermore, galleries promote intellectual stimulation and social inclusion in a way that positively repositions dementia in the public eye, delivering positive relational and emotional benefits for those with dementia and their caregivers (Camic et al., 2014). Of note, recent studies

indicate that art making and art viewing have the potential to stimulate memories and improve verbal fluency in people living with dementia (Young et al., 2015).

2.3.2.2 Interventions involving social engagement

As speech and self-sufficiency progressively declines, it becomes harder for people with dementia to satisfy their social needs (Unmet Needs Model: Cohen-Mansfield & Werner, 1995; Cohen-Mansfield, 2000). Within care homes, when social stimulation is inadequate or homogenous (e.g. discounting of lifelong habits, preferences, changes in ability and health), it can generate apathy, agitation, aggression, and disinhibition for residents (Cohen-Mansfield, Dakheel-Ali, Marx, & Thein et al., 2015). However, individuals with diagnosed dementia still retain universal psychosocial needs, in particular, the desire to feel useful and enjoy meaningful engagement (Cohen-Mansfield et al., 2015; Schölez-Dorenbos, Meeuwssen, & Olde Rikkert, 2010).

In particular, social-engagement interventions are demonstrating positive outcomes for people living with dementia. For example, brief social interactions referred to as ‘meaningful moments’ can improve mood (Stokes, 2013). Taking only a few minutes or less, and often prompted by photos and objects, meaningful moments are particularly suited to busy care homes and individuals experiencing rapid degradation of memory (Stokes, 2013). Of note, when meaningful moments reach a threshold of positive interactions, mood becomes increasingly sensitive to meaningful engagement beyond a threshold of positive interactions (Stokes, 2013).

Furthermore, simulated interactions using audio-recordings of a relative’s portion of a telephone conversation with a resident, or video-recordings of family members, reduce agitation (Werner, Cohen-Mansfield, & Fischer, 2000; Woods & Ashley, 1995). In comparison, general relaxation and reminiscence videos do not (Cohen-Mansfield, 2001). In particular, residents living with dementia engage the most with social and

purposeful stimuli involving one-on-one personal interaction, especially interactions with babies when that matches the person's preferences, identity, or family role (Cohen-Mansfield et al., 2010). Conversely, residents frequently refuse stimuli of plush animals, colouring markers, robotic animals, childish-looking dolls, and activity pillows (Cohen-Mansfield et al., 2010). This suggests that residents with dementia do not see themselves as childlike, but instead identify with prior roles in life. This is supported by residents living with dementia who describe their life in terms of their relationships, social roles, occupation, and caring for and being cared for by others (Surr, 2006).

2.4 Impacts on health care staff

2.4.1 Systemic impacts on health care staff

On the margins of the curative medical model for more than 60 years, aged care has been by-passed by generations of health practitioners. Many have sought general medical practice or more stimulating specialist opportunities over the 'supervision of an institutionalised population' (Hunter, 2005). For those who have sought aged care practice, they frequently face conflicting institutional, client, and family demands that challenge moral integrity and interfere with their delivery of the 'right' support (Corley & Minick, 2002; Erickson-Lidman, Norberg, Persson, & Strandberg, 2013; Glasberg, Eriksson, Dahlqvist, & Lindahl et al., 2006; Jameton, 1993; McCarthy & Deady, 2008; Westin & Danielson, 2006). Such moral distress may even contribute to negative wellbeing (Edberg, Bird, Richards, Woods et al., 2008), emotional exhaustion (Juthberg, Eriksson, Norberg, & Sundin, 2008) and poor coping (Glasberg et al., 2006; Redfern, Hannan, Norman, & Martin, 2002).

Compounding this situation, the aged-care workforce often experiences insecure employment, challenging work conditions, low staffing levels, and excessive paperwork (Martin & King, 2008; Sargent, Harley, & Allen, 2008, 2009, 2010). In addition,

occupational health and safety hazards include back injuries from repositioning, lifting and transferring residents (De Cieri, Shea, Sheehan, & Donohue et al., 2015; Shea, De Cieri, Donohue, & Cooper et al., 2016). Similarly, they experience more violence and aggression from patients, 'role overload' and 'emotional labour' than staff in mainstream hospital settings (Bailey, Scales, Lloyd, & Schneider et al., 2015; De Cieri et al., 2015; Shea et al., 2016). 'Role overload' conceptualises too many tasks within given time constraints (De Cieri et al., 2015; Shea et al., 2016). 'Emotional labour' refers to the relational challenges of providing care, and requisite strategies of emotional engagement and detachment that help staff display socially acceptable emotions and align conflictual emotions with hierarchical demands (Bailey et al., 2015; Hochschild, 1983; Smith, 1992).

Of further concern, health care assistants in the UK and Australia are poorly remunerated (Martin & King, 2008; Sargent et al., 2008, 2009, 2010; UK Department of Health, 2011). In fact, most health care assistants in Australia are paid little more than a supermarket checkout operator and less than an entry-level zookeeper (Fair Work Ombudsman, 2010). In the UK, some do not even receive the national minimum wage (Hussein, 2011). Cumulative upon an already challenging role, poor remuneration justifies inaccessible training and encourages staff-turnover of nearly 40% per year (Department of Health, 2011; Innes, 2002; Martin & King, 2008; Sargent et al., 2008, 2009, 2010). Training is inaccessible because it allows care home management to pay minimum wages, and thus limit their chief operating expense (Shonan, 2015).

Strikingly, aged care is the only division of medical services where the majority of its health care assistants have no formal training prior to employment (Ayalon, Arian, Bornfeld, & Beard, 2009; Ballard, Fossey, Chithramohan, & Howard et al., 2001; Gallagher, Bennett, & Halford, 2006). Furthermore, health care assistants, who have the

daily contact with residents, also receive the least pay and least access to training (Beck, Törnquist, Broström, & Edberg, 2012; Erickson-Lidman et al., 2013). Furthermore, the time that health care assistants are able to spend with clients offers little opportunity for reflective practice, in turn compounding poor practice (Ayalon et al., 2009; Gallagher et al., 2006).

Moreover, when treatment facilities for stigmatised diseases such as dementia are devalued and health care practitioners lose social status, it is referred to as an experience of 'structural discrimination' (Link & Phelan, 2001, 2006; Chapter 5). In turn, practitioners seeking to offer quality care can become demotivated (Cheung & Chow, 2006; Nuffield Council on Bioethics, 2009) and 'courtesy stigma' by their affiliation with another stigmatised individual (Goffman, 1963) leads to a further loss of professional power, and medical hierarchy separation into in and out groups (Link & Phelan, 2001, 2006).

Furthermore, although the role of health care assistants holds both meaning and purpose, it is one of the least valued in terms of economic and status systems (ADI, 2015), and "over half of all care homes [in Australia]... have nursing levels so low that most residents suffer harm" (Saltarelli, 2015, as cited in Allard, 2016). Additionally, residents living with dementia in Australian care homes are primarily supported by health care assistants, of whom 90% are women (Aged and Community Services Australia [ACSA], 2015; AIHW, 2012, 2013). Such inequity and disempowerment that characterises the lives of residents and staff raises questions regarding the exploitation of women (Greer, 2015). Aside from the expense of staff wages for this primarily female workforce, care homes can also cut costs by employing fewer staff overall, limiting training opportunities, and in extreme cases reducing the hours of care for each resident

(Shonan, 2015). As such, inequity and disempowerment also speaks of the limited political power held by older women who live in care (Greer, 2015).

Furthermore, a “cult of task and time” dominates most western care homes (McLean, 2007 p. 360), which leaves health care assistants without “sufficient time or opportunity to engage in the caring tasks for which they were employed” (Martin & King 2008, p. 28). Furthermore, the immediacy and demands of a medical model of dementia care competes with required time for personal reflection and experiential learning (Ayalon et al., 2009; Castle & Engberg, 2005; Zimmerman, Williams, Reed, & Boustani et al., 2005). In turn, residents live within a time constrained medical model of care that becomes compartmentalised into artificial time-periods (McLean, 2007). Residents who need extra staff support, or who need that extra time to decide or do something are likely to miss out (Ward, Vass, Aggarwal, & Garfield, 2008). When the anger of residents breaks a stigmatising standard of perfect behaviour, (e.g., “We’re not supposed to get angry. We’re supposed to be on the receiving end of care”, Bowly, 2013), the subsequent use of sedating psychotropic medications and anti-psychotics further disempower their ‘free expression’. In extreme circumstances, health care assistants come to see the reliance on psychotropic medications as “unworthy” (Kristiansen, Hellzen, & Asplund, 2006, p. 251) and “their own caring for the patient as meaningless and their work as worthless” (Ericsson, Kjellstrom, & Hellstrom, 2011; Norberg, 1996, p. 108; Norberg et al., 2006).

As in any situation in which people live together under force rather than choosing friendship, relationships can degenerate, especially when health care assistants find it hard to interpret and respond to residents’ alternate communication pathways (Athlin & Norberg, 1998). In difficult circumstances, staff members can even stop thinking of residents as individuals who can interact with others and their environment (Lakey,

Chandaria, Quince, & Kane et al., 2012). At worst, stigmatising labels for residents, such as “zombies”, “fading away”, and “dying twice” can emerge (Power, 2014, p. 46). For senior healthcare management and professionals within hospital settings, this calls for commitment and leadership in staff education and culture change (Alzheimer’s Australia, 2014).

However, communication pathways once believed lost, can reappear once resident-staff relationships improve (Normann, Asplund, Karlsson, Sandman, & Norberg, 2006; Zingmark, Sandman, & Norberg, 2002). This has renewed the challenge for managers to review protocols of care and lead staff in both physical care and advanced communication skills that support changing awareness and speech (Magai et al., 1996; Norberg et al., 2001; Edvardsson, Sandman, Nay, & Karlsson, 2009; Zingmark et al., 2002). As relationships improve, it may be that individualised care can restore relational connections and relational rewards between staff, residents, and families (Allen & Killick, 2010; Brodaty, Draper, & Low, 2003; Downs, 2010; Gannon & Dowling, 2011; Pilkington, 2005; Sabat, 2010). Indeed, relational reciprocity with residents can transcend to care and protection of non-family clients as if they were family (Gannon & Dowling, 2011; Phillips, Davidson, Jackson, Kristjanson, & Daly, et al., 2006; Touhy, Brown, & Smith, 2005).

2.5 Impacts on families

2.5.1 Systemic impacts on families

Dementia care pathways are complex, unpredictable, and constantly changing in high-income countries, including Australia, the UK, and USA (Borson & Chodosh, 2014; Goodman, Gordon, Martin, & Davies et al., 2014; Peel & Harding, 2014; Runge, Gilham, & Peut, 2009). As a result, there are a confusing array of contact points, including primary care settings, memory clinics, community respite programs, day centres, home-care

services, hospitals, and care homes (AIHW, 2012; Goodman et al., 2014; Peel & Harding, 2014). Of concern, many families delay medical support for dementia when they anticipate humiliation and discrimination within the health care sector (Phillipson et al., 2012), which may explain why most families delay diagnosis for three years following dementia onset (Speechly, 2008).

For many families, their first contact with this confusing health sector is through a primary care setting, where brief consultations are complicated by medical nihilism that surrounds this 'incurable' condition (Edwards, Voss, & Iliffe, 2014; McCormack, Tillock, & Walmsley, 2016; Peel & Harding, 2014; Phillipson et al., 2012; Phillips, Pond, & Goode, 2011). Family members describe feeling anxious as they glimpse the caregiving challenges ahead of them, and angry as they take on greater caregiving responsibilities (Cooper, Katona, Orrell, & Livingstone, 2006; Frank, 2010; Harris, Adams, Zubatsky, & White, 2011; Tabak et al., 1997; Walmsley & McCormack, 2014).

When family members eventually relinquish home care, it can be one of the most difficult and distressing decisions that they face (Bauer & Nay, 2003; Bramble, Moyle, & McAllister, 2009), even if it temporarily eases their sense of caregiver burden (Oldman & Quilgers, 1999). For many families, when a member enters aged care it is seen as that person's last refuge and representative of community isolation, dependence, and depersonalisation (Askam, Briggs, Norman, & Redfern, 2007; Clare et al., 2008a, 2008b; Meuser & Marwit, 2001; Moyle, Venturto, Griffiths, Grimbeek, & McAllister et al., 2011). For some family caregivers, the transitional distress, guilt, and regret of aged care placement is cumulative on the earlier distress of a dementia diagnosis and transition through hospital to a care home (Bauer & Nay, 2003; Bramble et al., 2009; Callahan, Boustani, Weiner, & Beck et al., 2012; Martin, Gilbert, McEwan, & Irons, 2006; Scott, Lewis, Loughlin, & Chambers et al., 2005). It may be that such conditions of dependency

and disempowerment even add to a sense of betrayal when family caregivers strive to remain a part of the caregiving role (McCormack et al., 2016). Indeed, in a hierarchical system that impacts, often authoritatively, on family relationships, family caregivers direct energy towards survival and defence rather than opportunities for social engagement (McCormack et al., 2016).

2.5.2 Relational impacts on families

Not without reason, has dementia been described as a ‘long goodbye’ (Dorenlot & Fremontier, 2006). As a terminal condition that can progress over ten years or more (Anderson, Lolk, Martinussen, & Kragh-Sorensen, 2010; Xie, Brayne, & Matthews, 2008), family members alternate between coping, letting go, interacting, hoping, and readjusting their social worlds in response to ongoing losses (Rando, 1986; Shuter, Beattie, & Edwards, 2014). Similarly, family members often experience exhaustion, worry, low mood, disturbed sleep, relational strain, and caregiving dissatisfaction (AIHW, 2012). Documented as a stigmatising condition for those who live with dementia, and their family members (Goffman, 1963; MacRae, 1999; Werner & Heinik, 2008), spouses describe isolation, loneliness, and difficulty re-entering social worlds as a single-yet-married person owing to the ambiguity of their loss (AIHW, 2012; Lakey et al., 2012; Harris et al., 2011; Sanders, Ott, Kelber, & Noonan, 2008). Pleasant activities between couples diminish (Gallagher-Thompson, Dal Canto, Jacob, & Thompson, 2001) as frustrations with taking on household chores and decision-making escalate (Harris et al., 2011). As a result, spousal connections can deteriorate with the pressure of increasing daily support (Svetlik, Dooley, Weiner, Williamson, & Walters, 2005), especially when a partner is negatively positioned as ‘child-like’ (Harris et al., 2011).

Grief is also a constant companion for family members. Anticipatory grief was once thought to mitigate the grief experienced by families when a member dies with

dementia, however it is now considered a risk factor for extended grief post-bereavement especially when relationships were close (Givens, Lopez, Mazor, & Mitchell, 2011). In addition, when grief remains unintegrated into everyday life post-bereavement and normal mourning is disrupted, it can become 'complicated grief' (Schulz, Boerner, Shear, Zhang et al., 2006; Shuter et al., 2014). Although 20% of families experience complicated grief, it usually resolves within 6 to 12 months of bereavement (Prigerson, Shear, Frank, & Beery et al., 1997; Schulz et al., 2006). In the context of the extended journey with dementia, this does not seem problematic.

Indeed, the anticipation of grief is similar to anticipatory trauma experienced by first responders such as police personnel (McCormack & Riley, 2016). Apart from direct or vicarious trauma, those whose career or caring for others places them in a constant state of anticipation, is postulated as the first stage of trauma, or the 'anticipation of trauma' (van der Kolk, McFarlane, & Weisaeth, 1996; McCormack & Riley, 2016). This anticipation occurs prior to any actual exposure, with stress elicited from potential anticipation and negatively influencing decision making, irrespective of whether information is known regarding the outcome of the situation (Papazoglou, 2012).

Even worse, chronic anticipation of grief is heightened when losses and grieving are experienced by family members as 'disenfranchised' (Betts Adams & Sanders, 2004; Boss, 2004; Doka, 2002). 'Disenfranchised grief' refers to situations when family members are denied the right to grieve or opportunities to receive support when their grief is underestimated or unacknowledged by significant others (Doka, 2002). However, where positive relationships and connectedness existed pre-dementia, this can help family members adjust to progressive social and relational losses (La Fontane & Oyeboode, 2014; Quinn, Clare, & Woods, 2009, 2013).

However, positive aspects of dementia caregiving are also recognised (Folkman & Maskowitz, 1997; Kramer, 1997; Lawton, Moss, Kleban, & Glicksman et al., 1991) and around one-in-five family members experience caregiving satisfaction (AIHW, 2012). Spouses can enjoy greater physical intimacy and emotional connection when their pre-dementia relationship was close and reciprocal (Harris et al., 2011; Steadman, Tremont, & Davis, 2007). Similarly, adult-children can encounter closer sibling ties, new outlooks on life and ageing, and greater relational appreciation (Meuser & Marwit, 2001; Ott, Sanders, & Kelber, 2007). In light of returning past favours, adult-children also describe a sense of greater self-worth (Meuser & Marwit, 2001).

Section 2:

2.6 The historical narrative

2.6.1 Dementia care, from antiquity to the Victorians

From the Egyptians through to the Greco-Romans, ageing and dementia were synonymous, except for attempts to classify dementia as a mental disorder secondary to disease in various bodily organs (Boller & Forbes, 1998; Signoret & Hauw, 1991; Torack, 1983). By the Middle Ages, crowded and unhygienic living conditions in Europe meant that dementia received little medical interest, owing to epidemics such as the plague (Boller & Forbes, 1998). Where it did, the term senility emerged to describe dementia secondary to original sin (Roger Bacon, 1214-1294), and by 1247 the world's oldest psychiatric hospital, Bethlehem Hospital or 'Bedlam', opened in London (Arnold, 2008). From ramshackle beginnings, Bedlam offered refuge for around two dozen 'sick' and 'poor'. Moving through the Elizabethan era and Renaissance, *lethargie* (Cosin, 1592), *stupidity* (Willis, 1684), and *insensitivity* (Battie, 1758) were used to describe dementia (Andrews, 1997; Arnold, 2008), and ageing was portrayed through Shakespeare as a

“second childishness and mere oblivion; Sans teeth, sans eyes, sans taste, sans everything” (Shakespeare, *As You Like It*, 1623, Act 2, Scene 7, Page 7: Craig, 1959).

As longevity increased, during the European industrial and agricultural revolutions, the first cases of people living with dementia began to emerge. In fact, Jonathan Swift (1667-1745), author of *Gulliver’s Travels* (1726), may have been one of those first individuals, when he wrote to warn a friend of his decline:

I desire you will look upon me as a man worn with years ... I have entirely lost my memory, incapable of conversation by a cruel deafness, which has lasted almost a year, and I despair of any cure (Jonathan Swift, 1738).

By now, a ‘New Bedlam,’ in a grand public building for 140 patients represented a new London emerging from the Plague, civil war, and Great Fire (Arnold, 2008). However, rather than a public health testimony, New Bedlam was a distraction along with the travelling puppet shows, whereby visitors could pay to goggle the ‘inmates’ (Arnold, 2008). Even grim insignia above New Bedlam’s entry gate featured a figure in pitiful ‘dementia’ vacantly “moping on the ground” (Andrews, 1997, p. 223).

From the Napoleonic era, ‘démence’ (from the Latin stem ‘demens’ for ‘without mind’) emerged as a French psychiatric categorisation and it entered lexicons across Europe (see Philippe Pinel [1745-1826] the founder of modern psychiatry; Torack, 1983). By the mid-to-late 19th century, with advancements in staining techniques and microscope technology, the link between clinical symptoms of various mental illnesses and autopsied brain lesions began to emerge (Andrews, 1997; Arnold, 2008; Cipriani, Dolciotti, Picchi, & Bonuccelli, 2011). However, it was not until the early 20th century that Dr Alois Alzheimer (a German psychiatrist; 1864-1915) matched clinical symptoms of *démence* with specific microscopic post-mortem neuropathology to confirm the first diagnosis of dementia, in a Mrs Auguste Deter (1850-1906).

2.6.2 Dementia care at the turn of the 20th century

In 1901, Mrs Auguste Deter was described by her general practitioner as “suffering a long time from weakening of memory, persecution mania, sleeplessness, restlessness ... unable to perform any physical or mental work” (Maurer & Maurer, 2003, p. 19). Her husband Karl described her mistakes with cooking, fearfulness, suspicions of his infidelity, slamming doors, and ringing neighbourhood doorbells (Maurer & Maurer, 2003; Page & Fletcher, 2006). Moreover, Mrs Deter’s intake assessment at an inpatient unit indicates that when she was unable to recall her name, she replied, “I have, so to speak, lost myself” (Maurer & Maurer, 2003, p. 8).

Mental health staff described Mrs Deter as a “tall woman with long brown hair, brown eyes, and elegantly long fingers” who was alternately fearful, agitated, calm, polite, and forgetful (Page & Fletcher, 2006, p. 578). To treat her agitation, Mrs Deter was subjected to sedatives, social isolation, and extended baths (Maurer & Maurer, 2003). By 1905, her health had deteriorated to the point where staff saw her as “completely stupefied, always lying in bed ... never says anything, mutters to herself” (Maurer & Maurer, 2003, p. 154). Regardless, Auguste’s husband Karl and daughter Thekla continued to visit (Maurer & Maurer, 2003; Page & Fletcher, 2006). However, sedatives failed to lessen Mrs Deter’s agitation and baths became a daily occurrence. In light of these treatments and her declining condition, Mrs Deter died in 1906, due to both pneumonia and septicaemia related to sacral pressure sores (Page & Fletcher, 2006).

2.6.3 Contemporary models of dementia care

Through the mid-20th century, medical advancements, government funding and a focus on training, cure and patient turnover generated a thriving model of individualised health care (Hunter, 2005). Regardless, aged care in many ways continued to operate

within earlier philanthropic models, and a medicalised approach to service delivery in high-income countries (Hunter, 2005; WHO, 2015). As a result, care homes appeared hospital-like rather than home-like (WHO, 2015). Indeed, it would seem that dichotomous values still confuse the over-riding mission of aged care services. On the one hand a homogenised medical model approach has been superimposed on aspects of aged care without due regard for the pace and quality of aging (Beck et al., 2012; Clark, 2002; Hunter, 2005; Kitwood, 1993, 1997). On the other, health care managers, practitioners, and assistants lack the authority to diversify that model for the autonomy and wellbeing of clients (Edberg et al., 2008; Erickson-Lidman et al., 2013; Glasberg et al., 2006; Juthberg et al., 2008).

In extreme circumstances, expert-down approaches create a poor environment for recovery and limit the expertise of practitioners. A paternalistic approach to treating dementia is established, individuals become framed by their labelled condition, and an overemphasis on curative treatment fosters therapeutic nihilism (Power, 2014). Although dementia is a “constellation of degenerative diseases of the brain that are largely progressive, irreversible, and ultimately fatal” (Power, 2014, p. 14), when this expert-down medical approach becomes systemic, it establishes a paternalistic approach to dementia care that “generates an almost exclusive focus on deficits and losses, caregiver burdens, and care systems” (Power, 2014, p. 14). However, it is increasingly recognised that individuals living with dementia are more than a set of disease symptoms and a list of things they cannot do. From a more holistic perspective, the changing social behaviour of a person with dementia represents ongoing adjustment to damage within a brain, in which many millions of neurons and synaptic pathways are still working to solve problems and create new narratives.

However, contemporary medical models are emerging with a person centred approach, to complement ‘person-centered’, ‘supportive’, and ‘recovery oriented’ approaches to dementia care (Alzheimer’s Australia, 2014; Hughes, 2014; Power, 2014; Willemse, Depla, Smit, & Pot, 2014; WHO, 2016). Like other models of health care, dementia care models have successively broadened, and with each iteration, they have refined the view of dementia, improved quality of care, and challenged historical views of dementia as a ‘living death’ (Cohen & Eisdorfer, 1986; Sabbat, 2001; Woods, 1989, 2001).

2.6.3.1 Contemporary medical models of dementia care

Traditionally, a pure biological view of dementia regarded neuropathology as the sole cause of behavioural change and functional losses in a person with dementia (Hughes, Andel, Small, & Borenstein et al., 2008, 2014; Power, 2014). Although concern for biological aspects of dementia are important, dementia is also a psychosocial condition shaped by the person’s response to living with dementia and their reactions to how others view and treat them (Downs et al., 2006; Sabat et al., 2004). This is why contemporary medical models have adjusted over time, to include person centred approaches that complement a modern ‘biopsychosocial’ view of disease (Engel, 1980; Hughes, 2014; WHO, 2002, 2016).

In Australia for example, contemporary medical models include the ‘Confused Hospitalised Older Persons’ (CHOPS) model of care, which has recently been trialled in acute hospital settings for patients displaying confusion (Alzheimer’s Australia, 2014). This person-centred adaptation of the medical model seeks to: (1) identify older people showing confusion within hospital settings; (2) understand the source of the person’s confusion; and (3) apply evidence-based interventions, including communication to facilitate person-centred care (Alzheimer’s Australia, 2014). Central to the CHOPS model

of care, is a person centred focus on assessment, care planning, and decision making, underpinned by communication between staff, family members, and the person with dementia. Early investigations of patient outcomes indicated that hospital staff felt more confident in recognising and responding to patients who had dementia, because of the CHOPS model of care (Alzheimer's Australia, 2014).

Furthermore, service delivery in hospital settings and care homes in Australia, Germany, Japan, the Netherlands, Sweden, and the United States is evolving to provide a more homely atmosphere and care that emphasises the person first, not their illness (Alzheimer's Australia, 2014; Pot, 2013). Examples include smaller group living in cottages for eight residents and several staff, which is promoting attentiveness and responsiveness to the psychosocial wellbeing of residents (van Zadelhoff, Verbeek, Widdershoven, & van Rossum et al., 2011). Indeed, where care homes adopt a homely environment, efforts to individualise care and adopt a relationally oriented approach to dementia care reduces the impact of institutionalisation (Lee & Yu, 2009; McCormack et al., 2016). Furthermore, rostering for staff continuity builds rapport, trust, and sense of attachment for residents (Bergland & Kirkevold, 2006; Cooney, Murphy, & O'Shea, 2009; Coughlan & Ward, 2007). It also supports efforts to treat the person as an individual first, not as a symptom of their illness (Jenkins & Smythe, 2013; Pot, 2013).

Further examples of the contemporary medical model in practice include innovative care homes, such as 'Hogeweyk' near Amsterdam in the Netherlands. Hogeweyk features 23 units, which have been designed to match the previous lifestyle of residents. This offers a segmented approach to meeting the lifestyle needs of residents, in which staff seek to offer care on an individualised basis (Jenkins & Smythe, 2013). Indeed, Hogeweyk seeks to replicate the feel of the village in which it is located, with a similar style supermarket, pavement café, restaurant, theatre, and hairdressers (Jenkins

& Smythe, 2013). Shopping and cooking are part of the daily routine, and although it is designed to represent what an individual might feel as normal, the environment has been carefully considered (Jenkins & Smythe, 2013). Each apartment hosts six to eight people, including one qualified nurse and two health care assistants, who wear street clothes and act like “supportive friends rather than clinically oriented problem-solvers” (Jenkins & Smythe, 2013, p. 19). At Hogeweyk, even those individuals living with severe dementia, limited or absent speech, and poor orientation, are involved in daily household chores (Jenkins & Smythe, 2013). In comparison, these types of opportunities are unavailable for similar residents living in the UK (Jenkins & Smythe, 2013). It may be that validation for the Hogeweyk approach to support person-centred care occurs when residents are found “living their lives” (Jenkins & Smythe, 2013, p. 18).

In Australia, care homes are increasingly assessing the positive returns of innovative service delivery through contemporary medical and person centred models of care. For example, replacing rotating rosters with dedicated staff assignments in a group of 26 care homes has; (1) decreased the number of different health care assistants per resident from 30 to four, per month; (2) rapport, trust, and relational attachment have developed through staff continuity (Bergland & Kirkevold, 2006; Cooney et al., 2009; Coughlan & Ward, 2007); and (3) delivered medical outcomes included a reduction in chest infections by 70% and pressure sores by 100% (Arcare, 2013). Additionally, financial benefits came by being able to reduce staff numbers by 54% (Arcare, 2013). In the USA, similar dedicated staffing in one Californian care home has helped reduce staff turnover by up to 75%, while resident occupancy increased from 82% to 94% (Farrell & Frank, 2007).

Again, in Australia, and New Zealand, implementation of the ‘Eden Alternative’ culture-change program in 36 care homes sought to: (1) restore meaningful living

within a more homelike environment; and (2) reduce feelings of loneliness, helplessness, and boredom by building companionship, purpose, variety, and spontaneity into daily life (Brownie, 2011). Positive outcomes from that program included reductions in staff absenteeism and turnover (Ransom, 1998; Steiner, Eppelheimer, & De Vries, 2004; Thomas, 1996), and staff experiencing greater passion for their work that translated to their seeking further qualifications (MacKenzie, 2003). For residents, the Eden Alternative contributed to their sense of satisfaction, as they were encouraged to take responsibility for their own health and wellbeing (MacKenzie, 2003). Similarly, residents reported less helplessness, boredom, and greater sociability despite their continued sense of loneliness (Bergman-Evans, 2004). This would seem to support the importance of family visits for reducing loneliness in residents. Indeed, where families visit infrequently, residents describe longing for family connection (Clare et al, 2008a, 2008b; Moyle et al., 2011) and when loneliness is extended, it even erodes their capacity to enjoy further family visits (Chang, 2013; Shin, 2011).

2.6.3.2 Person centred, supportive, and recovery-oriented models

Person centred care seeks to enlarge the medical model, rather than deny the importance of biological care for people living with dementia (Hughes, 2014). Person centred care emphasises the 'biopsychosocial' model of care to promote the centrality of the person with dementia and the importance of their family members for helping that person retain their sense of identity (Brooker, 2007; Kitwood, 1997; Phinney, 1998, 2002). It is a model of care underpinned by an inherent belief in the value of human lives regardless of age or cognitive ability (Brooker, 2007). In particular, it posits that relationships and social opportunities compensate for current losses and enhance personal growth (Brooker, 2007). This is underpinned by the view that when dementia starts to undermine an individual's sense of self, relationships become salient for

retaining sense of self (Brooker, 2007; Kitwood, 1997). Furthermore, individualised care is enabled when practitioners provide social opportunities that facilitate psychological needs and understand the lived experiences of patients, residents, and their families (Brooker, 2007).

More recently, a 'supportive' model of dementia care has emerged (Hughes, Lloyd-Williams, & Sachs, 2010). Aligned with the palliative model of care, the supportive model goes beyond biological, psychosocial, and spiritual aspects of dementia care to include ethical and legal implications and any intervention that might be regarded as helpful to the individual's care and treatment (Hughes, 2014). Therefore, supportive care seeks to maintain and prolong life, in both a patient and carer-centred way, while emphasising support around loss and grief for all, and eventual bereavement for family members (Hughes et al., 2010). Unlike traditional views of palliative care as an intervention when cure is unattainable, the supportive model of dementia seeks to intervene plaintively from the time of the person's diagnosis until their death, and beyond for their family members (Hughes et al., 2010).

Similarly, a 'recovery-oriented' approach to dementia care has recently emerged to optimise wellbeing for individuals living with dementia (Daley, Newton, Slade, & Murray et al., 2013; Downs et al., 2006; McKay, McDonald, Lie, & McGowan, 2012). Recovery oriented approaches provide a collaborative and strengths-based approach to dementia care, requisite upon the knowledge and skills of all parties, inclusive of the individual with dementia (Daley et al., 2013; Downs et al., 2006, McKay et al., 2012). Although recovery appears counterintuitive in the context of a terminal prognosis, recovery is possible when dementia care practitioners look beyond symptoms of illness to the recovery of positive attributes in the individual, such as identity, personhood, dignity, control, hope, and wellbeing (Daley et al., 2013; McKay et al., 2012). This supports a

meaningful and satisfying life regardless of age or cognitive ability (Daley et al., 2013; McKay et al., 2012). Furthermore, people living with dementia are advocating for such a rehabilitative approach to their support (Bryden, 2016; Friedell, 2002).

2.6.3.3 Applying models and implications for clinical psychologists

Despite which model of dementia care is applied, the real test for contemporary dementia care models is to be found in their application and quality of care pathways (Hughes, 2014; Power, 2014). All too often, care pathways can become a bureaucratic and confusing maze of forms and 'tick-boxes' to be completed by busy staff (Hughes, 2014; Peel & Harding, 2014), especially when tasks come to dominate staff-resident relationships (Martin & King 2008; McLean, 2007). However, efforts to introduce person-centred and recovery oriented approaches to contemporary models of medical care are attempting to reinforce the importance of detecting and treating pain and discomfort, while also providing opportunities for individualised socialisation and meaningful activity (Hughes, 2014). Moreover, where conflicts in care arise, returning to a values-based approach to care can offer guidance (Hughes, 2014; Fulford, Peile, & Carroll, 2012). Indeed, when values converge and diverge, or the values of a person with dementia are difficult to discern, efforts to communicate with that person, supporting family members and staff, is the key to resolving difficult moral choices and conflicts in care (Hughes, 2014; Fulford et al., 2012).

Section 3:

2.7 Constructs and theoretical underpinnings of this thesis

Numerous constructs and theoretical underpinnings talk to the individual experience of dementia, and many dementia studies in this area have tended to focus on constructs and theories related to caregiver burden, grief, and relational loss (as presented in Section 2.5, page 73). While the researcher has considered a range of

interpretations of the dementia experience for this thesis, an early pilot study in this PhD suggested that adversities and distress related to dementia could generate vicarious traumatic responses in family members. Although this view is supported by emerging literature, it remains poorly researched. Similarly, another early study by the researcher (submitted exclusively for a Master's degree) highlighted the possibilities that surround retained awareness and social interaction in those living with dementia, even in the profound and non-speech stage of dementia (Walmsley & McCormack, 2014).

Therefore, in this thesis, the researcher has focused on constructs and theories that offered best fit with the thesis topic and received literature support. They were: (1) foundational constructs for retained awareness and social interaction (Clare et al., 2011; van Lagenhove & Harré, 1999); and (2) constructs and theoretical models for the dementia caregiving experience, which focus on the continuum of caregiving from negative to positive, and in particular, psychological responses following adversity (Broese van Groenou, de Boer, & Iedema, 2013; Folkman & Maskowitz, 1997; Iecovich, 2011; Joseph, 2011; Kramer, 1997; Lawton et al., 1991; Pearlin, Mullan, Semple, & Skaff, 1990; O'Leary & Ickovics, 1995; Power, 2014). See table 6, pp. 96-98.

2.7.1 Levels of Awareness framework

From a clinical psychological perspective, awareness can be conceptualised as a phenomenological 'Levels of Awareness' framework (Clare et al., 2011). First, 'sensory registration' is considered to be underpinned by the ability to direct attentional resources to sensorial and perceptual information, resulting in an appraisal and/or a behavioural response. Social cues and stimuli and environmental stimuli affect sensory registration more than thoughts and feelings. Second, 'performance monitoring' occurs and represents ongoing tracking of task performance by comparing actual with expected performance and noting of errors and/or success. However, for some residents, a lack of

recent comparable experiences limits their performance monitoring ability (Clare et al., 2011). Third, 'evaluative judgement' reflects awareness of change in a specific aspect of one's situation, functioning, or performance. Involving simultaneous comparison of one or more aspects of experience (e.g., past and present, change in mood and/or behaviour), such evaluative judgement is particularly affected by attributes such as self-confidence, degree of introspection, and ability to communicate. It is also shaped by emotional responses and beliefs regarding experiences, situational expectations, and social stereotypes (e.g., ageism, dementia-related stigma). Fourth, 'meta-representation' is regarded as the most complex proposed level of awareness involving self-reflection and ability to adopt the perspective of others (e.g., awareness of worsening memory and regard to how family members might respond). At this level, awareness of broad concepts such as illness or relationships are defined by lived experiences, knowledge, socio-cultural attitudes, and opportunities for self-reflection (Clare et al., 2011).

2.7.2 Social Positioning Theory

In relation to social interaction, 'social positioning theory' describes how a person positions himself/herself or how others position that person in relation to social attributes such as right or wrong, well or unwell, powerful or powerless (van Lagenhove & Harré, 1999). Against the backdrop of one's life story, positioning explains social behaviour and sets expectations based upon the premise that 'we see what we expect to see' (Taner & Swets, 1954). Although dementia brings disability, when caregivers underestimate the abilities of a person with dementia, that person becomes viewed and treated accordingly.

However, the extent by which positioning impacts upon us depends on: (1) our interpretation of interactions (Heidegger, 1927/1962); (2) the extent that we 'allow' ourselves to be positioned negatively; and (3) how we 'choose' to subsequently position

the other person (van Lagenhove & Harré, 1999). Indeed, negative positioning even if unintended, is likely to generate frustration and anger particularly when perceived as unfair. In particular, when a person lives with dementia they may be less equipped to reposition themselves positively, owing to their slower mental speed, losses of speech, and negatively biased expectations about self, others, and the world. As such, their efforts are often misinterpreted as ‘resistive’, ‘behavioural’, or ‘unawareness’.

2.7.3 Theories related to caregiving adversity and its impact

2.7.3.1 *Models of caregiver impact*

It has long been recognised that dementia caregiving can be both negative and positive (Folkman & Maskowitz, 1997; Kramer, 1997; Lawton et al., 1991). For example, it is known that ‘caregiver burden’ is generated by caregiver stress but reduced by caregiver satisfaction (Lawton et al., 1991). Similarly, Kramer (1997) recognised that perceived ‘role strain’ negatively influences caregiver stress, whereas ‘role gain’ positively impacts on stress for caregivers. However, both of these models failed to recognise that a range of negative and positive aspects of caregiving occur at the same time (Broese van Groenou et al., 2013; Wolverson et al., 2016; Iecovich, 2011), or that caregiver gain and caregiver strain are negatively correlated (Monin, Schulz, & Feeney, 2015; Quinn, Clare, McGuinness, & Woods, 2012; Rapp & Chao, 2000).

As such, no dementia caregiving models have yet investigated whether an increase in negative aspects of caregiving can in fact promote positive outcomes. In light of the earlier pilot study in this PhD (see Chapter 4), which suggested that caregiving adversities were experienced as traumatic by families, the researcher now turns to trauma models and how individuals respond to extreme adversity. In dementia caregiving research, this is a new area of research.

2.7.3.2 Systemic Trauma Theory

For most families, the lived experience of dementia is one of cumulative stressors (Bauer & Nay, 2003; Scott et al., 2005), and even “traumatic ambiguous loss” (Boss, 2010, p. 138), when a member with dementia is physically present but socially absent (Blieszner, Roberto, Wilcox, Barham et al., 2007; Boss, 1999, 2002, 2004, 2006, 2007a, 2007b; Boss & Greenberg, 1984). Experienced as “confusing and incomprehensible”, subsequent losses in reciprocal communication are a source of distress and burden for families that can be immobilising, emotionally painful, and difficult to cope with (Boss, 2010, p. 138; Meuser & Marwit, 2001; Shuter et al., 2014).

Traumatic responses involve immobilisation (e.g., shock, numbness, and denial), the intrusive re-experiencing of memories, and oscillating efforts to both avoid and bring meaning to those memories (Horowitz, 1976; Joseph, 2011). Prolonged exposure to recurrent stressors can negatively affect core schema and attachment models, fostering negative beliefs about self, safety, trustworthiness and life purpose (Bowlby, 1969; Duckworth & Follette, 2011; Courtois & Ford, 2013; Kira, Templin, Lewandowski, & Ramaswamy et al, 2010). Divergent relational boundaries and triggered attachment issues contribute to emotion dysregulation encompassing anxiety, depression, and anger, loss of self-integrity, and relational disturbance such as being torn between need for connection and the danger of being close (Courtois & Ford, 2013).

Indeed, family members are at risk of vicarious distress as they care for their family member with dementia, particularly if they are vulnerable to emotional contagion. According to Systemic Trauma Theory, prolonged exposure and empathic caregiving for individuals experiencing adversity can lead to traumatic responses, especially when the caregiver is vulnerable to emotional transference (Figley, 1995; Figley & Figley, 2009; Saakvitne, Pearlman, & the Staff of the Traumatic Stress Institute,

1996). This is regardless of whether respite services offer a valuable break for family members overwhelmed by the enormity of caregiving (Gústafóttir, 2011) or care homes restore relational roles for relatives and offer reassurance concerning safety, diet, and medical support (Bramble et al., 2009; Buttar, Mhyre, Fries, & Blaum, 2003; Power, 2014).

As such, Systemic Trauma Theory explains the mirroring effect that occurs when caregivers are involved in prolonged empathic and emotional support of individuals experiencing emotional disturbance (Figley, 1998; Figley & Figley, 2009). In these situations, subclinical signs of traumatic stress often reflect those of the individual experiencing the trauma first-hand (Arnold, Calhoun, Tedeschi, & Cann, 2005; McCann & Pearlman, 1990; Pearlman & Saakvitne, 1995; McCormack & Joseph, 2013). It is almost as if the caregiver has “taken over the pathology” of the care recipient (English, 1976, p. 191), which becomes magnified when there is a deep emotional concern for the person experiencing the trauma first-hand (Figley, 1998). In extreme situations, those watching alongside can oscillate between seeking to rescue and contrarily seeking emotional distance in response to feeling helpless (Figley, 1998).

When transference occurs, it can negatively change the caregiver’s schematic views of self, others, and the world (Adams & Riggs, 2008; Kadambi & Truscott, 2004; McCann & Pearlman, 1990; Pearlman & Saakvitne, 1995; Schauben & Frazier, 1995). This can distort their worldview and generate irrational perceptions that become a maladaptive form of self-protection (Trippany, White Kress, & Wilcoxon, 2004; Young, Klosko, & Weishaar, 2003). Repeated vicarious traumatisation reinforces this schematic change, especially schemas that hold personal significance (McCann & Pearlman, 1990). In turn, specific schemas become generalised and maladaptive forms of self-protection increase (McCann & Pearlman, 1990). When individual caregivers feel overwhelmed,

avoidance of further distress and social withdrawal are common but maladaptive forms of self-protection (Figley, 1995).

In a professional domain, the degree of vicarious traumatisation is mediated by seniority (Pearlman & Mac Ian, 1995), with junior staff reporting cognitive disruption (Pearlman & Mac Ian, 1995; Schauben & Frazier, 1995), emotional exhaustion, depersonalisation, and sense of inadequate achievement (Ackerley, Burnell, Holder, & Kurdek, 1988). Conversely, senior staff experience fewer disruptions to their view of self in relation to trust, intimacy, and esteem (Pearlman & Mac Ian, 1995). This may be because junior staff members are reluctant to seek support due to a personal sense of shame, incompetence, or anxiety relating to their traumatic responses (Neumann & Gamble, 1995; Pearlman & Mac Ian, 1995). From a social constructivist stance, systemic trauma theory explains the relationship between cognitive schemas and the process of maladaptive psychological adaptation (Figley, 1995).

2.7.3.3 Organismic Valuing Process Theory

Trauma represents a response to unexpected, uncontrollable, and unpredictable events that present experiences beyond the existing hermeneutic boundaries of an individual's worldview (Joseph, 2011). Subsequent disruption to worldview highlights a distressing search for meaning and meaning making, the intensity of which varies according to the gap between subjective worldview and new traumatic information (Joseph, 2011; Joseph & Linley, 2005). It is experienced as distressing because successful integration of traumatic memories involves oscillating between revisiting and avoiding traumatic information (Courtois & Ford, 2013; Joseph, 2011; Joseph & Linley, 2005). Typically encompassing violent assault, disasters, military combat, severe accidents and chronic illness, suffering and death of a family member (Breslau & Kessler, 2001),

trauma may also include witnessing helplessly as a person succumbs to dementia (see chapters 4, 5, and 7; Boss, 2010; McCormack et al., 2016).

However, a growing body of literature indicates that adversity can in fact facilitate and coexist with psychological growth (Joseph, 2011; McCormack, Hagger, & Joseph, 2011; McCormack & Joseph, 2013; McCormack & Sly, 2013; McCormack et al., 2016; Park, Cohen, & Murch, 1996; Tedeschi & Calhoun, 1996, 2004; see Chapter 5). Encompassing transformative positive change, psychological growth refers to greater wellbeing that emerges over time following adversity (Joseph, 2011). It encompasses three domains of change after traumatic distress: (a) 'personal change', encompassing new personal strengths, greater wisdom, and more compassion; (b) 'philosophical change', including new priorities in life and enhanced spiritual beliefs; and (c) 'relational change', comprising new approaches to relationships and greater appreciation of others (Durkin & Joseph, 2009; Janoff-Bulman, 1992; Joseph, 2011; Joseph & Linley, 2005; O'Leary & Ickovics, 1995; Ryan & Deci, 2001; Ryff & Singer, 1996; Smith, Dalen, Wiggins, & Tooley et al., 2008; Tedeschi & Calhoun, 1996, 2004). Although immunological change is possible (Cruess et al., 2000; Milam, 2004) this thesis is particularly concerned with psychosocial change following the adversity of dementia.

Furthermore, converging studies (Joseph, 2011; Joseph & Butler, 2010; Joseph & Linley, 2006) indicate that people may be 'hard-wired' for psychological growth. As such, traumatic distress marked by the intrusion and avoidance of trauma-related cues is increasingly considered a normal search for comprehension and existential significance following adversity, rather than a mental disorder (Joseph & Linley, 2005). In fact, more recent growth theories posit that for successful integration of trauma-related information at a personal level, an individual must find personal significance and comprehensibility in their current life (Joseph & Linley, 2008). As such, both

independent dimensions, positive and negative assessment of any adversity must be acknowledged if growthful adaptation is to occur (Aldwin, Levenson, & Spiro, 1994; Fontana & Rosenheck, 1998; Schok, Kelber, Elands, & Weerts, 2008; Spiro et al., 1999). This search for meaning and meaning making appears to play a role in coping with adversity (Durkin & Joseph, 2009; Janoff-Bulman, 1992; Joseph & Linley, 2005; Lepore & Revenson, 2006; O'Leary & Ickovics, 1995; Smith et al., 2008).

However, psychological growth requires openness to existential questioning, particularly if a supportive social world promotes autonomy, self-efficacy, and meaningful relationships (Joseph & Linley, 2005; Ryan & Deci, 2000). In fact, a curvilinear relationship is suggested between distress and growth whereby the greater the distress the greater the opportunity for growth (Joseph, 2011). Once positive meaning-making takes hold, distress ultimately declines (Butler, Blasey, Garlan, & McCaslin et al., 2005; Linley, Joseph, & Goodfellow, 2008). Therefore, while traumatic responses negatively disrupt life, they paradoxically present opportunities for enormous positive change (Courtois & Ford, 2013; Csikzentmihalyi & Csikzentmihalyi, 2006; Seligman & Csikzentmihalyi, 2000).

As such, the 'Organismic Valuing Process Theory' (OVP; Joseph & Linley, 2005) is concerned with the co-existence of and curvilinear relationship between growth and distress that is underpinned by five theories of traumatic stress (Creamer, Burgess, & Pattison, 1992; Horowitz, 1976; Joseph, Williams & Yule, 1995; Rachman, 1980). As a pathway to mental recovery that involves a normal search for meaning following adversity (Tedeschi & Calhoun, 1995, 1996), when negative and positive appraisal of adversity leads to personal significance and meaning, it allows for the successful integration of traumatic memories (Aldwin et al., 1994; Fontana & Rosenheck, 1998; Joseph & Linley, 2008; Schok et al., 2008; Spiro, Schnurr, & Aldwin, 1999). By oscillating

between reforming a sense of safety, processing and resolving traumatic memories, and applying adaptive schematic definitions to self, others, and the world, individuals come to experience positive change (Courtois & Ford, 2013). As a result, individuals are able to gain strength and wisdom from their traumatic experiences (Joseph, 2011; Tedeschi & Calhoun, 2004; Werdel & Wicks, 2012). Indeed, positive change is experienced by 30% to 70% of individuals following trauma, especially those with personality traits of optimism, extraversion, positive emotions, social support, and coping strategies of problem solving, acceptance, and positive reinterpretation (Linley & Joseph, 2004).

Table 6
Constructs and underlying theories in this thesis

Construct	Theoretical definition	Underlying theory
Dementia	Dementia is a hypernym to describe sets of disease symptoms for terminal chronic conditions that: (a) progressively impair brain functioning; (b) represent the dynamic interplay between biological, psychological, and social aspects of disease; and (c) reflect the individual's responses to living with dementia and their reactions to views and treatment (APA, 2013; Downs et al., 2006; Draper, 2011; Sabat et al., 2004; WHO, 2015).	Biopsychosocial model of disease (WHO, 2002)
Awareness	A purposeful response to a specific aspect of one's situation, functioning, or performance conveyed through speech, behaviour and emotion (Clare et al., 2011).	Levels of Awareness framework (Clare et al. 2011)
Selfhood	Multiple manifestations of identity that encompass: (1) 'self' reflecting one's unique view of the world, attitudes, beliefs and experiences. It is expressed through first-person pronouns and observed when an individual seeks protection or responds to their name; (2) 'self' encompassing one's past and current physical/psychological attributes, and one's beliefs about these. Reactions and responses, negative or positive, reveal this self; and (3) 'self' encompassing personas manifest through others (Sabat & Collins, 1999).	Socio-biographical theory of self (Sabat & Collins, 1999).
Personhood	"A person standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997, p 8).	Person-centred dementia care (Kitwood, 1997)
Social Positioning	Being occupied by or involved in interpersonal interactions, in which one's social behaviour is positioned relative to social attributes, and explained in light of one's life story and others' expectations (van Lagenhove & Harré, 1999; Taner & Swets, 1954).	Positioning theory (van Lagenhove & Harré, 1999)

Table 6 (Continued)
Constructs and underlying theories in this thesis

Stigma	An attribute that is deeply discrediting whereby individuals become seen as shamefully different, devalued, and depersonalised. This can become a self-fulfilling prophecy (Goffman, 1963).	Stigma (Goffman, 1963)
Courtesy stigma	Societal stigma that transfers to an individual through their affiliation with a stigmatised individual, rather than any discrediting characteristic of their own (Goffman, 1963).	Courtesy stigma (Goffman, 1963)
Structural discrimination	The devaluation of treatment facilities for stigmatised diseases, and subsequent loss of status in staff by association with the facility (Link & Phelan, 2001; 2006).	Structural discrimination (Link & Phelan, 2001; 2006)
Ambiguous loss	Confusing losses experienced when a family member with dementia is physically present but psychosocially absent (Boss, 2004).	Ambiguous loss (Boss, 2004)
Anticipatory grief	A struggle to cope, let go, interact, hope, plan, and readjust social worlds in the context of ongoing and anticipated social and relational losses (Rando, 1986).	Anticipatory loss (Rando, 1986)
Disenfranchised grief	When mourners are denied the right to grieve or opportunities to receive support because their grief is underestimated or unacknowledged by significant others (Doka, 2002).	Disenfranchised grief (Doka, 2002)

Table 6 (Continued)
Constructs and underlying theories in this thesis

Anticipatory trauma	A constant state of anticipation, posited as the first stage of trauma, or the 'anticipation of trauma.	Anticipatory trauma (van der Kolk et al., 1996)
Complex trauma	Events experienced as directly threatening oneself, or events witnessed as directly threatening or profoundly affecting another, that recur over an extended time with cumulative impact on those experiencing or witnessing such events.	Complex trauma (Courtois & Ford, 2013)
Systemic trauma	Prolonged vicarious exposure and empathic caregiving for individuals experiencing adversity can generate traumatic responses in caregivers, leading to negative schematic views of self, others, and world (Figley, 1995; Saakvitne, et al., 1996). Efforts to avoid further distress and social withdrawal are common, but maladaptive forms of self-protection, because they inhibit help seeking, recovery, and growth (Figley, 1995).	Systemic Trauma (Figley, 1995)
Posttraumatic growth	The co-existence of and curvilinear relationship between growth and distress that is: (a) underpinned by a purposeful search for significance; (2) results in positive schematic change concerning self, others, and life philosophy; and (3) generates functioning that exceeds former levels (Joseph & Linley, 2005).	OVP (Joseph & Linley, 2005)

2.8 Chapter close

This literature review presented a critique of dementia and its impact from a biopsychosocial, historical, philosophical, and theoretical stance. It was particularly interested in literature that offered insight into relational and social engagement within families, or interventions that encouraged relational and social engagement for those with dementia across the stages of dementia. Relevant to this thesis, presented theories of wellbeing inform how individuals make sense of chronic and cumulative exposure to distress. Next, the researcher will present the philosophical and methodological objectives of this thesis.

CHAPTER 3 Methodology

3.0 Introduction

Ontologically, this qualitative thesis is a critical realist investigation. It is concerned with how individuals experience their world and how they make sense of that experience. Epistemologically, a hermeneutic and phenomenological stance allowed exploration of how the world is socially constructed, interpreted, and understood. The collection and analysis of data occurred in multiple ways. As such, this methodology chapter presents three sections, encompassing:

- Section 1: Ontology (the nature of the world);
- Section 2: Epistemology and philosophical concerns (how we can know about the world); and
- Section 3: Methodology and Method (data collection and its analysis).

Section 1:

3.1 Ontological concerns

Ontology concerns what there is to know in the world and the nature of truth (Harper & Thompson, 2012). Ontology spans a continuum of perspectives from those that are extremely objectivist (that seek to 'explain') to those that are extremely interpretivist (that seek to 'understand').

3.1.1 Objectivist ontology

Objectivism has dominated the study of psychology throughout the twentieth century. As an ontological approach, objectivism seeks to explain principles and

processes in the natural sciences. It is foundational upon ontological principles that purport:

- A single, uniform, and law-bound world of objects, events, and phenomena;
- Measurable and enduring events, such as thoughts, memories, and emotions that interact with each other in a determinate way. As such, the world: (1) mirrors reality; and (2) exists independently of human descriptions of the world (Smith, 2008).
- A straightforward relationship is purported to exist between objects, events, phenomena, and their human representation. Thus, “the external world itself determines absolutely the one and only correct view that can be taken of it, independent of the process or circumstances of viewing” (Kirk & Miller, 1986, p. 14).

When objectivist researchers attend to external reality, they consider only observable events and testable propositions to have a claim to truth (Popper, 1959). Objectivists underscore each experimental investigation with a hypothesis and model psychological processes to reveal causal relationships (Popper, 1959). Objectivists regard study findings to derive from existing knowledge and add to the sum-total of future knowledge (Ackroyd, 2004). Thus, science moves steadily towards an explanation of reality. Through a process of elimination, researchers adopting an objectivist stance seek to disconfirm existing theories and establish generalisable scientific laws. Quantitative methods include statistical analysis, structured interviews, questionnaires, randomised controlled trials, and systematic reviews.

3.1.2 Post-objectivist ontology

Researchers with a qualitative sensibility argue for a return to the origins of early twentieth century psychology, and philosophies that seek an understanding of

individual experience. As early as 1923 psychiatrist and philosopher Karl Jaspers questioned the attribution of causality ('erklären') in the natural sciences, versus the attainment of conceptual understanding ('verstehen') in the social sciences. According to 'verstehen', researchers achieve a conceptual understanding of phenomena when they 'go back to things themselves', and participants react and respond towards things according to the meaning those things hold for them (Weber, 1924). From a post-objectivist stance, an individual's thoughts and identity illuminate sociocultural meanings, and interpersonal engagement helps individuals interpret their identity (Mead, 1934). Thus, individuals can change through interpersonal engagement, and interpersonal engagement can change society (Mead, 1934).

By the mid-twentieth century, experimental approaches were criticised for their piecemeal rejection of false-hypotheses that impeded revolutionary leaps in science (Khun, 1962/1970). Comparatively, emerging interpretivist philosophies such as 'phenomenology' (Heidegger, 1927/1962; Husserl, 1952/1980; Merleau-Ponty, 1945/1962) allowed unanticipated themes to emerge during analysis. As a result, qualitative researchers argued that scientists faced with unsupportive evidence were inclined to blame experimental design or researcher skills, instead of rejecting a theory due to weak scientific evidence (Khun, 1962/1970). By focusing on group-level claims rather than substantive ideographic insights, it is argued that objectivism has impoverished our understanding of human experience (Smith, Harré, & Van Lagenhove, 1995; Smith, 2008).

3.1.3 Interpretivist ontology

An increasing focus on human endeavour in the natural sciences during the twentieth century has seen interpretivist research philosophies emerge. By exploring how individuals experience their world and how they make sense of their lived

experiences, interpretivism seeks to understand rather than predict causality. As such, there are no pre-existing hypotheses in interpretivist studies. From an interpretivist stance, research is conducted in natural settings where conditions develop, interact, and meaning unfolds in a dynamic way. Interpretivist research draws upon researcher reflexivity, which asks the researcher to reflect on the ways that their involvement with a study “influences, acts upon, and informs” the study (Nightingale & Cromby, 1992, p. 28). Reflexivity concerns the researcher’s awareness of co-constructed meanings that unfold during the research process, and the impossibility of remaining outside of one’s subject matter while conducting research (Nightingale & Cromby, 1992). This includes both ‘personal reflexivity’ by the researcher on their personal biases and preconceptions, and ‘epistemological reflection’ on how the research question, data collection, and analytic strategy could influence their understanding of the topic.

3.1.4 Dynamic between objectivism and interpretivism

Despite the contention that surrounds the extent to which human description of the world can approach an objective truth, both causal and constitutive accounts can give meaning to mental phenomena:

“Although statistical techniques of empirical studies can clarify findings across a large random sample, ideographic interpretations complete the story (Parker, 1999, pp. 83–84)”.

Thus, interpretivism can complement objectivist approaches with broader research questions, flexible data collection, and researcher engagement during analysis, especially when seeking to understand complex aspects of daily life (Joseph, Beer, Clarke, & Forman et al., 2009; Polkinghorne, 1983; Smith, 2011). Interpretivist approaches recognise participant’s self-determination to allow unexpected ideographic insights to emerge without generalisation of the unique relationship between

individuals and their world (Smith, 2011). In this thesis, the dissent between extreme objectivism (only one valid perspective for meaning making) and extreme interpretivism (perspectives are alien from each other) is surpassed to foster multiple ways of interpreting experience (Bernstein, 1983).

3.1.5 Critical relativism

Extremely interpretivist in its ontology, 'critical relativism' investigates multiple realities through a discursive construction of reality. Critical relativists seek to deconstruct expressions and conversations as a way of understanding social interactions (Foucault, 1972/2002). The discursive approach provides "a language for talking about, a way of representing the knowledge about, a particular topic at a particular historical moment ... Discourse is about the production of language ... since all social practices entail meaning and meanings shape and influence what we do, our conduct, and all practices have a discursive effect (Hall, 1992, p. 291). Thus, topics gain meaning by the language and actions that surround them, which creates opportunities for a future discourse to evolve with the authority to change social practices (Hall, 1992). From an extremely interpretivist stance, critical relativists consider all knowledge and moral concepts to be relative to a time and place. Relativist investigation focuses on what is directly available during research (e.g., dialogue) whereas abstract entities (e.g., underlying emotional states) are considered accessible through an inferential leap (Potter & Lopez, 2001).

3.1.6 Critical realism

From a moderate interpretivist stance, critical relativism is seen as socially restrictive and an impediment to further layers of interpretation. As an alternate paradigm, 'critical realism' assumes that what exists is not limited to sensory stimuli alone. Thus, critical realists also attend to individual experiences expressed through

speech, understanding, describing, interpretation, and meaning making. This involves the interpretation of phenomena, language systems, meaning systems, symbolism, and the interactions between them. From a critical realist perspective, participants are 'active agents' striving to make sense of their subjective experiences (Blaikie, 1991). Critical realists consider the interface between the natural and social worlds to be in a constant state of flux (Blaikie, 1991). Moreover, critical realists disregard the generalisation of findings to a wider population (Blaikie, 1991).

Section 2:

3.2 Epistemological and philosophical concerns

Epistemology concerns how we can know about the world and how close we can come to explaining or understanding the truth. Epistemologically, objectivism proposes that data mirrors reality, whereas interpretivist epistemologies explore multiple interpretations of the same observation. This thesis aligns with interpretivist ontology of 'critical realism', whereby participants' subjective experiences mediate their access to the world. The studies in this thesis draw upon phenomenology, underpinned by ideographic, symbolic interactionist, and hermeneutic paradigms, to describe how the world is socially constructed, interpreted, and understood (Blaikie, 2000).

3.2.1 Phenomenology and transcending knowledge

Phenomenology is a philosophical stance for studying how individuals interpret their world (Smith, Flowers, & Larkin, 2009). Phenomenologists seek to provide an in-depth way of investigating and comprehending participants' subjective experiences, by seeking to understand those things that matter most to individuals in their everyday life (Smith et al., 2009). During research, phenomenologists seek to remain open to all

possible meanings in the data, while concurrently limiting their personal biases and preconceptions.

Phenomenology evolved through two phases, first encompassing ‘transcendental phenomenology’ (Husserl, 1952/1980) and then ‘interpretive phenomenology’ (Heidegger, 1927/1962; Merleau-Ponty, 1945/1962). From an epistemological stance, transcendental phenomenology seeks to identify the essence of particular experiences through a process of methodological reductions (Husserl, 1952/1980). By returning to things themselves as experienced, transcendental phenomenologists seek to clarify ambiguous psychological concepts. Transcendental phenomenologists also argue that interpretation mediates experience of a world that exists independently of human consciousness. Therefore, the physical world is ultimately considered unknowable, because there is nothing more fundamental than human experience or ‘life-world’ (Husserl, 1952/1980).

Within this paradigm, ‘life-world’ consists of interrelated meanings that are greater than the sum of its parts. Therefore, subjective meaning making surpasses rule-bound causal variables as the key to understanding experience (Husserl, 1952/1980). From Husserl’s perspective, suspension or ‘bracketing’ of personal assumptions (e.g., history, context, and culture) can reveal the universal essence of a phenomenon as it presents itself to human consciousness. As a result, Husserl sought to ‘transcend’ everyday assumptions about phenomena.

3.2.2 Phenomenology and interpretation

Unlike Husserl, Heidegger (1927/1962) and Merleau-Ponty (1945/1962) did not seek to transcend everyday assumptions about phenomena, but rather understand the ‘assumed’ ways that individuals navigate their life-world. Accordingly, Heidegger (1927/1962) and Merleau-Ponty (1945/1962) were more concerned with interpreting

the uniqueness of individual experience than Husserl (1952/1980) who focused on the identification of essences (Spinelli, 2005).

From an interpretive phenomenological stance, individuals ('dasein' or 'there-being') are inherently involved in the world and social relationships (Heidegger, 1927/1962). As embodied beings in the world (Merleau-Ponty, 1945/1962), human relatedness with the world allows individuals to attach meaning to their lived experiences. This interpretive phenomenological emphasis on 'worldly', 'social directedness', and 'embodied' reinforces individuals as 'situated beings' or 'beings-in-the-world' (Spinelli, 2005). Therefore, individuals are a function of their relatedness with the world. As such, understanding the world is possible through an individual's interaction with the world and the meaning that they bring to their experiences (Heidegger, 1927/1962).

According to interpretive phenomenology, although an individual's experience of their life-world might be specific; all life-worlds are proposed to share common features of temporality, spatiality, subjective embodiment, intersubjectivity, selfhood, personal project, moodedness, and discursiveness (Ashworth, 2006; Chung & Ashworth, 2006). Individuals are considered to have the ability to imagine alternatives to current experience, and language is a tool for thought. However, from an interpersonal to political level, supportive social structures are required to help individuals exercise this freedom. However, interpretive phenomenologists did not regard reality as entirely relative to one's involvement with the world, for "what is real is not dependent on us, but the exact meaning and nature of reality is" (Larkin et al., 2006, p. 107).

Therefore, the core assumptions underlying the interpretive phenomenological paradigm include:

- The world requires pre-understanding of experience;

- The researcher draws out and engages with the subjective accounts of participants who are already immersed in a lingual, relational, cultural, and physical world;
- An ideographic approach promotes detailed focus on the particular;
- Experiences are not accessed directly from participant accounts, but through a process of intersubjective researcher-participant meaning making; and
- Researchers cannot escape interpretation, yet they can engage in personal and epistemological reflexivity. The researcher can critically examine their typical ways of knowing when they bracket their own experiences and assumptions to engage with another's experience. When the researcher continually returns to meaning making and repeatedly brackets their biases and preconceptions, they can deliver interrogative and reflexive analysis (Larkin & Thompson, 2012).

3.2.3 Phenomenology and hermeneutic enquiry

Hermeneutic enquiry refers to a process whereby individuals bring subjective meaning to their experiences to transform the 'novel' into the 'familiar' (Heidegger, 1927/1962; Merleau-Ponty, 1945/1962). Meaning making encompasses our way of being in the world (e.g., walking), our interaction with objects (e.g., walking frames), and includes communication (e.g., storytelling). Communication captures the performance between speaker and listener (e.g., speech, body gestures, facial expressions, and vocalisations) and emerges from the sociocultural practices that shape human interaction. Thoughts, emotions and behaviour are able to find expression during communication, but as communication occurs at a particular time and place, such displays cannot represent the 'absolute truth' (Gergen, 2001). Therefore, from a hermeneutic stance, individual aspects of communication do not have meaning in

themselves. Instead, meaning derives from context. As a result, observable associations are considered just as meaningful as silence and missing behaviours. Finally, engaging in hermeneutic enquiry occurs through communication, as communication is the foremost way of constructing meaning.

3.2.4 Hermeneutic circles

According to Heidegger (1927/1962), human existence and everyday interaction occurs without deliberation, and requires no mindful awareness or preparation. Indeed, Heidegger argued that human existence is 'being-in-the-world'. However, to make sense of a situation, we already need to be able to manage the situation and see it as a specific situation. Thus, prerequisites and preconceptions stemming from our knowledge of managing situations allows interpretation without interpretation starting afresh each time. However, this delivers a 'hermeneutic circle' whereby we are only able to understand if we already understand. Nevertheless, a hermeneutic circle is not a vicious circle. While prerequisites and preconceptions enable interpretation, further interpretation refines our preconceptions and understanding of prerequisites. Therefore, to handle ongoing situations, individuals are continually involved in efforts to interpret and make sense of their world.

3.2.5 Contextual and co-constructed meaning

According to critical realism, it is impossible for an objective outer-reality independent of our descriptions to exist. Critical realists consider knowledge to form through the meaning that individuals attribute to experiences when they are involved, implanted, and immersed in the everyday world (Heidegger, 1927/1962; Shotter & Gergen, 1989):

"It is ourselves who give meaning to the world that we inhabit; we construct our world as we live in it" (Bracken, 2002, p. 88; Heidegger, 1927/1962).

Thus, critical realists make a constitutive claim rather than a causal claim about psychological phenomena. They consider phenomenological experiences to exist in reactions and responses rather than semi-permanent mental entities (Harré & Gillett, 1994, p. 22). As such: (1) meaning makes sense to those involved in the context of the social actions they generate; (2) interactions are situated constructions, unique to a time and place; and (3) the mind represents a privatised part of the overall interaction in which meaning is co-constructed and contextual (Edwards & Potter, 1992; Sabat & Harré, 1994).

Therefore, from a critical realist stance, meaning is inherently shareable rather than an internal state of mind. A shared view of the mind embeds meaning in both the 'public world' and everyday interactions. In terms of dementia care, a shared view of the mind encourages individualised and interpretational approaches to care, rather than a symptom-focused view of deficits (Kitwood, 1997; Sabat, 2001). Furthermore, it encourages each interlocutor to become involved in the 'co-creation' of meaning rather than the 'detection' of meaning (Hughes, Louw, & Sabat, 2006).

As such, co-construction of meaning does not require interlocutors to share an equal load in maintaining the conversation. One can compensate for the other. By considering meaning as something that is both 'outer' and 'public', critical realism avoids the problematic connections of inner states to the outer world, and private meaning to public meaning (Harré & Gillett, 1994). Thus, critical realism avoids concerns regarding the existence of private meanings and internal psychological phenomena in individuals living with dementia. As such, critical realism overcomes a traditional Cartesian view of the mind, as a self-contained 'inner-world' that exists independently of the 'outer-world' (Descartes 1596–1650).

3.2.6 Hermeneutic breakdowns

A 'hermeneutic breakdown' occurs when 'horizons' or viewpoints diverge between individuals (Heidegger, 1927/1962). In particular, dementia threatens the hermeneutic process of meaning making (Widdershoven & Berghmans, 2006). Objects and individuals, as part of a self-evident whole of reactions and responses, may no longer make sense to the person with dementia, and their reactions and responses to hermeneutic breakdowns may leave others feeling puzzled or even frustrated (Widdershoven & Berghmans, 2006). This is likely to represent a distressing loss to each of the individuals engaged in that interaction (Widdershoven & Berghmans, 2006).

While hermeneutic breakdowns can generate a sense of crisis, they can also deliver opportunities for revolutionary leaps in understanding (Khun, 1962/1970). As a result, the challenge for family members is to reintegrate perspectives 'creatively' without abandoning preconceptions for understanding (Heidegger 1927/1962). This is possible when family members are able to change familiar ways of interacting and invite new ways of handling situations. For example, 'ritualised play' involving shared activities such as creative arts activities and interpersonal engagement, facilitates reintegration because it involves conventions that allow individuals to reorient within a common world (Gadamer, 1960/2013). This can be further supported when the unique horizons of individuals are able to meet and merge through: (1) an understanding that others hold unique views; (2) a willingness to move beyond self-absorption towards common ground; and (3) attractive requests to enter another's horizon that are polite and honourable rather than offhand or enforced (Gadamer, 1960/2013). In illustrating this concept, "to reach an understanding in a dialogue is not merely a matter of asserting one's own point of view, but a change into a communion in which one does not remain what one was" (Gadamer, 1960/2013, p. 379).

Section 3:

3.3 Methodology and Method

3.3.1 Participants

In this thesis, 52 participants represented a *triad of relational and social dementia expertise* of individuals living in the mild to profound stages of dementia, their family members, and supportive health care managers. As the overarching phenomenological enquiry of this thesis, this triad formed a purposive sample of participants for whom the research topic held personal significance (Smith & Osborn, 2008). As such, the researcher sought a purposive sample for detailed insights on the experiences of a particular group of individuals rather than general insights on all individuals in a similar situation (Harper & Thompson, 2012).

Following ethics approval, the directors of aged care services at participating care homes invited family caregivers with guardianship status to participate. Criterion for inclusion was an in-resident family member with mild, moderate, severe, or profound dementia, as assessed by the directors using the Clinical Dementia Rating (CDR) Scale (Morris, 1993). In addition, the primary researcher invited interdisciplinary health care managers from religious and community organisations, private-for-profit establishments, and state government facilities to participate. The participating health care managers supported staff, residents, and family members on a daily basis. The researcher sought the experiences of managers rather than assistants due to their overarching view of the dementia care hierarchy, inclusive of other practitioners, staff, patients/residents, and families. Furthermore, with a career in dementia care spanning nine to 19 years, these health care managers could access lived experiences over an extended period, in both a professional and personal context. For demographics, see tables 7 and 8.

Table 7
Family groups at the time of data gathering

Resident, age (years), stage of dementia	Visitor/s, age (years), relationship	Caregiving (years)
Jack, 96, mild	Linda, 67, Daughter Stephen, 52, Son	3
Rose, 83, mild	Gail, 55, Daughter	6
Frank, 82, mild	Danielle, 42, Daughter	10
Jessie, 73, mild	Kym, 52, Daughter Craig, 56, Son-in-law	12
Edith, 93, moderate	Janet, 54, Daughter Becky, 23, Grand-daughter	4
Ruth, 76, moderate	Lori, 51, Daughter Kaye, 49, Daughter	7
Phyllis, 80, moderate	Bob, 80, Husband	7
Alice, 84, moderate	Lucy, 61, Daughter	7
David, 76, moderate	Julie, 65, Wife	9
Don, 70, severe	Joan, 70, Wife	4
Ross, 72, severe	Dawn, 71, Wife Lisa, 48, Daughter	4
Harry, 84, severe	Joy, 80, Wife	4
Esther, 80, severe	Cathy, 57, Daughter Diane, 53, Daughter Megan, 27, Grand-daughter Kayla, 26, Grand-daughter	5
Ron, 84, severe	Betty, 76, Wife	5
Pam, 74, severe	Doug, 77, Husband Tracy, 51, Daughter	6
Helen, 96, profound	Gary, 72, Son Susan, 64, Daughter-in-law	10
Deborah, 69, profound	Richard, 72, Husband	10

Table 8
Health care managers at the time of data gathering

Manager, age (years)	Work role	Overall career / Dementia care (years)
Cheryl, 59	Director of Aged Care Services, Care home	42 / 19
Carol, 59	Director of Aged Care Services, Care home	35 / 10
Sandra, 59	Director of Aged Care Services, Care home	41 / 10
Gillian, 60	Director of Aged Care Services, Care home	40 / 9
Stephen, 55	Aged Care Chaplain, Care home	22 / 8
Peter, 51	General Practitioner, Palliative care	28 / 12
Linda, 48	Nurse Unit Manager, Inpatient dementia care	14 / 12
Kelly, 48	Regional Manager, Community organisation	30 / 10

3.3.2 Data collection and analytic procedures

Family caregivers participated in individual, triad, or focus group interviews and health care managers completed individual interviews. Video-recorded observations were conducted with family groups, inclusive of a member in the moderate or severe stages of dementia. IPA and Thematic Analysis were combined in this thesis. IPA informed the semi-structured interviews, transcription, and analysis of interview data, and Thematic Analysis informed the transcription and analysis of data gathered from the video-recorded observations (see Table 9, p. 118, and Table 10, p. 121: Braun & Clarke, 2006; Palmer, Larkin, De Visser, & Fadden et al., 2010; Smith et al., 2009). Guidelines for video recording as a method of participant observation were followed from Latvala, Voukila-Oikkonen, and Janhonen (2000).

IPA and Thematic Analysis were combined because although IPA required the a 'double hermeneutic' process of meaning making (whereby the interviewer seeks to make sense of the participant's experience or help participants bring meaning to their experience, Smith, 1996), Thematic Analysis was unencumbered by this requirement (Braun & Clarke, 2006). Indeed, a 'double hermeneutic' process of meaning making was only possible during interviews, therefore the researcher used IPA to analyse the interview data (Smith, 1996), whereas Thematic Analysis allowed a more flexible approach for understanding the video-recorded observational data (Fereday & Muir-Cochrane, 2006; Joffe, 2012). Both IPA and Thematic Analysis allowed the researcher to capture the idiosyncratic nature of each participant's phenomenology and explore latent patterns of meaning in their interpreted experiences (Braun & Clarke, 2006; Smith, 1996; Willig, 2013).

3.3.2.1 Interviews

According to the literature, some participants find interviews intensive and intrusive, whereas others feel secure due to relative privacy (Frith & Gleeson, 2004; Yardley, 2008). Consistent with this view, small group interviews involving fewer than six participants can encourage participant reflexivity and disclosure, even when the research topic is of a sensitive nature (Farquhar & Das, 1999; Flowers, Knussen, & Duncan, 2001; Frith, 2000; Wilkinson, 2008; Willig, 2013). Moreover, analysis of group interactions during focus group or triad interviews (e.g., when participants closed or expanded conversational threads, justified responses or persuaded others) can reveal unexpected social norms and cultural views (Willig, 2013).

Although IPA does not prescribe a single process, it follows an iterative and inductive cycle of analysis (Smith, 1996). When using IPA, the researcher was challenged to provide interpretation rather than description, and to illuminate patterns of shared meaning rather than specific insights (Reid, Flowers, & Larkin, 2005; Smith, 2007). This required the researcher to set aside his personal biases and preconceptions to avoid eclipsing the data (Smith, 1996). However, it is impossible to bracket every bias and preconception because subjectivity is accessed for interpretive analysis (Heidegger, 1927/1962).

3.3.2.1.1 INTERVIEW DATA COLLECTION

To collect the interview data, the researcher first emailed the participants detailed information about the study, following their verbal consent to participate. Twenty-four hours before the interview he emailed participants a copy of the semi-structured interview to encourage their engagement with the research topic of interest (Smith, 1996). The researcher before each interview collected signed participant consent-forms. Interviews, including the focus-group, were held in a private room at participating

facilities, at a time convenient for all. Participants provided demographic information, and the interviews inclusive of the focus-group interview lasted from 45 minutes to 2 hours each. All interviews were digitally recorded.

The use of semi-structured questioning allowed participants to respond flexibly to a brief set of questions that ‘funnelled’ down to the topic of interest (Smith & Osborn, 2008). For a copy of the interview schedule for family members, see Appendix 4, p. 339 of this thesis. A funnel approach to interview design refers to starting with broad questions that increasingly narrow in topic area towards the research topic of interest (Smith & Osborne, 2008). Therefore, sensitive topics are left towards the end of the interview, and the researcher is able to capture both broad views and concerns specific to the topic of interest (Smith & Osborne, 2008). By adopting a funnel approach, the researcher avoids gathering data that is biased in the direction of his or her specific concerns (Smith & Osborne, 2008). In this thesis, interview questions followed a sequence of: (1) researcher and participant introductions, and discussion of the research purpose, use of audio/video recording, anonymity, and the voluntary nature of participation; (2) demographic information and broad experiences; and (3) specific reactions and responses in relation to the research area of interest. By adopting a flexible approach to questioning, the researcher could engage participants in double hermeneutic process of meaning making (Heidegger, 1927/1962). Following the interviews, the researcher transcribed the interview recordings verbatim. The interview transcripts were then filed electronically to form the data set.

3.3.2.1.2 INTERVIEW DATA ANALYSIS USING IPA

To analyse the interview transcripts using IPA, the researcher read and re-read each transcript line-by-line, to identify the experiential claims, concerns, and understandings of participants. Next, he summarised specific insights, sorting them into

convergent and divergent patterns of shared meaning (Reid et al., 2005; Smith, 2007). To go beyond description of the findings to interpretation, the researcher explored the following domains: (1) positionality; encompassing the stance of self-as-researcher (permissions, encouragements, and redirections) and the intention behind participant statements; (2) the roles and relationships, organisations and systems described by participants and the meanings, expectations, and consequences they attached to these; (3) how participants supported or impeded each other to share stories; and (4) language and the context in which it was used (e.g., metaphors, stand-out words and phrases, repetition, jargon, turn-taking, and emotive language). In particular, the researcher sought to understand how and why language was used (e.g., whether to emphasise, shock, lighten the mood, or provoke argument).

This analysis helped the researcher validate emergent themes that he continued to refine through an iterative and inductive cycle of revisiting the data, reinterpreting, and revalidating themes. In IPA, there is no clear distinction between analysis and write up (Smith, 1996). Therefore, in writing up the results, some themes fade and others become more evident. As a result, presented themes were chosen because they were strongly evidenced by participant material that illuminated the research topic of interest. Conversely, themes were rejected when they were unsupported by the data. In concluding the analytical process, the researcher presented an interpretive narrative for the reader with rich extracts grounded in the data. As such, he sought to present an account of the data and establish meaning (Smith et al., 2009).

Table 9
Analytical process for IPA for interviews (Palmer et al., 2010; Smith et al., 2009)

Stage	Process
1	Bracket personal biases and preconceptions that could influence interpretation of the data.
2	Establish an audit-trail of the data, so that interpretations can be traced from initial themes to the final thematic narrative.
3	Line-by-line reading of the data to select experiential claims, concerns and understandings of individual participants.
4	Identification of the emergent thematic patterns, noting convergence and divergence.
5	Cross-referencing of emergent themes with psychological and theoretical knowledge and analysis of 'positionality', 'roles and relationships', 'organisations and systems', 'stories', 'language and its context' to interpret participant meaning.
6	Generating an illustrative structural-map of themes.
7	Completing an independent audit of the data with consensus reached through robust debate.
8	Engaging in an iterative and inductive cycle of continually returning to the data and revising interpretation.
9	Developing a narrative, with vivid extracts grounded in the data, to take the reader through a convincing interpretation theme-by-theme.

3.3.2.2 Video-recorded observations

The making of video recorded observations, and analysis, presented a novel research method. It was chosen because other research methods, such as speech-based and self-report assessments, exclude full participation by individuals living with dementia (Clare, Marková, Verhey, & Kenny, 2005). In using video recording as a method of observation, the researcher sought to capture detailed and precise observations of: (a) levels and expressions of retained awareness in the speech, voice, facial expressions, and body gestures of participants with dementia; and (2) reciprocal communication patterns between family members, inclusive of those with dementia (Walmsley & McCormack, 2014).

Each family group in this Doctoral thesis were video-recorded during two 15-minute visits to a member living in care. These brief observations provided rich data without tiring participants (see Walmsley & McCormack, 2014). Completing multiple

video-recordings accommodated the fluctuating nature of awareness in participants with dementia (Clare, 2010; Walmsley & McCormack, 2014, 2016b). The data from video-recorded observations offered density for the researcher to observe the data as often as required, frame-by-frame, in slow motion, forwards, or backwards (Latvala et al., 2000). This contributed to both the credibility and depth of phenomenological knowledge gained from this research method.

3.3.2.2.1 VIDEO DATA COLLECTION

The process for collecting the video data involved the researcher emailing detailed information about the study to family members with guardianship status, who had provided verbal consent to participate to the directors of aged care services. On the day of video-recording: (1) the researcher spoke with the directors of aged care services and other care home staff to inform them that specific family groups were being video-recorded that day; (2) spent time talking with family members to put them at ease with the video-recording process. This involved researcher and participant introductions and discussion of the research purpose, use of video recording, anonymity, and the voluntary nature of participation; and (3) collected signed consent forms and demographic information from the participants with guardianship status.

The video recording of family interactions was conducted in the private room of resident family members, at a time convenient to all. The camera-recorder was placed unobtrusively on bedroom furniture or a tray table at a height and angle to capture the family group interacting. Furthermore, by setting the camera-recorder to run, video recording remained as unobtrusive as possible, to minimise participant staging and anxiety (Götell et al., 2009; Latvala et al., 2000; Walmsley & McCormack, 2014, 2016b). During video recording, the researcher waited in the lounge area of the care home and timed the length of video recording. After 15 minutes, the researcher knocked and

entered the room to switch-off the camera-recorder and thank the family group. Following video recording, the recordings were downloaded onto a secure computer file. Then, the researcher began the process of watching and re-watching the video-recordings to transcribe the speech, voice, facial expressions, and body gestures of all family members, sequence-by-sequence and verbatim.

3.3.2.2.2 THEMATIC ANALYSIS FOR VIDEO DATA OBSERVATIONS

To analyse the video recorded data using Thematic Analysis (Braun & Clarke, 2006), the researcher read and re-read each transcript and viewed and re-viewed the corresponding video-recorded observation to identify: (1) levels and expressions of retained awareness in the speech, voice, facial expressions, and body gestures of the participants with dementia; and (2) the reciprocal communication patterns between family members, inclusive of those with dementia (see Walmsley & McCormack, 2014). This involved watching the family interactions as often as required, frame-by-frame, in slow motion, forwards, or backwards, and transcribing the speech, voice, facial expressions, and body gestures of all family members, including those with dementia.

Next, the researcher summarised specific observations, sorting them into a thematic map of convergent and divergent patterns of shared meaning (Braun & Clarke, 2006). To interpret the findings rather than describe them, the researcher explored the following domains: (1) positionality between family members, including the intention of interactions; (2) how participants understood and described roles and relationships, organisations and systems; (3) how family members supported or stopped each other from interacting; and (4) speech, facial expressions and body gestures and the context in which they were expressed, to understand how and why these family members interacted.

Then, the researcher pursued an iterative and inductive cycle of revisiting the data to reinterpret and revalidate themes. In writing up the results, analysis continued, with some themes diminishing and others becoming more evident. Chosen themes were supported by participant material that revealed the research topic. Conversely, rejected themes were unsupported by the data. Finally, the researcher provided the reader with an interpretive and meaningful account of the data, with themes supported by rich extracts from the data (Braun & Clarke, 2006).

Table 10

A process for Thematic Analysis for video-recorded observations (Braun & Clarke, 2006)

Stage	Process
1	Set aside biases and preconceptions relating to the research phenomenon and literature.
2	View the videos and read the transcripts several times each, for note making and a sense of the participants' levels and expressions of awareness.
3	View the videos and read the transcripts again, to develop initial psychological concepts.
4	Cluster the psychological concepts into themes and subthemes, while retaining the participant's authentic speech and non-speech expressions.
5	Generate a thematic map of themes and subthemes.
6	Refine the essence of each theme, noting convergence and divergence across the data set.
7	Support the themes with rich extracts from the data. Interpret extracts in the context of the research phenomenon and literature.
8	Complete an independent audit of the data with consensus reached through robust debate.
9	Pursue an iterative and inductive cycle of returning to the data to reinterpret and revise themes.
10	Develop a narrative, with vivid extracts grounded in the data, to take the reader through a convincing thematic interpretation.

3.3.2.2.3 PRACTICAL AND ETHICAL IMPLICATIONS FOR VIDEO AND ITS ANALYSIS

The making of video recordings of highly personal family interactions, and analysis, presented complex ethical issues. As a result, to justify the intrusion on participant privacy versus the need to preserve it, the researcher explored the practical

and ethical implications for participants relating to: (1) privacy; (2) informed consent; and (3) self-efficacy (Latvala, Janhonen, & Moring, 1998).

First, to protect the privacy of participants, video recording took place in the private room of resident family members, and the camera-recorder was set to run. As such, family interactions were not influenced by the presence of researchers, care home staff, other visitors, or residents (Latvala et al., 2000). Moreover, the subsequent video files and transcripts were then stored securely in a password-protected computer folder, and a locked filing cabinet in the primary supervisor's office at the University of Newcastle. Only the researcher and primary supervisor were allowed to review the video recordings and transcripts. Furthermore, pseudonyms were used throughout the transcriptions to protect the privacy of participants. Second, regarding informed consent, consent-by-proxy was sought for those family members living with dementia or aged younger than 18 years old. In those situations, a relative with guardian status provided consent for those family members. Third, in relation to self-efficacy, the study participants volunteered for this study, understood the purpose of the study, and could withdraw from the study at any time without repercussion. Similarly, family members with guardianship status were encouraged to discuss the purpose of the study with family members who were unable to give direct consent. Guardians could also withdraw that family member from the study at any time, without penalty. Therefore, because of these practical and ethical precautions, the researcher could justify the intrusion on participant privacy versus the need to protect it.

3.3.3 Data quality

Qualitative research represents a shift away from measurement, causation, and statistical analysis towards understanding, meaning, and interpretation (Smith et al., 1995). Therefore, this phenomenological interpretative thesis did not seek causal

evidence or inter-rater reliability (Yardley, 2008). Instead, every attempt was made by the researcher to: (1) identify his personal perspective and how this could have influenced the data (see Section 3.3.31 below); and (2) externalise his biases and preconceptions through reflexivity (Smith, 1996). Independent auditing and an audit trail brought further credibility to this study (Smith, 1996). Moreover, the multi-angled perspectives of the *triad of relational and social dementia expertise* lent support to interpretation.

Therefore, a range of quality measures was applied throughout the research process to verify trustworthiness during the course of investigation (Guba & Lincoln, 1981). In support of this, the researcher remained flexible and responsive to change during the research process (Guba & Lincoln, 1981). In addition, the researcher and primary supervisor engaged in weekly supervision during completion of this thesis, to continually check on biases and preconceptions that could otherwise overshadow the data.

3.3.3.1 The researcher's perspective and their reflective journal

Qualitative analysis is necessarily influenced by what researchers bring to interpretation, despite making every attempt to remain neutral around values and assumptions. In the past decade, the researcher has worked as a clinical psychologist providing specialist mental health services for older people and their family members. He has conducted dementia research as part of a Master's degree. In particular, his mother lived with dementia. Those experiences led to the researcher to question whether people living with dementia are more aware than otherwise assumed, and whether despite the distress of secondary exposure to health adversities, many individuals do not develop psychopathology. Finally, he considered whether the

individual meaning brought to their experiences facilitated their positive adaptation and personal growth.

To set aside his personal biases and preconceptions, the researcher kept a reflective journal. By engaging in critical reflection, the researcher sought to bring transparency to the research process. In this journal, the researcher documented his biases, preconceptions, choices, behaviour, and experiences during the research process. In doing so, the researcher sought to understand how his personal and professional experiences had influenced his chosen research interests, methods, and portrayal of the research findings (Harrison, MacGibbon, & Morton, 2001). Throughout this process, the researcher was challenged to reflect on: (1) why this topic was of interest to him; (2) what personal investments drove that interest; and (3) what expectations the researcher held in regards to outcomes and hypotheses that could influence his collection of data and its analysis (see the Preface of this thesis).

For the researcher, ongoing critical reflection led him to revisit and revise the research process, and chart his self-development as a researcher. For example, he noted that during his early interviews he found it hard to maintain a non-reciprocal person-centred stance during his sense making of the participants' lived expertise and their interpretations of the research topic. As such, the researcher found himself seeking to impose his biases and preconceptions on participants or his analysis of the observational data. Further, he noted that he offered advice, overrode silences, and shut down threads of conversation or emotions in interviewees. Subsequently, he found that his anxiety as researcher transferred to interviewees, contributing to missed opportunities for double hermeneutic dialogue.

3.3.3.2 Independent Audit

Through an independent audit, the researcher aimed to deliver one account of the data that systematically achieved internal coherence and presentation of evidence (Smith, Michie, Stephenson, & Quarrell et al., 2002; Spencer & Ritchie, 2012; Yardley, 2008). To achieve this, he completed an initial thematic audit of the data, while the primary supervisor independently analysed the data. The researcher then met with the primary supervisor to discuss and debate independent interpretations, arriving at evident and agreed themes supported by extracts. Although the researcher collected and transcribed the data, the independent auditor did not enter into discussion with him about his experiences during the interviews or video-recorded observations. Therefore, it was only at the point of independent auditing that discussion between the researcher and primary supervisor took place. Using a primary supervisor who was experienced in IPA ensured that data quality and analytic processes had not been breached. It also ensured that the data spoke for itself.

3.3.3.3 Audit Trail

A supporting audit trail provided evidence of the sequential rigour involved in linking the data with the study findings (Flick, 2015; Smith et al., 2002; Spencer & Ritchie, 2012; Yardley, 2008). The audit trail encompassed digital recordings, transcripts, independent descriptions of theme development, and the preliminary and final thematic definitions substantiated by data extracts, notes, and diagrams. Rich data extracts that depicted the agreed themes were included in the final study to demonstrate that the results linked to the data. Ties to existing theoretical constructs provided evidence of deductive rigour (Braun & Clarke, 2006; Smith & Osborn, 2008).

3.3.3.4 Method and data source triangulation

In this thesis, method and data source triangulation enriched the findings by exploring the research topic from different angles (Burck, 2005; Flick, 2015; Frost, 2008; Starks & Brown-Trinidad, 2007). Although the interpretation of responses, and responses and awareness in participants with dementia, were challenging aspects of this thesis, the responses of visiting family members lent support to interpretation. Despite the researcher being unable to engage participants in double hermeneutic process of meaning making during the video-recorded observations, the interviews encouraged reflexive meaning making between researcher and participant (see Heidegger, 1927/1962). Furthermore, what participants' experienced, and how they brought meaning to those experiences offered a qualitatively different perspective on a complex and sensitive topic, despite potential biases in participant memory, perception, and recall.

Similarly, by gathering data at different types of institutions (religious and community organisations, private-for-profit establishments, and state government facilities) across three regions of southeast Australia the researcher sought to avoid the specific characteristics of any one setting influencing the data. Although he did not seek to generalise findings beyond the purposive sample, the emergent themes in the data set have the potential to contribute to theory. Finally, the study findings can inform hypothetical questioning in future quantitative research, to determine whether findings are generalisable.

3.3.4 Studies of this thesis

This thesis contains seven studies that connect the supporting, close-up, and contextual perspectives on relational and social engagement across a *triad of relational*

and social dementia expertise. The studies adopted the following data collection methods:

- Study 1: A focus group interview with family groups, each with ten years of experience supporting a family member with dementia (See Chapter 4);
- Study 2: Individual interviews with health care managers to explore a continuum of positive and negative interpretations related to their working within a systemic model of care in dementia (see Chapter 5);
- Study 3: Individual interviews with health care managers to seek their subjective insights from witnessing the impact of dementia on family relationships (see Chapter 5);
- Study 4: Multiple video-recordings of family visits, inclusive of a family member with moderate dementia, to observe and describe the explicit patterns of retained interpersonal awareness and social engagement during the moderate stage of dementia (see Chapter 6);
- Study 5: Multiple video-recordings of family visits, inclusive of a family member with severe dementia, to observe and describe the explicit patterns of retained interpersonal awareness and social engagement during the severe stage of dementia (see Chapter 6);
- Study 6: Individual, triad, and multiple interviews with family caregivers to explore a continuum of positive and negative interpreted experiences when supporting a family member with dementia prior to and during admission to a care home within a western health care system (see Chapter 7); and
- Study 7: Individual, triad, and group interviews with family caregivers to seek their subjective insights and meaning making regarding the psychosocial

impacts of dementia on the individual caregiver and family relationships (see Chapter 7).

These studies are now presented by the researcher throughout the following chapters 4, 5, 6, and 7.

CHAPTER 4 Pilot Study with Family Caregivers

Synthesis of meaning: Negative and positive change in family members following the adversity of dementia

4.0 Introduction

Cumulative upon the distress of diagnosis and the transitional distress of relinquishing home care, it is possible that family caregivers experience events while supporting a family member who has dementia, that precipitate primary, vicarious, and even anticipatory grief and traumatic responses as they strive to make sense of the condition known as dementia. However, despite experienced distress, research that has grown out of the positive psychology movement reveals that individuals can experience psychological growth over time. Nevertheless, few studies have sought the perspectives of family caregivers to explore whether they perceive positive and negative psychosocial impacts of living alongside a family member who has dementia, especially as it affects family relationships. Furthermore, little is known of the concerns of families trying to make sense of dementia and the hierarchical health care system in which dementia care is positioned.

Following my Clinical Masters' thesis, a study on reciprocal family interactions when living with profound dementia (see Walmsley & McCormack, 2014), the researcher now presents a pilot study seeking the subjective interpretations of those

same family members regarding their dementia experience. In particular, he was interested in positive as well as negative sense making of their dementia experiences. Therefore, this chapter presents a qualitative study seeking the subjective interpretations of family caregivers as they experience: (1) the fluctuating psychosocial landscape of dementia pre and post aged-care; (2) perceived psychological consequences of supporting a family member with dementia; and (3) transition to, and navigation of a hierarchical health care system. By choosing a qualitative method this pilot study aimed to supplement objectivist investigations, by contributing to theory concerning interpersonal awareness and engagement in dementia, particularly as they affect family caregiving and dynamics.

4.1 Method

4.1.1 Participants

Following university human ethics clearance, nine individuals (four family groups) who had consented to being involved in future research, were contacted from the pilot study conducted for my Master's degree (see Walmsley & McCormack, 2014), to participate in this focus group. Two of the family groups declined, and two family groups (three individuals) agreed to participate. See Table 11. The study used pseudonyms throughout.

Table 11
Family groups at the time of data gathering

Resident, age (years), stage of dementia	Visitor/s, age (years), relationship	Caregiving (years)
Helen, 96, profound	Gary, 72, Son	10
	Susan, 64, Daughter-in-law	
Deborah, 69, profound	Richard, 72, Husband	10

4.1.2 Procedure

The researcher conducted the focus group at a care home, at a time convenient to participants. The focus group lasted one hour and 50 minutes, and it was recorded digitally. For further detail on data collection and analysis using IPA, see sections 3.3.2.1.1 and 3.3.2.1.2, pp. 115-116 of this thesis. For a copy of the interview schedule used in this focus group, see Appendix 4, p. 339.

4.2 Results and Analysis

One superordinate theme: *Synthesis of Meaning* emerged from the data using Interpretative Phenomenological Analysis (IPA). This overarched two subordinate themes: (1) *Steps backward*; encompassing those times when relatives hovered uncertainly, missed opportunities to engage due to advancing dementia, and felt regret; (2) *Steps forward*; encompassing moments of unexpected rewards, acceptance, self-forgiveness, and empathic connection with others on a similar journey. These sub-themes represent the complexity of living with the impact of dementia as described by the participants. See Table 12 (Notations: Appendix 1).

Table 12

Superordinate theme: Synthesis of meaning, overarching sub-themes:

Steps backward: negative change for relatives characterised by anxiety, preoccupation with loss, and regret.

- *Helicopter supporters:* anxious relatives tended to hover overprotectively around a family member with dementia.
- *Missing out:* preoccupied with loss and grief, relatives missed opportunities to engage with the family member with dementia.
- *Regret:* described feelings of remorse concerning dementia care decisions and perceived inadequacy of care.

Steps forward: positive change for relatives characterised by acceptance, self-forgiveness, and empathic support of others.

- *Acceptance:* coming to terms with daily developments, relatives were able to cope more flexibly.
 - *Self-forgiveness:* as a caregiver, accepting efforts and intent helped resolve regrets.
 - *Unexpected rewards:* unexpected moments of interpersonal connection and positive relational change.
 - *Empathic insight:* reciprocal concern, compassion, and wisdom between families living with the impact of dementia.
-

4.2.1 Steps backward

Steps backward describes negative change characterised by family members struggling to keep pace with change in a family member with dementia. It describes how family members feel trapped in a process of engaging and disengaging unable to accept the unexpected impact of living alongside a family member with dementia. Discordant interactions and distress appear a necessary catalyst for meaning making and potentiate psychological growth. The sub-themes capturing the domains of *steps backward* include *helicopter supporters*, *missing out*, and *regret*.

4.2.1.1 Helicopter supporters

This subtheme describes shifting consciousness as family members try to make sense of what they are observing and begin to hover anxiously around a family member who has dementia. As the hovering increases, a game of hide and seek commences as the relative living with dementia tries to hide failing competencies and the family members

carry out risk assessments surreptitiously. Facing a decaying illusion of control both Susan and her father-in-law draw inevitably towards loss and change:

He'd have the house all nice ... but — towards the end ... we'd realised that the burnt curtains were because she'd put something on the stove and it had burnt (Susan).

Growing concern, even fear creeps into Gary's awareness of change in his mother:

I watched her attempt to wash the electric kettle — in the sink, still plugged in.
This is a worry (Gary).

Furthermore, Richard's hovering means that his life becomes subjugated to Deborah's every need. Thinking back, he recognises how guilt and discomfort led him to place his life on hold while he adjusted to life without Deborah at home:

If I had gone away for holidays [from Bangkok or somewhere or other] and I arrived back here at 11 o'clock ... I'd be in here for lunchtime (Richard).

Promises made in the early days overwhelm the participants as the years roll by. The enormity of the task of supporting a family member in a health care system leaves family members exhausted with their own lives on hold:

He promised Dad that we would look after Mum, that was no problem, but sometimes it gets a bit difficult (Susan). We've had an eleven-day break in seven years (Gary).

Recognised as counterproductive, the hovering eventually decreases. A relational turning point highlights how old conflicts can give way to new ways of communicating:

She knew that she was losing the ability to do things, and in my trying to help her, I was reminding her that she didn't have that ability, and she snapped, but after that there was never anything negative (Susan). No, she was good (Gary).

4.2.1.2 Missing out

This subtheme describes the loss and sadness as relational opportunities diminish as dementia advances. Less able to reciprocate and unable to comprehend the change in his grandmother, from a “very strong woman who played golf and ran the household”, Susan’s son Jason makes a hasty retreat:

Everybody came in, in their wedding gear to show her. ... he was so shocked. ...
he just said “Mum I can’t see her. I can’t see Nanna like that” (Susan).

Shattered expectations confront adult-grandchildren and adult-children:

She turned to him and said “Do you have any children?” and his face – just. ...
she didn’t connect those children with (him); that’s what broke his heart
(Susan).

And:

To see her mother walk in, in and not sort of interact and say “Oh wonderful”
you know “Who’s this baby”? [It] really hit home (Richard).

4.2.1.3 Regret

Feelings ranging from remorse to hurt embody this theme. Remorse is commonly expressed, as is guilt over broken promises when home care is eventually relinquished:

You’re going against a promise that you’ve made to this person, you just make
a rod for your own back, which makes it that much harder for you to
emotionally cope with what really is an extremely difficult situation (Richard).

Hurt is never far from these participants’ experiences:

She turned around to me and said to me “What are you doing here?” and I got
so upset and I walked off into another room (Susan).

However, redefining the experience of hurt positively assists the journey of support:

Don't take it personally. She's not reacting to you; she's reacting to inner turmoil and once I realised that that was right, I just went back and sat down beside her (Susan).

4.2.2 Steps forward

In contrast to *steps backward*, insightful moments of meaning making highlight positive change, as well as flexibility to change, as participants draw meaning from the impact of supporting a family member with dementia. Engaging and disengaging begins to be experienced more easily. Acceptance of the impact of living with dementia gives opportunities for psychological growth and reciprocal quality of life for all family members despite the inevitable outcome of dementia. The sub-themes capturing the domains of *steps forward* include *acceptance*, *self-forgiveness*, *unexpected rewards*, and *empathic insight*.

4.2.2.1 Acceptance

This subtheme reflects being-in-the-moment with whatever occurs daily while supporting a family member who has dementia. Attempts at persuasion begin to be seen as counterproductive. Desire for control gives way to new ways of interacting:

If she didn't want to cooperate, it was easier just to walk away, and give her space, and come back later (Susan).

Accepting repetitive conversation as a way of being connected maintains relationships:

Then he'd go through it all again (Gary). But, that's fine (Susan). It didn't matter (Gary). We don't put any pressure on him at all. We don't ask him questions (Susan).

This turning point in acceptance keeps family members connected:

We were just familiar faces, and that's a bit hard to, to come to terms with, but once you do ... then that's okay. ... we do know that we're important to her (Susan).

4.2.2.2 Self-forgiveness

Self-forgiveness brings resolution of regrets. Remaining connected as families supporting a family member who is diagnosed with dementia helps cohesion:

I don't think we could have done any more. I know there are residents here that never see anyone (Gary).

Similarly, accepting effort and intent rather than craving awareness and reciprocity allows past mistakes to be viewed more kindly:

I don't think it had any impact on her, and at the time you know I just thought I was doing the right thing (Richard).

Self-forgiveness allows Richard to live fully again:

Whereas now if I arrive back now at 11 o'clock and I've just had an overnight flight from Hong Kong... I think "stay home" (Richard).

4.2.2.3 Unexpected rewards.

This subtheme describes unexpected positive interactions and inter-relational moments that connect the family group despite the intrusion of dementia. Gratitude is seen emerging in the moment:

The children themselves, she interacted with exceptionally well. ... that's all they could remember of this lady. ... it was great! (Gary)

They also redefine dementia behaviours with historical meaning:

When younger children are around ... it boosts their whole life ... It's obviously a part of their life ... that stays there ... in some shape or form (Richard).

Because that was their life...They were the *stay at homes* (Susan).

Although Richard describes such interactions as a “pleasure for both them and me” it leads to mixed emotions for Susan:

(It’s) a really lovely thing, but it was — it is sad, that they don’t recognise their grandchildren (Susan).

Positively, memory loss also erases old conflict:

We didn’t get on well – she and I. ... but when she came here and into care we were the best of friends. ... I was a familiar face who would talk to her, and take her to things ... and suddenly I was her very best friend (Susan).

4.2.2.4 Empathic insight

This subtheme describes the reciprocity of empathic concern, compassion, and wisdom between families living with the impact of dementia.

It broke my heart because he feels that he’s being judged by people he knows, but we don’t, and it’s because we’ve lived with Mum (Susan).

Inner strengths are linked directly to living with the impact of dementia:

My ability to assess and accept the situation as it exists and respond to that — rather than wishing it didn’t happen or getting bogged down in thinking about what should have been and trying to correct it (Richard).

Reflexive dialogue illuminates compassion and understanding:

I mean that’s all it is! You really only have to listen! – But you listen in the context of knowing where they’re [families are] coming from (Richard).

It becomes apparent that living with the impact of dementia offers these participants the opportunity to become more compassionate individuals as they move away from struggling to hold on to past ways of being with their family member and project forward.

One of the things I do ... the Alzheimer's Association in the region here has a men's support group ... I've been coordinating that for now probably 10 years (Richard).

Richard's "satisfaction" at making "things easier for others in a similar situation" is described as offering the opportunity for growth and contribution resulting from their experiences. They find that they begin to see life differently as a direct consequence of having experienced a long journey with dementia:

Life is a circle. They look after us when we're small and we look after them as they get older. That has rattled around in my brain so often. ... and I'd think it's so different feeding a 12 month old baby than it is feeding a 90 year old woman ... but when I think about what he said, I think "Yes it is the natural order of things. This is okay" (Susan).

4.3 Discussion

This qualitative study has highlighted that despite the traumatic distress of living alongside a family member with dementia, psychological wellbeing and a positive redefinition of self in the world can emerge for family members. It also indicated that similar to many relational journeys, a process of engaging and disengaging occurs (Rando, 1986; Shuter et al., 2014). Consistent with this, at times of great distress, games of engaging and disengaging emerged for these participants. For example, a game of 'hide and seek' becomes apparent early on as the family member with dementia tried to hide failing competencies juxtaposed with family members carrying out risk

assessments surreptitiously. Ultimately, family members sought positives to facilitate personal growth in their own lives.

Findings from this study recognised that meaning making for these participants was an oscillating process seeking personal significance and comprehensibility in their current life (e.g., when relational interactions were dissonant, relatives hovered uncertainly, missed opportunities to engage due to the advancing nature of dementia, and felt regret). When relational interactions were positive and brought insight and meaning, participants experienced unexpected rewards, acceptance, self-forgiveness, and empathic connection with other families supporting a family member with dementia. Each family member struggled to make sense of their dementia experience in a unique way. Similarly, patterns of meaning making illuminated converging themes across the data set.

Various responses to distress were illuminated and supported Joseph and Linley's (2005) theories of individual differences in reactivity to traumatic distress. For example, Helen's decline in awareness and communication distressed Jason who expected his "very strong" grandmother to connect with him, and congratulate him on his wedding day. Surprisingly, the younger family members appeared confident of positive moment-to-moment experiences. As such, meaning making supported positive adaptation to adversity (Durkin & Joseph, 2009; Janoff-Bulman, 1992; Joseph & Linley, 2005; Lepore & Revenson, 2006; O'Leary & Ickovics, 1995; Smith et al. 2008).

Furthermore, psychological growth appeared to affect quality of care and quality of life positively. Individual coping styles in Gary, Susan, and Richard appeared to transform over time from that of a *helicopter supporter* to one characterised by *acceptance, self-forgiveness, and empathic insight*. A sense of *regret* and *missing out* paralleled awareness of *unexpected rewards* as their journey progressed. As

psychological growth took hold, family members increasingly found positive meaning in their adversity (Butler et al., 2005; Linley, Joseph, & Goodfellow, 2008). As such, Gary, Susan, and Richard appeared to adjust more flexibly to whatever occurred daily with fewer feelings of guilt, regret, worry, and disappointment.

In addition, pre-existing relational patterns continued to shape the lived experiences of family members in the early years. Past discord appeared to magnify distress in some family members. When support was offered, or rebuked, feelings of guilt surfaced in light of broken promises. However, over time new insights gave way to relational turning points (e.g., “suddenly I was her very best friend”) which allowed past discord an opportunity to exchange places with greater understanding and appreciation of self and others. From a hermeneutic perspective the challenge for family members was to reintegrate perspectives with their family member who had dementia without abandoning pre-dementia assumptions (for understanding requires pre-understanding; Heidegger 1927/1962).

In fact, new ways of communicating appeared to follow times when family supporters could disengage from the daily demands and distress of living alongside a family member who has dementia. These short breaks appeared to offer family supporters the time to face existential challenge and connect insights, reminding them of their autonomy and self-efficacy. Thus, they moved beyond self-absorption to reconsider mutual views and re-engage on common ground (Gadamer, 1983). Although distressing, it appeared to offer leaps in understanding (Khun, 1962/1970). For example, in redefining her experience of hurt with Helen, Susan was able to continue supporting her. Furthermore, the reflexive nature of the focus group itself appeared to give Richard the time to recognise his inner strengths, greater wisdom, and new outlooks on life. In reflexive dialogue with Susan, his meaning making appeared to take hold when he

exclaimed, “I mean that’s all it is! You really only have to listen! – But you listen in the context of knowing where they’re [families are] coming from.” However, these moments of psychological insightfulness appeared to emerge over time when triggered by past distress. Susan’s reflection that a health care assistant’s empathic insights “rattled around in my brain for so often” appeared to offer further support for the view that psychological growth is elusive when cumulative stressors overwhelm each step forward.

Although past research has identified *cascading consequences* which contribute to caregiver distress and feelings of being overwhelmed (Meuser & Marwit, 2001; Nay & Garratt, 2010; Shuter et al., 2014), a *synthesis of meaning* relates to an ongoing journey of autonomy and self-efficacy rather than isolated efforts to positively cope. In fact, living with the impact of dementia offered family members positive transformative opportunities for life. For example, this study reveals that life alongside a family member with dementia was a pendulum of *steps forward* and *steps backward* for these participants. While it was an accumulation of past and present traumatic events cascading through the journey, these participants experienced intrinsic drives to redefine their life positively out of the dementia journey. Though this may complicate comprehensibility and significance, the possibility of psychological growth despite distress adds a new dimension to our understanding of dementia. For example, Susan’s ongoing support of Helen remains possible by synthesising individual moments of meaning: (a) understanding that her offers of support may have confronted Helen with her decline; (b) attributing Helen’s rebukes of support as her dementia advanced to “internal turmoil” rather than taking it personally; (c) reconciling Helen’s apparent unawareness of family relatedness with her great granddaughter yet recognising that Emily was important to Helen and allowing an important aspect of Helen’s identity to re-

emerge; (d) accepting Helen's friendship despite interpreting Susan and Gary as being "just familiar faces"; and, (e) reconceptualising her support of 90-year-old Helen as the "natural order of things." Thus, individual moments of meaning now appeared interconnected and understandable in light of Susan's new holistic meaning making. For Susan, Gary, and Richard, a *synthesis of meaning* freed expectations of self and others and facilitated personal growth including acceptance, empathic insight, gratitude, self-forgiveness, and unexpected moments of intimate connection.

4.3.1 Conclusions and recommendations

This phenomenological investigation offered new insights on psychological growth while supporting a family member living with dementia. It described the continuum of subjective interpretations ranging from negative to positive, of individual family members exposed to dementia. Importantly, the coexistence of distress and growth, as families strive to make meaning of the adversity they face supporting a member on the long journey with dementia, is of interest in this study. In particular, this pilot study reveals the journey with dementia as a pendulum of *steps forward* and *steps backward*. Although it is an accumulation of past and present traumatic events cascading through the journey, these participants experienced intrinsic drives to redefine their life positively out of the dementia journey. Psychological growth over time was reported as participants found a *synthesis of meaning*. These families creatively reconciled past differences with the urgency of impending death and diminishing awareness and communication in their family member.

4.4 Chapter Close

Despite their distress, these family caregivers experienced psychological growth over time by redefining their caregiving role with personal meaning and purpose. Future studies could more closely examine changes in the method of engagement between

family members and the individual family member with dementia as they progress through the stages of dementia. Similarly, how pre-existing relationships limit or enhance commitment to the dementia journey in family members, is worthy of future research. Finally, this research offers a lens into traditional medical model approaches to dementia care and lends weight to staff and family collaboration in contemporary and holistic models of care.

In the next chapter, the researcher presents the supporting perspectives of health care managers to explore: (1) their perceptions of their work role and how they interpret the impact of such work on their own psychological wellbeing; and (2) how they position themselves as witnesses within a health care system that impacts, often authoritatively, on family relationships.

CHAPTER 5 Health Care Managers

Working in a systemic model of dementia care, and witnessing the impact of dementia on family relationships

5.0 Introduction

Experienced health care managers, often drawn in to complex decision making around ethical considerations for families confronting end of life dilemmas, are likely to experience moral challenges when working in dementia care within a hierarchical medical model. However, how individuals make sense of this distress, is a gap in the literature. Furthermore, how families adapt, both negatively and positively, and make sense of supporting a family member who has dementia is an new area of academic interest. One group uniquely positioned to shed light on the styles of care and interactions that keep families connected across the dementia trajectory are health care managers working in dementia care.

Therefore, this chapter seeks to present the subjective interpretations of health care managers regarding their dementia experience. It investigates both their positive and negative meaning making of their experience in dementia care. In particular, this chapter offers insights on: (1) their perception of their work role; (2) how they interpret the impact of such work on their own psychological wellbeing; and (3) how they position themselves as witnesses within a health care system that impacts, often authoritatively, on family relationships.

5.1 Method

5.1.1 Participants

Following university human ethics clearance, the primary researcher invited a purposive sample of interdisciplinary health care managers to participate in the research (Smith & Osborn, 2008). All invited health professionals volunteered for individual interview. See Section 3.3.1, p. 112, for further details on participant selection and recruitment. For demographics, see Table 13.

Table 13
Health care managers at the time of data gathering

Manager / age (years)	Role	Overall career / Dementia care (years)
Cheryl, 59	Director of Aged Care Services, Care home	42 / 19
Carol, 59	Director of Aged Care Services, Care home	35 / 10
Sandra, 59	Director of Aged Care Services, Care home	41 / 10
Gillian, 60	Director of Aged Care Services, Care home	40 / 9
Stephen, 55	Chaplain, Care home	22 / 8
Peter, 51	General Practitioner, Palliative care	28 / 12
Linda, 48	Nurse Unit Manager, Inpatient dementia care	14 / 12
Kelly, 48	Regional Manager, Community organisation	30 / 10

5.1.2 Procedure

See sections 3.3.2, 3.3.2.1, 3.3.2.1.1 and 3.3.2.1.2, pp. 114–116 of this thesis, for further details on the procedures for interview data collection and its analysis. For a copy of the interview schedule used with these health care managers, see Appendix 5, p. 340.

5.2 Results and Analysis

5.2.1 Results and analysis regarding a systemic model of dementia care

In presenting the results and analysis for Chapter 5, the researcher first addresses the subjective interpretations of these health care managers in relation to their view of their work role, and how they interpret the impact of that work on their own

psychological wellbeing. As such, one superordinate theme, *Honouring stigmatised self*, overarched four subordinate themes: *Systemic stigma*, *Invalidated*, *Self-respect* and *Moral integrity and Growth*. Stigma, considered as systemically entrenched, was felt as a mantle of minimisation on aged care and the aged-care workforce, including poor remuneration and training. Participants experienced peer invalidation particularly when attempting to resolve complex professional and moral challenges in dementia care. These often occurred in the context of efforts to individualise care, constrained within a medical model. Paradoxically, external invalidation motivated a search for redefining self and moral integrity. By wisely acknowledging career experience, growth domains of self-respect, optimism, humility, and innovation defined professional practice and personal choices. See Table 14 (Notations: Appendix 1).

Table 14

Superordinate theme: Honouring stigmatised self, overarching sub-themes:

Systemic Stigma: efforts by health care managers to bring meaning to entrenched stigma within aged care that was seen as minimisation of the workforce.

Invalidated: a search for self-advocacy and moral integrity by health care managers when unsupported by professional bodies and invalidated by peers.

Self-respect: authentic new outlooks underpinned by moral integrity.

- *Innovative thinking*: health care managers who sought innovation to individualise care for the needs and retained abilities of clients.

Moral integrity and growth: a mature confidence emerging from a struggle with moral integrity that led to optimism, humility, innovation and self-respect.

- *Wisdom*: positively redefining life itself, as a result of aged care exposure and becoming older themselves.
 - *Humility*: sense of humility and recognition of the difficulties facing individuals with dementia and their families.
 - *A calling*: a sense of being called to their profession and dedication surrounding their ability to make a positive difference.
-

5.2.1.1 Systemic stigma

A personal struggle to make sense of entrenched stigma associated with aged care infiltrates this data. Often exhausted emotional, physically and psychologically, the participants' remuneration juxtaposed the intense working situations under which these participants supported staff, families, and those at varying stages of dementia and dying.

A sense of systemic stigma in their working lives goes hand in hand with a pay structure that does little to validate the intensity of their work:

The nurse who works in ED [Emergency Department] seems to be held in higher regard than the nurse who works in the older person's unit ... and if you work in a nursing home, your wage is less (Linda).

In making sense of current events, many reflect upon their own early experiences working in aged care. In particular, they are able to muse on historical images of earlier models of aged care that continue to isolate them on the fringes of a progressive medicalised model of care in other areas of health. In many ways the negativity associated with the demise and dying of the aged remains for these participants, reminiscent of benevolent asylum:

I'm thinking back to 1976 ... I went onto my first ward ... it had an awful name ... 'The Hospital for the Incurables.' In that hospital was just a mish-mash of people. ... They only wore gowns ... there were no activities (Gillian).

Elements of guilt infiltrate their responses as they muse on the stigma of senility. These memories appear to unearth inner-discontent and a preference for advocacy:

I think the name [The Hospital for the Incurables] must have bothered me ... I remember working on that ward and thinking that we could do better than that, even as a 21 year old ... They deserve better (Gillian).

They note, “It’s the old traditional thing” that continues to linger with other disciplines of medicine whereby aged care remains perceived as “a place where people die. There’s no active medicine. There’s not really any involvement” (Peter).

Therefore, striving for an individualised, modern approach to dementia care creates a sense of inadequacy for these participants as they try to make sense of the medical model’s focus on routine and one-size-fits-all practice. They realise that efforts to modernise the aged care system paradoxically confuses the over-riding mission to individualise dementia care:

We still try to do personalised care ... but in a system like this the care happens in waves ...the trolley goes around ... medicines ... activities ... anything that is outside of the wave is really difficult to persist with — so that’s the challenge (Peter).

5.2.1.2 Invalidated

Sensing invalidation from peers, obstruction by their supporting professional body and professional disregard by mainstream health care practitioners, multiple challenges to self-advocacy and moral integrity appear. They speak of experiencing minimisation, disregard for their palliative management, and professional belittlement. Incredibly, authoritative directives by colleagues whose attitude to the dying is one of a godlike expert, reinforces the invalidation:

“You need to conclude this, because this man’s family is suffering. Whatever you need to give him, I give you authority to give him so that you can just stop his life” ... I said “No” ... the man was seriously offended (Peter).

For all participants, it is as if the wiser and more collaborative they became in understanding and accommodating the needs of people living with dementia, the more likely they are to be censored by a medical profession that prioritises the expert stance.

These participants speak of experiencing criticism, loss, and rejection at the hands of professional bodies. Their sense of invalidation includes loss of accreditation. Their negative willingness to engage at the forefront of daily aged care leaves them reduced as managers unable to supervise equally compassionate new health care practitioners:

Because I don't do mainstream practice ... I can't get accredited ... so I can't employ a registrar. ... things needs to change because I mean dementia ... It's going to be double ... where's this going to end up? (Peter)

Such invalidation produces a gnawing frustration and inner-disquiet:

The RACGP [The Royal Australian College of General Practitioners] don't classify me as a GP [General Practitioner] because I don't do mainstream practice (Peter).

A turning point of sad acceptance where these participants recognise a restrictive medical model as a blunt edge, inhibiting the opportunity for change, produces intense self-reflection and a search for personal significance and comprehensibility in their current role:

I thought I could at some stage in the role make a difference but directly I can't (Gillian).

5.2.1.3 Self-respect

Sadness brings efforts to embrace a new and personally authentic outlook. This allows these participants to bypass the trappings of convenience, status, and income of modern medicine and feel proud about their work despite poor monetary compensation. In time, they consciously chose to pursue an integral path:

Now it's much more fulfilling, it's one-third of the strain ... it's very rewarding for the staff, the patients and for me. Financially I'm being looked after ... totally enough to live a sustainable life. It's only a mind-set change that made the difference (Peter).

Moral dilemmas are frequent challenges and places them at odds with the system in which they work. They come to reject dismissive views that dementia care is “a matter of just showering someone or feeding someone” (Linda). Instead, despite criticism, they determinedly offer the right care to individuals living with an extremely variable condition, through respect for self. Forced into conscious and purposive rumination these health care managers positively redefine their moral and professional integrity in dementia care:

I am very unusual... I see the person first not their medical condition (Kelly).

In participants such as Stephen, this extends to considering themselves “a little bit different” to “very unusual” from the medical fraternity. Some even describe themselves as an “optimist” and “entrepreneur” within a medical model that limits the authority of staff to individualise care.

5.2.1.3.1 INNOVATIVE THINKING

Although often daunted by ageist censorship, lack of family support, and medical model constraints, rather than despairing, these health care managers seek innovative practice. Similarly, they view clients as people living with agency rather than passive recipients of care. They reflect this in their view of self as a supporter of residents’ individual needs and retained abilities, for example:

It’s more planning and more thinking outside the square for me as to how we’re going to give an extra bit of support (Gillian).

Alternatively, at times controversial issues “never ever talked about” leave them feeling “old school” (Gillian). Therefore, they overcome subjective biases and preconceptions to consider other possibilities in relational intimacy. These managers challenge conservatism internalised in themselves and residents:

I'm more comfortable with spirituality than I am with sexual issues. ...

Everyone has [sexual] needs, no matter how old they are, but I just wonder how I'm going to address it? ... Everyone's entitled to love no matter what. ... You know whether they're two males or two females or a heterosexual couple, it doesn't make any difference. My concern is not how we deal with them, it's how the residents would see it. I can understand their feelings, I can also understand that there's a lot of bigotry (Gillian).

They sense groundbreaking change within themselves and accept that innovation is risky within a medical model that affords little compromise between residents' personal freedom and their exposure to danger. Gillian muses over practice-based evidence, as she considers feeling panicked “during the night ... [at] the thought of finding someone dead ... because they managed to leave without us knowing”, and having to call the “Department of Health” and be “scrutinised” by “groups of auditors coming through the place” who can decide “business continuity”. Underpinned by their own maturation as health care managers, seniority, wisdom, and integral drive to “find the answer” (Stephen), these participants find themselves questioning expert authority within the medical fraternity:

I was told as a student nurse you never get involved ... now I think "I do get involved. I am committed to them. I have relationships with them" (Gillian).

5.2.1.4 Moral integrity and growth

For these participants, their struggle with self-integrity allows the emergence of personal qualities that they see as positive self-development. It was as if a mature

confidence is born out of their struggle facilitated by growthful domains of optimism, humility, innovation, and self-respect.

5.2.1.4.1 WISDOM

For participants such as Linda, redefining life through emerging professional wisdom, acceptance of self and others has partly matured “as a natural progression as I’ve gotten older anyway” and dementia care that is recognised as having exposed her to the “challenges of getting older”. Even within the interview, she reflects that everyone is vulnerable to conditions of ageing, even herself:

When you work with people with dementia ... you question your life a lot more, because ... you know your life at the moment, but in time, will I be that same person? So I guess because you see it a lot ... you prioritise what you want to do in your life, and you make the most of your life (Linda).

Fearful of their own risk of developing dementia they choose to “focus on the balance of life”. This includes making the most of limited time with family members:

I think the relationship with my parents has probably changed, because while they’re well and healthy and don’t have dementia, I sought of look upon them and think how lucky are they, how blessed are they not to have dementia, and so I try and spend more time with them, and do valuable things ... doing things with them that they enjoy, the things that I enjoy (Linda).

In fact, coming to terms with the incurable nature of dementia and perceived shortcomings as a caregiver, generated positive redefinitions of personal journeys with dementia. Self-forgiveness furthers optimism and the capacity to help other families:

I wasn't even sure what was causing the problem [at the time], but in hindsight I've come to the conclusion that it was ... an addiction to prescription drugs. Hindsight is twenty-twenty. ... You can't change what's in the past, but there's always potential to change what's in the future (Stephen).

Similarly, internal-locus-of-control is strengthened in their personal lives. Rather than blame circumstances now recognised as lying beyond their control, these professionals choose to redirect energy towards opportunities for personal growth:

If things aren't going exactly right for me I try to change the way I'm looking at the world or maybe the way I'm approaching things ... I try and change myself.
(Linda).

5.2.1.4.2 HUMILITY

Coming to terms with medical model constraints also generates humility and acceptance of the difficult role faced by people with dementia and their family members:

We make all sorts of assumptions about people's capacity... I would always give the benefit of the doubt to the person with the diagnosis to try things first before I would do it for them. That's just me. ... You know making a cup of tea ... [even] if it takes two hours ... How important it is that they make that cup of tea or do you do it for them? ... but in saying that I'm not the person who is there 24/7 [all day every day] ... that's one two-hour episode with that person. How many other episodes during that day? So that's a very nice philosophical thing I could say sitting on my 'red chair' here (Kelly). *(Note: 'red chair' is an idiom referring to the voice of the customer, or in this context, the voice of the family caregiver. In business practice, an empty red chair is placed at the conference table during business meetings to remind the meeting attendees to consider how a customer might react to the meeting dialogue. Therefore, in this extract, Kelly acknowledges that although she is expressing the caregiver's view, she is not actually the caregiver.)*

Similarly, an internal struggle with two views of self, that of 'humble supporter' and that of 'dementia expert' allows objection to a hierarchical approach to dementia care. As a result, Stephen focuses on "empowering and growth" and "what can we do." In

turn, participants such as Kelly, bypass the ‘expertise’ of a medical fraternity inclined to “over-package people”.

5.2.1.4.3 A CALLING

For these health care managers, there is a sense of dedication to a greater cause.

This extended to a spiritual calling for some:

Coming from a traditional Church there is always the drive that you need to evangelise people ... I’ve matured to work it out for myself, that my ministry is my work. Whatever my hands find to do, I do as is if I do the best because I’m doing it for God (Peter).

For others, living alongside a family member with dementia has precipitated their unexpected career:

Ten years ago, I would have never dreamed I would be doing what I'm doing; Never. I've always had a personal philosophy from the spiritual viewpoint. The best way to meet a person spiritually is to first meet their physical need. ... I feel like I can accomplish both here (Stephen).

For all participants, there is a striving to free clients from limiting changes in awareness and engagement, if only for a moment:

We've got one gentleman here who's 99, who's really, really, really been struggling. Actually, he's given up. He was a bookmaker for years ... Well I found another gentleman who's also a retired bookmaker, and another guy in self-care whose father was a bookmaker. I got them all three together this morning for coffee, it brought that one guy alive. So to me, that was identifying a need, working out a solution and enhancing his life, and to me, I was walking on ‘cloud nine’ ... [because] he was able to recall and enjoy, and [he] said “that was very interesting” ... That's why I do what I do (Stephen).

Similarly, Peter muses on the capacity of a holistic model of dementia care to “make a difference in people’s lives”. This is underpinned by his inherent belief that a holistic model of dementia care can reveal “the real value of life” for all those bound on the journey with dementia, especially when:

You know the family is suffering, but in that same process I had three opportunities to speak with the children, who had no idea what was going on with their Dad, who had no idea of dealing with death ... so over the two weeks that this man was palliated, we had three opportunities to deal with their own emotions, guilt, the process of bereavement, and the disease and that brought that whole family together like nothing else could do, whereas they would have been shattered broken and disillusioned and, you know, the specialists just look from the outside and say “listen it’s too hard, you no, you need to fix it” (Peter).

5.2.2 Results and analysis regarding the familial impact of dementia

Now, the researcher presents the results and analysis regarding these health care managers’ subjective interpretations of witnessing the impact of dementia on family relationships, and how they position themselves as witnesses in an often authoritative health care system that impacts on family relationships. As such, one superordinate theme, *Dementia naiveté and redefined intimacy*; overarched the subordinate themes: *Witnessing embarrassed shame*; *Modelling hope*; *Validating a model of intimacy*; and *Gratitude and authenticity in others’ psychological growth*. Within these themes, the participants are able to shed light on what they perceive is hurtful embarrassment and shame in families associated with the diagnostic label that is now part of their family group. Participants recognise a dichotomy of responses to embarrassment and shame

where either separation, hurt, and immobility through ignorance occurs, or family members naively seek that elusive cure.

Indeed, the participants see their role as one of modelling a new way of connecting *what was* with *what can be*. Thus, they demonstrate the strengths of advocacy, integral care, and relational intimacy in the hope that family members will learn to create their own opportunities for wellbeing rather than linger in distress. Validated, they come to witness a redefining of intimacy in many families who are able to embrace that holistic and empathic approach to the shifting presentation of dementia. Participants experienced authenticity in their witnessing of positive change in those family caregivers who could engage with acceptance, hope, relational closeness, and altruistic concern for other families, and appeared to psychologically grow. See Table 15 (Notations: Appendix 1).

Table 15

Superordinate theme: Dementia naiveté and redefined intimacy: overarching four sub-themes:

Witnessing embarrassed shame: attempts to empathically care for families and help them make sense of a dementia diagnosis that precipitated relinquishment of home care.

- *Invalidation:* Health care managers sense of invalidation, when families in their distress deny association with dementia and its carers.
- *Neglectful carers:* Vigilance in response to families who resist a more collaborative and inclusive style of dementia care.

Modelling hope: When health care managers model hope for families it encourages those families to move beyond adverse outcomes.

- *What now?* A solutions-focused approach helps families move beyond embarrassment, shame, frustration, and negativity.
- *Shifting identity:* Witnessed struggles in family members to resolve conflict between 'self as relative' and 'self as carer'.
- *Not without a fight:* Noting that some visiting family members remained stuck in out-of-date relational frames of reference.

Validating a model of intimacy: Observing the disabling effects of low dementia literacy, health care managers sought to model new ways to link 'what was' with 'what could be'.

- *Relational inroads:* Filled with amazement, these health care managers witnessed retained awareness and relational preference in residents, even those dying.
- *Seeing the person:* Health care managers avoid functional and superficial interactions with residents, and instead seek to connect with the individual character of each resident.
- *Holding the person:* Health care managers' coaching intimacy for families, helps those families overcome shame and hopelessness.
- *Restoring agency:* An inherent belief in individual agency motivates health care managers to empower residents living with dementia.
- *Validation:* Validation from residents and families enhances fulfilment as carer in these health care managers.

Gratitude and authenticity in others' psychological growth: Validation for health care managers that they were following the right approach in helping families bring meaning to dementia.

- *Growthful redefinitions:* Witnessed psychological growth in family members who are able to accept a more holistic and empathic care package.
 - *Bold opportunities:* Witnessing the power of individuals to make a difference, it leaves these health care managers considering opportunities to individualise care.
-

5.2.2.1 Witnessing embarrassed shame

This theme describes the participants' attempts to walk in the shoes of the families in their care and making sense of a dementia diagnosis that resulted in the relinquishment of home care. The secrecy of families "embarrassed to tell" (Carol),

because others “don’t understand what dementia is” (Carol), was recognised by these health care managers as part of the overarching stigma of aged care. They saw it as maintained through “helplessness [and] fear” (Stephen). On one hand, they empathise with family members for shielding a relative from hurtful judgement by delaying or denying diagnosis. On the other, they suspect over-protectiveness in families “embarrassed about behaviours” (Carol) and threatened by rejection:

People say, “Oh, they don't have dementia ... Well I think he’s just putting it on” ... [dementia] stigmatises a person ... everybody's afraid of it ... there's no cure (Stephen).

However, they muse on witnessing unaware relatives seeking to constrain the *embarrassing* family member when their behaviour is perceived to fall short of dignified behaviour:

They expect Mum and Dad to be who they are. ... when they're not, they don't understand why (Stephen).

Rather than stay silent, carers seek to advocate for their client through family meetings, regardless of their acute awareness of the embarrassment in family visitors:

I think it’s ... a non-understanding of dementia ... lack of flexibility. ... I’m meeting with the family tomorrow. ... [this] gentleman ... he took to a doll ... his communication was like this [she makes a whistle sound] ... he’d lost his verbal communication ... he’d call you over so you could make a fuss ... then he’d lay it on the table and try and change clothes ... and I thought: “Oh what a lovely Dad you must have been”; but ... his adult sons weren’t happy that he had this thing with the doll (Cheryl).

Similarly caught unaware, carers witness struggles for agency between residents living and dying with dementia. Seen as masking embarrassed shame and loss of self-esteem in a “hierarchical” environment (Gillian), human competitiveness and status is

alive and well. Motivating advocacy and altruistic-self, care managers intervene to stop further hurt and minimisation. Residents regarded unaware by peers for lack of speech are protected from indiscriminate verbal attacks:

“That lady's got my shoes on. I wanted to buy those shoes but she's got them!”

— “She's silly! She can't understand” (Gillian).

5.2.2.1.1 INVALIDATION

The existence and support of these participants is often negated by families who in their own distress deny association with dementia and its carers. Invalidated, they note concealment:

In the death notices ... they don't actually say died at ... a specific nursing home (Carol). They mused at exclusion from “eulogies” while acknowledging that “dementia as being part of the journey of that person” (Carol), means avoidance behaviours are often part of giving meaning to their journey. Unrecognised for the intensity of their role in monitoring high-risk situations, they struggle with the dual role of enemy and ally. On the one hand, they recognise a need to remain vigilant for opportunism by families who “take advantage” (Gillian), yet on the other hand, become the conduit for relational trust in family interactions.

Notwithstanding their years of practice, perceived invalidation leaves participants questioning their competent-self both as carer and as manager. They feel conflicted by the boundaries of care often expected in a medical model framework. Despite a commitment to autonomous and individualised care, self-doubt continues to be experienced as they sense the tension between family members and health care assistants. Uncertain, they seek to liaise with individuals around expectations and roles:

“Why do you feel the need to do this? Are we lacking in some way?” (Carol)

5.2.2.1.2 NEGLECTFUL CARERS

For these carers, the need to remain vigilant left them experiencing “frustration” and “disappointment” and feeling “overwhelmed” (Gillian), particularly when families resist a more collaborative and inclusive care package:

I'd like families to be aware and be involved and not shirk responsibility
(Gillian).

Noted by carers, families neglectful of their care responsibilities lash out in blame:

You haven't done your job properly! (Gillian)

Indeed, family members perceived to be unreliable or “not prepared to give anymore”, are perceived as individuals who “take advantage” of outreach support:

“I'm busy today, but someone needs to call in and see my mum. She's upset.
She lost her brother last weekend” (Gillian).

Similarly, “distress,” “emotional burden,” and “guilt” compound the instability and unreliability of family support. With lives often put on hold due to the complex demands of dementia care, these participants viewed family members as erratically present and rejecting efforts to model appropriate care. They interpret such rejection as guilt driven:

If they feel guilty ... it's like a madhouse [a scene of extreme confusion] ... the
poor patient is totally out of sorts ... he's just absolutely confused ... [and
family members] fiddle with medicines without talking to you (Peter).

5.2.2.2 *Modelling hope*

5.2.2.2.1 WHAT NOW?

Participants see a solutions-focused approach as one way to release families from “frustration” and “depression” (Stephen). Embracing hope marks a turnaround in agency for many families and releases them to consider present and future possibilities with greater optimism:

“Why?” is not the right question to ask. The question to ask is “What now?”

“Why?” leads to frustration, depression, and defeat. “What now?” ... leads to motivation in what you can proceed into now because of this. So it changes the groundwork completely (Stephen).

From a personal perspective, the participants such as Kelly appreciate families who assertively organise themselves through “education, support groups, and establishing who does what” for their family member:

“Well look it’s a fait accompli. I’m going to learn and understand it.” ... they embrace it. Very adaptive people (Kelly).

The participants recognise that some families engage with caring with a sense of pride and consequently, often free themselves of the embarrassment of stigma and embrace relational opportunities despite the shifting presentation of dementia:

They tend to have a fairly realistic understanding ... of the disease; its impacts, its progression and its place I suppose in the whole family structure ... that then frees them up to make the best of what they have left (Kelly).

5.2.2.2.2 SHIFTING IDENTITY

However, participants speak of family members as having internal struggles over two views of self, that of relative and that of carer.

I think it's a real struggle to try and be the person who is the carer ... first of all you're the wife ... that's your relationship; second, you're taking on a role (Kelly).

Unable to help family members resolve these aspects of self, in light of the “dramatic change in the status of their relationship” (Kelly), some seem to fuse with self as carer. They note that for some, enmeshment with a family member seen as increasingly reliant on their support, is an opportunity to become intensely involved with “education” and “support groups” (Kelly):

Sometimes those families look for the cure ... forget about communication ... forget about the day-to-day (Kelly).

A drive to remain hopeful is seen as a double-edged sword by these participants. They consider that it clouds opportunities for enjoyable day-to-day relational opportunities and outpaces family members search for the “big picture” (Kelly). To the participants, this drive also complicates relational ease that would more likely occur for these family members if the status of carer was felt with less intensity. Conversely, they recognise that in those who remain optimistic and hopeful for that elusive cure often find ways to redefine hope adaptively.

5.2.2.2.3 NOT WITHOUT A FIGHT

These participants witnessed needs of both clients and family visitors expressed within a relational frame of reference that often reflected an earlier time and place. The medicalised framework of care in which they work, poorly equips them to support family members wanting to retain pre-dementia interactions:

You need to establish what ... gives him comfort ... he can still understand ... he still can enjoy ... It doesn't matter what your needs are. When you come into this tiny little world, this is what you focus on...you just focus on their little world (Peter).

Sadly noted, families “committed totally in the wrong direction” lash out in blame (Peter). ‘Fix-it’ expectations can leave carers feeling hollow and inadequate (Peter):

Most people are still in sort of a mind fail. “You know this is 2014. There is medical science. ... you're the doctor, fix it!” (Peter)

With poignancy, they remember some family members witnessed as missing opportunities to enjoy their remaining time, resolve past wounds, and prepare for their family member's death:

They struggle right to the end. They never ever accept it (Sandra).

5.2.2.3 *Validating a model of intimacy*

Witnessing the disabling effects of low dementia literacy motivates these carers to enact a new way of connecting what was and what can be. Thus, they seek to model advocacy, integral care, and relational intimacy for uncertain families. Validation comes in redefining retained awareness, self, and communication in people with dementia.

5.2.2.3.1 RELATIONAL INROADS

Filled with awe as dementia carers, they witness expressions of retained awareness and relational preference in residents, even those dying. Regarding behaviour as meaningful and understandable to them, carers are often motivated to dispel misassumptions of unawareness when speech is lacking:

We had a man who didn't speak the entire time that he was with us... he was on his deathbed ... he was going downhill very quickly ... he just looked really frightened ... and then Kim came in ... and his face just lit up the room. It was just amazing (Sandra).

Revealing distaste for presupposing needs, these carers make the time to understand residents' lived experience. Such efforts are considered meaningful engagement, and as such, they encourage others to prioritise a consistent, safe, and familiar presence. In turn, they are acutely aware that a respectful and patient will to bridge horizons, is recognised by those with dementia:

They recognise a friendly face ... someone who is prepared to put the time in to understand what it is that they want. ... what it is that they're trying to communicate (Sandra).

These participants embrace modelling as a major role. Even though experiencing odd family behaviour, modelling is adopted enthusiastically. They recall surprising the closest family members through modelling a person-focused approach, to help caregivers register that inroads to communication are still possible:

We had a couple, the guy was a ventriloquist who worked puppets ... and his wife came into my office. We were having a chat I was speaking to the husband, I wasn't speaking to the wife ... and I said ... "Hello Barry, how are you?", and she's saying "I'm good thanks" ... and I'm thinking "Pardon? ... How odd is that?" ... that wouldn't happen if he didn't have dementia. ... Barry is

looking at me, and ... rolls his eyes, cause Barry thinks “I’m sick of this. I’m sick of her answering for me”, so I continue on, and I said “Barry it’s really good to see you. ... What have you been up to?” Barry goes to answer, and out of the left comes “Barry’s been doing ...”, so I put my hand up to his wife ... I know Barry over here is dying to tell me, so all of a sudden Barry goes “Oh I’ve been...”, ... and his wife goes “How did you do that?” (Kelly)

5.2.2.3.2 SEEING THE PERSON

Dissatisfied with functional and superficial interactions, these participants connect with the individual character of each resident. They recognise that people with dementia remain the same person throughout their illness:

We’ve got a sailor in here, and he is rude and rough, and he’s still rude and rough but now without any inhibition (Peter).

Like a detective, they seek clues for reconstructing residents’ pre-dementia character, by observing adult children’s’ behaviour:

I see people with dementia who have had very creative kinds of minds ... artistic, social ... great networks of friends ... I see her lovely daughters ... how bubbly and friendly and what warm personalities they have (Sandra).

Similarly, these participants encourage staff to make time to listen to life histories and demystify unusual moods. Once narratives are valued and heard understanding and empathy from staff is noted to improve awareness:

She certainly has a background of depression, given that her husband and her son died around Christmas time and we’ve just gone through Christmas (Sandra).

5.2.2.4.3 HOLDING THE PERSON

Participants, such as Gillian, drew upon her evolving ease with non-speech intimacy: “I am more tactile”, and increasingly sees her role as supporting family groups to connect with their resident member through touch and emotions. Observing residents’ behaviour as coherent, they guide family members to still look for meaning:

We’re all on ... this journey in life together ... people who have got very limited cognition still respond very well to a smile and a warm touch ... a friendly and loving approach (Sandra).

Moments of guidance for uncertain family members helps them to seek “a decent adult conversation” (Kelly), deserving of deep respect as an adult, despite dementia:

He’s a 70-year-old man, and I’m going to have a decent adult conversation ... that’s what we have to model all the time (Kelly).

Without romanticising the lived experience of dementia, carers such as Kelly remain ready to support with “cues” and “prompts” to help others flourish:

He knows that if there is a difficult situation, that I will support him through that (Kelly).

5.2.2.4.4 RESTORING AGENCY

Revealing a deep belief in individual agency, participants, such as Sandra, empower residents within the facility viewing it “as their home” with “some control over it”. Promoting activities that call on earlier life-skills such as “making a cake for afternoon tea” (Gillian) is viewed as reflected managerial vision and purpose. Moreover, they seek a restorative focus through metaphors that indicate their belief that individuals can make a difference:

What I like particularly is to take an old antique that’s ruined, and bring it back to new (Stephen).

Wonder and curiosity, is witnessed in “all” residents interacting with babies and children during family visits (Cheryl). This provides ammunition for motivating protective carers and works against overprotection of residents that strips joy from their life. They ponder on the restorative impact of non-judgemental acceptance, reciprocal admiration, and agency:

It’s just amazing the reaction ... these babies get. ... little children ... we’ve *never* had an incident — *never* — I don’t know what it is (Cheryl).

5.2.2.4.5 VALIDATION

For these participants, such as Sandra, validation comes in many forms when caring with a sense of service, even from residents on their “deathbed”:

He just looked really frightened ... then Kim came in and ... his face just lit up the room. ... Years later I can still see his face ... that’s the reward that you get ... you know that the systems and processes that we have in place for supporting people ... in the last phases of their lives are so important to them ... we know that we’re going down the right track when you get that kind of response (Sandra).

They muse on the reciprocity of this career path:

I just feel that it’s very comforting for someone ... you hold their hand ... I get comfort from it, and they do too ... I think it’s good for all of us to be wanted (Gillian).

These participants convey an advanced insight into dementia care:

If you’re saying something in a nice tone of voice ... you’re conveying empathy (Linda).

They equally recognise that expressing negative emotions traps residents in a bewildering search for the source of their anxiety:

When they see you upset and ... agitated ... it's quite disconcerting ... for them (Linda).

They also feel honoured that end of life care provides them a vision of the spiritual bridge between life and death:

I see them talking to someone who's not—I can't see. I see that satisfaction on their face ... a peace. So, I believe that ... at the end of life, there is something there. I don't know what it is (Sandra).

5.2.2.5 Gratitude and authenticity in others' psychological growth

5.2.2.5.1 GROWTHFUL REDEFINITIONS

Once able to embrace a holistic and empathic approach to care, these participants witness family members experiencing psychological growth:

They've noticed things in themselves ... their own self-growth ... personal journeys ... things they thought they could never do or achieve (Kelly).

Similarly, watching families engage in what appears to be a positive shift in how they view relational intimacy in response to their relative's shifting presentation of dementia brings joy for carers and validates their own beliefs that relational intimacy is possible over time:

Communication gets better with that parent ... they report that there is a closer relationship (Kelly).

Noted with surprise, is that perhaps embracing positive change, some family members found ways to erase old conflict with their family member throughout their illness:

"Look my Mum's nicer since she's had dementia" (Kelly).

Similarly, carers such as Kelly witnessed “a stronger family bond amongst the siblings” in many families as siblings once considered in a “shambles” “had to bond together” to coordinate support.

Participants mused at unexpected family testimony that brings recognition of their vital support as carers, Positive life-changing outcomes are reported by families once “totally opposed” to holistic intervention (Peter):

It happened the other day I walked into town and this guy walked up “Look you treated my mum, and that day ... you wouldn’t even know what you said, but that changed my life” (Peter).

Witnessing such positive change in families once in hiding due to stigma or seeking elusive cure, offers carers such as Peter, the “courage to struggle with twenty more difficult, aggressive, disappointed, disillusioned families!”

5.2.2.5.2 BOLD OPPORTUNITIES

These participants describe families reaching beyond embarrassed shame and unrequited hope to extend relational opportunities to other families inclusive of a member who has dementia. In witnessing reciprocity, families appear to view residents’ thoughts and behaviour as aligned with their own:

You know it’s just brilliant to see that huge turn-around. And they get so emotional because they know that they’re making a difference in that person’s life (Carol).

Revealing the power of individuals to make a difference, it leaves these health care managers boldly musing at future opportunities to individualise care:

I think families could offer that individualised care program ... they’ve already got a relationship ... a history (Gillian).

5.3 Discussion

This chapter highlights the personal and professional impact of a career in dementia care on health care managers. Specifically, it provides an understanding of the subjective interpretations of health care managers regarding their dementia experiences, ranging from negative to positive, in relation to: (1) their perception of their work role; (2) how they interpret the impact of such work on their own psychological wellbeing; and (3) how they position themselves as witnesses within a health care system that impacts, often authoritatively, on family relationships.

In regards to their perception of their work role, and how they interpret the impact of such work on their own psychological wellbeing, one superordinate theme, *Honouring stigmatised self*, overarched four subordinate themes: *Systemic stigma*, *Invalidated*, *Self-respect* and *Moral integrity and Growth*. These health care managers interpreted systemic stigma as minimisation of aged care as “the end-of-the-line” (Linda), poor staff remuneration, and inadequate access to training. Participants experienced peer invalidation when attempting to resolve complex professional and moral challenges in dementia care. A systemic model of medical care hindered innovation and efforts to individualise care. For these participants, external invalidation motivated a search for personal authenticity and moral integrity, which foundational upon career experience, contributed to growth domains of self-respect, optimism, humility, and innovation that re-defined professional practice and personal choices. Although each manager’s struggle to make sense of their lived experience was unique, patterns of meaning making illuminated convergent themes across the data set.

Stigma, experienced by these health care managers, was perceived as systemic within aged care. This perception reinforced other studies that have found low pay and inaccessible training (Inness, 2002; Martin & King, 2008; Sargent et al., 2008, 2009,

2010; UK Department of Health, 2011) and other implications from stigma for health care managers, practitioners, and assistants (Link & Phelan, 2001, 2006). In seeking to understand the lived experience of this stigma, this chapter is novel in exposing out-of-date perceptions of aged care that linger in the medical fraternity. Harking back to the philanthropic beginnings of benevolent asylum for the senile and incurable, these participants considered that aged care continues to be burdened by care that “happens in ways ...medicines ...activities ...” (Peter) that disregards the living and dying individual. Such stigmatisation based on health care managers’ work within the context of ageing and dementia reveals courtesy stigma as first conceptualised by Goffman (1963) and found in families inclusive of a member living with dementia (MacRae, 1999; Werner & Heinik, 2008).

Although meaning making was constrained by a medicalised approach to dementia care, participants experienced intrinsic drives to redefine their life positively through past and present moral challenges cascading throughout their career. Specific to this chapter, the findings reveal that as psychological growth took hold, authority to flex autonomy and competence, bond with clients, and wisdom gained through career experiences, took priority. In particular, these participants identify that systemic stigma, professional invalidation and ill-conceived and homogenous aged care, presented a barrier to good practice in caring for people living with dementia. By acknowledging their wisdom gained through career experience, growthful domains of self-respect, optimism, humility, and innovation assisted them to redefine professional practice and personal choices.

Although this chapter supported negative consequences of moral challenges (Edberg et al., 2008; Glasberg et al., 2006; Juthberg et al., 2008; Redfern et al., 2002), it revealed concurrent opportunity for transformative positive change in personal,

philosophical, and relational realms. Specifically, the struggle with situations that triggered moral disquiet paradoxically created opportunities for self-reflection. By recognising their wealth of knowledge and experience, negativity gave way to growthful domains of optimism, humility, innovation, and self-respect. As a consequence, professional-self in these participants evolved over time from that of an uninvolved carer to that of confident relational supporters, whereby clients were people with agency rather than the passive recipients of care (Allen & Killick, 2010).

Demonstrating an important aspect of Kitwood's (1997) person-centred dementia care in action, this finding highlights how a person centred approach can restore personhood in those with dementia and facilitate relational connection (Allen & Killick, 2010; Downs, 2010; Sabat, 2010; see Chapter 4). Conversely, this chapter exposes a dichotomy can exist whereby modernising many aspects of dementia care through a task focus has paradoxically confused the over-riding mission to individualise dementia care. It may be that this task focus, and value attached to maintaining physical and social order, makes person centred approaches difficult to implement, not their vague conception (Davis, 2004; Ward et al., 2008).

Of further concern, in finding that psychological growth emerged over many years for these participants, such growthful care may be out of reach for many who embark on a career in dementia care as workforce turnover rates are approximately 40% per year (Ayalon et al., 2009; UK Department of Health, 2011; Sargent et al., 2008, 2009, 2010). Indeed health care managers, practitioners, and assistants are already struggling to support ageing populations (AIHW, 2012, 2013; Lakey et al., 2012), and as the majority of people in high-income countries will be touched in some way by aged care and dementia in coming years, the profile of dementia care needs scrutiny with concerted

efforts to address remuneration and training. In turn, this could diminish the stigma that is systemic within aged care.

Although results are not generalisable to other managers in aged care, this chapter highlights the authority within these managers to provide best practice in dementia care. Furthermore, it highlights their vantage point, spanning from negative to positive, as health care managers witness the impact of dementia on family relationships and position themselves as witnesses within a health care system that impacts, often authoritatively, on family relationships. As such, these participants regarded themselves as mentors of a person-centred, individualistic approach to care, and modelled a new way of connecting 'what was' with 'what can be' for families living with dementia.

Indeed, these participants demonstrated the strengths of advocacy, integral care, and relational intimacy in the hope that family members could learn to create their own opportunities for wellbeing rather than linger in distress. They experienced validation of their view of caring in dementia when they witnessed family carers attempting to redefine intimacy and embrace a holistic and empathic approach to the shifting presentation of dementia. Gratitude and authenticity sustained these participants' own commitment to aged care. For them, witnessing successful and positive change in those family carers who could engage in the dementia journey with acceptance, hope, relational closeness, and altruistic concern for other families, was determined as psychological growth.

From the perspective of senior carers, a diagnostic label of dementia brings a legacy of stigma and embarrassment to families. From their vantage point as health care managers, they perceived that dementia-related stigma was likely to be internalised by the families they sought to support. In the supporting family members, stigma appeared to them to align to threat of judgement. For those with dementia, stigma appeared to

bring further loss of agency. In describing families' embarrassed shame, the participants suspected that individual family members feared being found out, judged, and rejected. Some denied diagnostic labels to them directly and appeared to distance themselves from a family member with dementia. Family members with dementia were seen distinguishing themselves from others' diagnoses. Therefore, they joined a hierarchy of retained ability by minimising others who were lacking speech. By doing so, they sought respect. Maintaining shame, fear, and ignorance of rehabilitative possibilities, these participants were also impacted by stigma as it disrupted yet motivated these carers to model advocacy, holistic care, and relational intimacy.

Of interest, this chapter offered examples of senior carers identifying and creatively responding to the retained awareness and communicative abilities of people with severe dementia whether speech or non-speech (Walmsley & McCormack, 2014, 2016b). In particular, it offered examples of senior carers recognising retained aspects of self in people with dementia, and even their ability to communicate preferences at end of life (Sabat, 2010; Sabat & Collins, 1999). Furthermore, the efforts of these health care managers to model *redefined relational intimacy and growth* reflected many elements of positive person work (e.g., validation of feelings, creation through useful activities, individual recognition, facilitating trust, comforting touch, and holding distress: Kitwood, 1997). Criticised for placing carers and relatives at risk of distress though ideals of genuine communication (Davis, 2004; Gibson, 1999), this chapter reveals that for these carers validation of person-centred ways of connecting to life came in witnessing client responses and being able to model intimacy and growth for family caregivers. In turn, they sensed their own authenticity and gratitude for recommitment to aged-care.

Just as individuals with dementia adapt to their changing awareness and communication, so must their family members. Therefore, this chapter revealed senior carers modelling adaptive ways of interacting, including: 1) making time to understand the lived experience of clients and allowing time for narratives; 2) adopting a philosophy of respect, patient determination, and open mindedness; 3) being present in the moment; and 4) guiding families to look beyond global assumptions of unawareness and to look for meaning. If family members become preoccupied with thoughts related to traumatic distress it may be that they will miss moments of relational opportunity.

Therefore, this chapter reveals that by defining their own intentional stance these health care managers perceived that they assisted families in overcoming the global misassumption of unawareness, especially when speech is lacking. Furthermore, in their ability to listen to residents as if there was a message to receive, these health care managers modelled positive communication for families. This promoted advocacy, integral care, and relational intimacy for uncertain families. These participants challenged their own thoughts around intimacy in end stages of life in dementia care. They recognised imposed morality in care facilities can minimise and restrict individuality. The curiosity and openness shown by these carers highlight that our assumptions surrounding relational intimacy may be considerably different from the lived experience of those diagnosed.

5.3.1 Conclusions and recommendations

This chapter offered new insights on how health care managers make sense of moral challenges that commonly emerge while working within a medical model of dementia care, and how they position themselves as they assisted families in overcoming the difficulties of changing communication pathways. In particular, this chapter demonstrated the positive views and actions of these managers and their

intrinsic drives to redefine life positively through moral dilemmas accumulated throughout their career. Of interest, co-existing with distress was the possibility of psychological growth that may result from a career in dementia care. In particular, this may contribute towards challenging systemic stigma, professional invalidation, and imposition of homogeneity that prevent good quality and individualised care for people with dementia and their family members.

Furthermore, new insights were revealed on how health care managers make sense of the impact of dementia on families that they care for. As such, this chapter provided a unique lens of interpretation into family dynamics, and sense making by family members living with the impact of dementia. It also highlighted the managers' own roles in that journey. Although this chapter does not have the interpretations of family members, the participants interpreted changing behaviours and emotions in some family members, as coexisting distress and growth over time, as families struggled to make sense of the unwelcome condition that was dementia. Importantly this chapter sheds light on the impact of cumulative distress experienced by family members on professional creativity, integrity, and authenticity in these managers, and their determination to enhance the relational experiences of those with dementia in their care.

Indeed, these managers of health care are well positioned to recognise the spectrum of negative and positive meaning-making in families struggling with dementia. As in supporting existing literature (Durkin & Joseph, 2009; Janoff-Bulman, 1992; Joseph & Linley, 2005; Lepore & Revenson, 2006; O'Leary & Ickovics, 1995; Smith et al., 2008; Walmsley & McCormack, 2016a) meaning seeking and meaning making was observed by the participants to play a role in helping these families cope with the adversity of supporting a member with dementia. As such, they witnessed families moving through

three stages of change from embarrassed shame and maintaining hope towards redefined relational intimacy and growth. Senior carers believed that they facilitated families' movement from the first to second stage by encouraging a solutions-focused mind set (e.g., what now?). Importantly, enacting 'a new way of connecting what was and what could be' helped families move onto a third stage of positive change. This process was described as complex, dynamic, and oscillating. Further, change was unique for every family in their care and also for individual family members. Accordingly, it would seem that family members can move from an experience of dementia dominated by negative domains (e.g., embarrassed-shame, denial, secrecy, fear, blame, obstructiveness, aggressiveness, disappointment, disillusionment, guilt, remorse, and relational distraction) to one accommodating growthful domains (e.g., acceptance, personal strengths, new perspectives, altruism, improved communication, relational valuing, and relational intimacy).

In seeking to enhance quality of care through communication programs for families and health professionals, future research merits exploration of the unique window of insight that health professionals can provide on ways of caring within dementia care settings. Furthermore, this research adds a new dimension to our understanding of dementia care and challenges traditional medical model views of dementia in favour of holistic models of support. In their efforts to support families holistically, these health care managers challenged traditional medical model views of dementia and lent support to new individualistic models of care.

5.4 Chapter close

These health care managers experienced peer invalidation when striving to offer a holistic yet individualised model of dementia care, constrained within a medical model. However, this invalidation motivated their search for personal authenticity and moral

integrity, which foundational upon career experience, positively redefined their professional practice and personal choices over time. Therefore, by modelling advocacy, integral care, and relational intimacy, these health care managers hoped that family members would find opportunities for wellbeing rather than remaining with distress. Gratitude and authenticity in these participants came from witnessing psychological growth in those family caregivers who were able to engage with dementia with acceptance, hope, relational closeness, and altruistic concern for other families.

Next, in Chapter 6, the researcher turns towards the family groups themselves, inclusive of members with dementia, to observe interactive communication patterns in families. In doing so, the researcher seeks to understand the understanding and receptivity between family members, inclusive of expressions of awareness and ways of interacting, when a member lives with dementia, across the dementia trajectory.

CHAPTER 6 Family Members who have dementia

‘Relational Social Engagement’ during family visits

6.0 Introduction

Dementia can be a stigmatising condition, which leaves individuals and their family members isolated and lonely (Skladzien & Holdsworth, 2013; Green & Lakey, 2013; Kane & Cook, 2013; MacRae, 1999, Werner & Heinik, 2008). Family and friends are often reported to stop visiting and calling (Kane & Cook, 2013; Skladzein & Holdsworth, 2013), especially when there is uncertainty about how to interact with a person who is so ‘deeply forgetful’ (Bryden, 2012; Green & Lakey, 2013; Kane & Cook, 2013; Power, 2014; Skladzein & Holdsworth, 2013; Taylor, 2011). However, family studies indicate that awareness may exist in people with dementia at levels previously unrecognised, when social cues support communication (Walmsley & McCormack, 2014, 2016b). Indeed, even in the profound stage of dementia, families strive to retain relational connections, through interactions that are *in-step* (*harmony, spontaneity, reciprocity*) or *out-of-step* when there is *disharmony, syncopation*, and *vulnerability* (Walmsley & McCormack, 2014).

However, less is known about retained awareness and communication during family interactions, in the moderate and severe stages of dementia. As a new area of dementia research, family studies have the potential to illuminate social relationships that are unique in both their intimacy and duration. Furthermore, qualitatively different perspectives may illuminate alternative pathways of retained awareness and

engagement, especially when speech in a person with dementia is limited or absent. Therefore, Chapter 6 seeks to illuminate retained awareness and social engagement observed when individuals living with moderate and severe dementia in care homes interact with visiting family members. Therefore, this chapter aims to interpret: (a) expressions of retained awareness in the speech, voice, facial expressions, and body gestures of a family member with moderate or severe dementia; and (b) the understanding and receptivity in the relatives reciprocating that individual's expressions of awareness.

6.1 Method

6.1.1 Participants

Following ethics approval, relatives with guardianship status were invited to participate by the directors of aged care services at six care homes. Criterion for inclusion was an in-resident family member with moderate or severe dementia, as assessed by the directors using the Clinical Dementia Rating Scale (CDR: Morris, 1993, see Table 16). For further details on participant selection and recruitment, see Section 3.3.1 on p. 112. For demographics, see Table 17 on p. 182.

Table 16

Clinical Dementia Rating Scale: moderate and severe dementia (CDR; Morris, 1993)

Stage	Rating	Symptoms
Moderate	2 (scale 0-5)	<ul style="list-style-type: none"> ▪ Only highly learned material retained: new material rapidly lost. ▪ Severe difficulty with time orientation; often disoriented to place, even in familiar locations. ▪ Definitely impaired in handling everyday tasks and unable to manage affairs; social judgment is often impaired and never seeks appropriate help. ▪ No pretense of independent function outside of room and off the unit. Appears well enough to be taken to functions off the unit. ▪ Only simple chores preserved; even TV watching poorly sustained; may still tidy up room; spends most of time just sitting in room or in day room, or wandering. ▪ Requires assistance in dressing hygiene, toileting and keeping of personal effects.
Severe	3 (scale 0-5)	<ul style="list-style-type: none"> ▪ Severe memory loss only fragments remain. ▪ Totally or almost totally disoriented. ▪ No pretence of independent function off the unit. Appears too ill to be taken to functions off the unit or needs one to one assistance in all activities off the unit. ▪ Requires total assistance with personal care; frequently incontinent. ▪ No significant function in room or on the unit. ▪ Unable to make judgements or solve problems; unable to seek appropriate help, needs staff help in all matters.

Table 17
Families at the time of video recording

Resident, age (years), severity of dementia	Visitor/s, age (years), relationship	Caregiving (years)
Edith, 93, moderate	Jan, 54, Daughter	4
	Lilly, 23, Grand-daughter	
Ruth, 76, moderate	Lori, 51, Daughter	7
	Kaye, 49, Daughter	
Phyllis, 80, moderate	Bob, 80, Husband	7
Alice, 84, moderate	Lucy, 61, Daughter	7
David, 76, moderate	Julie, 65, Wife	9
Ross, 72, severe	Dawn, 71, Wife	
	Lisa, 48, Daughter	4
Harry, 84, severe	Joy, 80, Wife	4
Esther, 80, severe	Megan, 57, Daughter	5
	Cathy, 27, Grand-daughter	
	Claudia, 2, Great-grand-daughter	
Ron, 84, severe	Betty, 76, Wife	5
Pam, 74, severe	Doug, 77, Husband	6
	Tracy, 51, Daughter	

6.1.2 Procedure

In seeking to understand awareness-related phenomena, a broad conceptual framework aimed to accommodate the multi-faceted and dynamic nature of awareness (see Section 2.7.1, p. 87 and Table 6, pp. 96-98: Levels of Awareness framework: Clare et al., 2011). A broad data-set of possible awareness expressions (speech, voice, facial expressions, and body gestures) were chosen to support this dynamic investigation of interpersonal levels of awareness and social engagement as they were co-constructed between family members (Bracken, 2002). For further details on the procedures for making video-recordings, transcription, and thematic analysis, see Section 3.3.2 on page 114, and sections 3.3.2.2.1 and 3.3.2.2.2, pp. 119–120 of this thesis. For insights on the practical and ethical implications for video and its analysis, see Section 3.3.2.2.3 on page 121.

6.2 Results and Analysis

Ten family groups (26 individuals) participated in ten 15-minute video-recorded family interactions, during the moderate and severe stages of dementia. Speech, voice, facial expressions, and body gestures were analysed using Thematic Analysis. In presenting the results for this chapter, the researcher first presents the results relating to family interactions during the moderate stage of dementia. Then, the results for family interactions during the severe stage of dementia are presented. The results are presented on an individual level and patterns in broader types of communication are described.

6.2.1 Results and analysis for interactions during moderate dementia

For family interactions, inclusive of a family member in the moderate stage of dementia, one superordinate theme, *Relational Social Engagement (RSE)* describes patterns of family interactions embedded in familial bonds. Sub-themes, *in-step* and *out-of-step* highlighted both positive and negative communication during social engagement in these families. During *in-step* interactions, attempts at social engagement by the resident member appeared confident and energised in response to *connectedness*, *security*, *inclusion*, and *meaning* within their family group. When *out-of-step*, attempts at social engagement by the in-care member were overlooked, and interpreted as *cover-up*, *control*, *indifference*, and a *retrogression*. Although awareness fluctuated in family members with moderate dementia, complex levels of awareness were observed. In response, visitors appeared to treat those thoughts and behaviours as consistent with their own. This chapter observed the possibility of *Relational Social Engagement (RSE)*, as a concept integrating retained awareness, relational and social engagement not previously noted at assessment. During *RSE*, individuals were observed to display optimal engagement within family groups. Although *RSE* could occur regardless of

whether interactions were positive or negative, *RSE* was most evident when interactions were positive. The results are presented on an individual level and patterns in broader types of communication are described. See Table 18. (Notations: see Appendices).

Table 18
Superordinate theme: Relational Social Engagement, overarching sub-themes:

<p><i>In-step</i>: positive communication during social engagement in these families.</p> <ul style="list-style-type: none"> ▪ <i>Connectedness</i>: reciprocal bond between relatives, whereby residents were in relationships and part of a family that offered meaning and supported identity. ▪ <i>Security</i>: reciprocal familiarity and trust, reflecting a deep knowing between relatives, and supporting openness and understanding. ▪ <i>Inclusion</i>: a sense of naturalness between relatives, reflecting an in-group of kindred spirits. ▪ <i>Meaning</i>: opportunities for usefulness, meaningful conversation, personal stories, and family rituals to enhance self-esteem in relatives with dementia.
<p><i>Out-of-Step</i>: negative communication during social engagement in these families.</p> <ul style="list-style-type: none"> ▪ <i>Cover-up</i>: efforts by a family member with dementia to cover losses in awareness by providing what they believed were acceptable responses. ▪ <i>Control</i>: A need for control, oscillating between visitor and resident family members, resulting in appropriate retort and annoyance in family members with dementia. ▪ <i>Indifference</i>: Indifference exposed feelings of boredom in family members living in care, and disconnection from everyday life. ▪ <i>Retrogression</i>: interactions by visitors, unintentionally creating self-withdrawal and negativity in a relative with dementia.

6.2.1.1 *In-step*

In-step interactions are experienced by families as reciprocating *connectedness*, *security*, *inclusion*, and *meaning*. This is underpinned by what appears to be a deep sense of knowing between family members. Naturalness observed during the family visits is interpreted as highlighting trust and familiarity within the family groups that facilitates reciprocal understanding, despite changes in communicative abilities. Although common patterns of *in-step* interactions are observed, how each family deals with fluctuating interpersonal awareness and engagement is unique. *In-step* patterns in communication are observed in visiting family members as open and relaxed postures, eye-crinkling smiles, chuckling, laughter, and friendly eye-contact. Similarly, positive *in-step*

expressions and gestures are common patterns in the family members who have a diagnosis of dementia, including: (1) frequent and friendly eye contact; (2) head nods; (3) eye-crinkling smiles, chuckling and laughter, often observed with playful gestures such as throwing the head back; (4) loud, clear voice; and (5) open facing palms and relaxed hand gestures. All family members are observed to frequently turn towards each other and lean in together.

6.2.1.1.1 CONNECTEDNESS

Connectedness describes a reciprocal bond between family members, whereby residents are relationally situated within a family that supports meaningful identity. For instance, Ruth's reaction to being told one of her family members is moving away long-distance is a natural one that most mothers might have in this situation. Her response to the irony in Lori's comment about "mature workers" reveals both positive maternal attachment and a continued ability to engage in conversation and to react to and use humour:

- | | |
|--------------|--|
| Lori (vis.): | Looks like we're going back to South Australia. Very shortly. |
| Ruth (PMD): | <i>(Looks to Lori. Grimaces, eyebrows furrowed, mouth falls ajar. Speaks quickly and clearly).</i> No! <i>(Mouth ajar, turns to Kaye and then Lori, eyebrows furrowed).</i> Oh no! <i>(Mouth ajar, she turns to Kaye).</i> That's too far. To live?! ... <i>(Rolls her eyes, rotates her head up to the left and down to the right, lips pressed tightly together, tipping head back).</i> |
| Lori (vis.): | They put the more <i>mature</i> workers on down there. |
| Ruth (PMD): | Oh well that's nice to know! <i>(Tipping head back, she chuckles, looks from Lori to Kaye).</i> |

Spontaneous fun, friendly eye contact, facial expressions, body gestures, and laughter flow effortlessly between a mother and daughter. There is a sense of reciprocal

understanding between Lucy and Alice and signs of positive attachment for having fun together in the moment:

- Lucy (vis.): *(Chuckles)*. What's your favourite song?
- Alice (PMD): *(Stops colouring, looks at Lucy)*. I don't know.
- Lucy (vis.): You don't know? How about 'Let me call you sweetheart?'
- Alice (PMD): Yeah. Yeah. ... *(Starts to sing in a clear voice, furrowing her eyebrows)*. "They call me sweetheart."
- Both: *(Sing in unison, holding eye contact)*. "I'm in love with you. ...
whisper that you love me too." *(Chuckle)*.
- Alice (PMD): *(Finishes the song in a loud, clear and theatrical voice, holding eye contact with Lucy)*. "I'm in love with you!!"
- Both: *(Erupt into laughter)*.

With a continued ability to engage in conversation and humour, Edith positively affirms her grand-daughter Lilly through humour of a baby photograph:

- Edith (PMD): Poor child. *(Chuckles)*. ... No wonder you weren't too happy.
(Laughs loudly).
- Jan (vis.): She was only like 5 minutes old.
- Edith (PMD): It was a bit mean wasn't it? Taking her so early. *(Chuckles looking to Jan then Lilly)*.
- All: *(Jan laughs, Edith smiles. They both look at Lilly, who is laughing)*.

6.2.1.1.2 SECURITY

Security describes reciprocal familiarity and trust that reflects a sense of deep knowing between family members. Meaningful connection between family members supports what appears to be a sense of openness and understanding between family members.

With sound awareness of the object and context, Alice appropriately assumes that when presented with a child's colouring book, it is for the children they are discussing. Like most adults, she does not expect to be brought a colouring book. However, Alice happily accepts the colouring book, suggesting that her sense of continuity is accurate yet unchallenged:

Lucy (vis.): We're going up to see the kids later. Stacey and Alex. *(Lucy holds a colouring book towards Alice).*

Alice (PMD): *(She reaches to the book with her right hand).* Oh have you got them a book?

Lucy (vis.): No. I bought you a new book. *(Lucy flips the book around towards Alice).*

Alice (PMD): *(Smiling, Alice takes the book in both hands. Smiling broadly, she turns the pages).*

Support is offered but not imposed by Ruth's daughters:

Kaye (vis.): *(Hands Ruth a coffee).* See if it's too hot. ... Is it alright?

Ruth (PMD): Yes. Hang on. Yes.

Kaye (vis.): Do you want me to put it back?

Ruth (PMD): No. ... I can hold it; I think. *(Chuckles, tipping her head back).*

And:

Jan (vis.): That's your son. Remember your son's name?

Edith (PMD): Do I remember my son's name? Oh I don't know. *(She looks at the photo, smiling, scratching behind her ear).*

Jan (vis.): *(Jan laughs, quickly touching Edith's shoulder).*

Edith (PMD): I ought to. Oughtn't I?

Jan (vis.): Oh that's okay.

Edith (PMD): Tony, he was. *(Smiles).*

Jan/Lilly (vis.): Yeah you got it! You got it! (*Smiling at Edith*).

Validation of Alice's experience without forcing her sense of time, allows for humour and exchanges that disregard factual conversation. Alice appears to be referring to the past to make sense of the present. Although challenging to interpret, this interaction appears to present new information to Lucy, and opportunity for reciprocal closure:

Alice (PMD): Are you pregnant?

Lucy (vis.): Am I pregnant? Would you like me to be?

Alice (PMD): Yeah. (*Smiles*).

Lucy (vis.): Yeah. Nah. No. Penny has a baby. I've just eaten too much.
(*Lucy chuckles*).

Alice (PMD): Oh (*Alice chuckles quietly*).

Lucy (vis.): Eaten lots of food. (*Lucy chuckles*). I think at 61 it might be a miracle if I was pregnant. (*Lucy chuckles*). What do you reckon?

Alice (PMD): Oh well.

6.2.1.1.3 INCLUSION

Inclusion describes a sense of naturalness between family members, who appear to be like an in-group of kindred spirits. Like an in-joke, a visiting spouse finds humour in the artificiality of care home living:

Bob (vis.): Did you go to afternoon activities? ... It keeps you moving. ...
And when you go and play housie you might win another
packet of crisps or something.

Phyllis (PMD): (*Chuckles*). Yeah-eh.

Bob (vis.): (*Chuckles*). Yep. —Yeah. — Yeah.

Mothers and daughters connect over what appear to be familiar ‘in-jokes’ within the family group:

- Kaye (vis.): Now that I’ve put it in my car I just can’t get it out.
- Ruth (PMD): No. *(Ruth purses her lips flat, turning her face to the right, looks upwards, raises her eyebrows and as she turns back towards the centre, nodding twice).* That’d be right.
- Kaye (vis.): *(Laughs).* Yeah I know.
- Ruth (PMD): *(Turning towards her daughter, she smiles).*

And, jokes at the expense of partners/sons-in-law bring sisters and mothers together. Synchronicity of thoughts, gestures, smiles and laughter affirm what appears to be an ongoing and humorous predicament:

- Kaye (vis.): Terry asked me why it [my back] was sore and I said “Ooh it might be the groceries and the washing?!”
- Lori/Ruth: Hm-hm. *(Nodding in unison).*
- Ruth (PMD): *(Grins, turning from Kaye to Rebecca).*
- Kaye (vis.): And he said “Oh well I’m not doing it right then.”
- All: *(Ruth tips her head back, chuckles, drinks coffee. Kaye/Lori smile).*

6.2.1.1.4 MEANING

For family members with dementia, *meaning* describes opportunities to feel needed and useful, meaningful conversation, stories of personal significance, and family rituals that support self-esteem. For example, satisfied with her recognition of past adventures, Edith’s self-esteem is validated through the broad smiles of grand-daughter Lilly:

- Edith (PMD): And this is me! *(Clear loud voice, leaning forward, firmly tapping a photo, eyes widely opened).*

- Jan (vis.): Yes.
- Edith (PMD): *(Looks from Lilly to Jan).*
- Lilly (vis.): *(Eye crinkling smile at Edith).*
- Edith (PMD): In the snow, in Canada. *(Smiling at the photo, Edith raises her eyebrows, nods, and vocalises "hmpf").*

Permission to continue family traditions through alternative pathways reflects a familiarity and respect for position held within the group:

- Lucy (vis.): Did you want to buy the ham like you usually do?
- Alice (PMD): *(Colouring).* Yes. I'll buy the ham.
- Lucy (vis.): You'll buy the ham. Okay. Do you mind if Angela organises that?
- Alice (PMD): *(Colouring).* No. I don't mind.
- Lucy (vis.): Okay. She'll organise it and probably cut it up for us.
- Alice (PMD): *(Colouring).* Okay.
- Lucy (vis.): And then you've bought the ham for Christmas lunch. You've always done that haven't you?
- Alice (PMD): *(Alice continues colouring without looking up).*

6.2.1.2 Out-of-step

Out-of-step interactions are characterised by *cover-up*, *integral assertion*, *social loss*, and *retrogression*. When family caregivers become caught-up in caregiver concerns, unintended negativity is generated, and *out-of-step* outcomes are noted. Although common patterns of *out-of-step* interactions are observed, how each family deals with fluctuating interpersonal awareness and engagement is unique. *Out-of-step* patterns in communication are observed in visiting family members as residents being cut short in response time, and hostile hand gestures of finger-pointing and finger-wagging. In turn, negative facial expressions and gestures, in family members with dementia, include: (1)

infrequent eye contact, looking away from a relative, looking about the room or at the back of one's hands; (2) biting bottom lip; (3) scratching elbows, face, forehead, behind ears, or back of head; (4) frowning and grimacing; and (5) frequent leaning away from a relative.

6.2.1.2.1 COVER-UP

Cover-up describes efforts by a family member with dementia to cover losses in awareness by providing what they believe are acceptable responses. For instance, by creatively using facial expressions, gestures, and sticking to formulaic responses, residents seek to hide their changed awareness and speech. Keen to spend time interacting with her daughters, Ruth even adopts what seems like mime to complement her safe responses. However, Kaye's muted response and mixed gestures reveal uncertainty:

- Kaye (vis.): Your back hasn't been sore lately has it?
- Ruth (PMD): No, no, no. *(Shaking her head left-to-right five times, moving her bottom lip over her top lip)*. It hasn't been too bad.
- Kaye (vis.): It's probably better too because you're taking the medicine regularly here?
- Ruth (PMD): *(Nodding twice, scrunching nose upwards)*. Oh yeah.
- Kaye (vis.): Do you think?
- Ruth (PMD): *(Juts out her bottom lip, moving her head back, shrugs shoulders. Raising her eyebrows, and relaxing, she looks to Kaye. Raising her eyebrows again, she raises hands off the chair. Raising her eyebrows again, she looks at Kaye)*. Who knows?
- Kaye (vis.): *(Without expression, Kaye shakes her head twice left-to-right and up-and-down)*.

Although it may also be a response to her current institutional status, remembering dyadic events allow Alice to maintain conversation with Lucy. Alice's playful cover-up attempts to both emphasise her positive attributes and distract from her losses in awareness:

Lucy (vis.): And what have you done today? It's Monday.

Alice (PMD): It's Monday. Oh I've been out to Thai Express.

Lucy (vis.): Who did you see?

Alice (PMD): You. *(Chuckles)*.

Lucy (vis.): Me! *(Smiles)*. I wasn't there!

6.2.1.2.2 CONTROL

A need for control permeates family relationships. Oscillating between visitor and resident family members, visiting family members seek to take over, and in-care family members strive to regain control. Wanting to be taken seriously, family members with dementia respond with appropriate retort and annoyance. For example, seeking to maintain aspects of her personal history and identity, Edith's sarcasm reveals a bid for control:

Jan (vis.): That was probably the car that Dad drove.

Edith (PMD): Most of the time.

Jan (vis.): When you went on your holiday.

Edith (PMD): *(Frowns)*. That may not have been the only car that he had.

Jan (vis.): Well it would have been about 1939 because you were nineteen.

Edith (PMD): Oh, are you working in episodes now are you?

At times this breaks down to a battle of wills:

Jan (vis.): Well I remember a few stories that you told about him.

Edith (PMD): Oh do you? Oh well, you can tell them again if you want to.

And, sensing challenge to her autonomy, Phyllis avoids being spoken for:

Bob (vis.): How did you sleep last night? ...

Phyllis (PMD): I can't remember ... *(She looks downwards, continuing to scratch her left elbow with her right hand).* ...

Bob (vis.): If you don't remember it means you've had a good night's sleep.

Phyllis (PMD): *(She faces him, before looking downwards again).* ... I don't know whether, that's what I'm saying.

Taking over, Julie overlooks David's basic choices. Not wanting anymore to drink, David responds normally by handing the glass back to Julie. However, she perceives unusual behaviour:

Julie (vis.): I'll just have a sip and then you drink the rest. Will you?

David (PMD): No.

Julie (vis.): Just have a little bit more.

David (PMD): *(Drink, passing cup to Julie).*

Julie (vis.): Why do you keep giving it to me? Do you like to share? It's very nice of you.

David (PMD): I don't want any more.

6.2.1.2.3 INDIFFERENCE

Indifference exposed feelings of boredom in family members living within care homes, and disconnection from former activities such as rugby, fishing, and child minding. When Julie points to a wall-mounted photograph, David appropriately assumes she is referring to a photo depicting the topic of their discussion. Though showing sound awareness of the object and context, David's response highlights greater interest in rugby than children:

Julie (vis.): Did you enjoy playing football?

David (PMD): Yeah I never ever wanted to retire.

Julie (vis.): Can you see that picture over there near your mirror? To your left.

David (PMD): *(He looks up, turning his head to the left).* Yeah.

Julie (vis.): Do you know who that is?

David (PMD): — I'd say it would be Collingwood United.

Julie (vis.): Oh, no the other picture with the two little children in it.

Again David responds with indifference, this time suggesting a greater interest in fishing:

Julie (vis.): Wow look at that. It's Tom and Ruby. Oh look and it's you and Ruby. How nice is that? *(Julie holds the photos up in front of David. She points to people in the photos).* — Oh, look at that one. *(She holds up a photo in front of David).*

David (PMD): Nice fish.

When David recalls a recent visit by his brother Gary, we glimpse interests unfulfilled in his care home, except through talk:

Julie (vis.): Do you remember, um, who came to see you on Sunday?
When your brother Gary came?

David (PMD): *(He moves his hands together in front of his chest clasping them together. He pauses before responding).* He bought a couple of young blokes. ...

Julie (vis.): Yeah, yeah, Neil and Doug. ... And you talked about rugby.

David (PMD): Something to do.

When conversation comes to a standstill during family visits, a husband recognises grandchildren as a missing attraction for his partner. Phyllis' response suggests that she sees his thoughts as aligned with her own:

Bob (vis.): Oh dear, we talk too much don't we? ... I should have got
Angela to bring Leo down. You wouldn't be sitting still then.

Phyllis (PMD): *(She smiles).*

6.2.1.2.4 RETROGRESSION

Despite visitors' best intentions, efforts to avoid what visitors perceive as unsafe conversational territory generate unintended upset and disengagement in the family member with dementia. For example, task focussed and concrete in his communications, Bob uses communication strategies that try to keep topics on concrete issues such as tasks, jobs, and daily routines. Seeking reassurance that Phyllis is happy and feeling well, Bob avoids discussing emotive issues and interactions that require him to work with information that is more abstract:

Bob (vis.): You know what this is all about don't you?

Phyllis (PMD): *(Turning to make eye contact, she speaks clearly).* No?
Dementia.

Bob (vis.): *(Turning quickly to Phyllis, mouth falling ajar).* It's, It's,
about, um, dementia, it's, it's about ... Did you understand
that?

Phyllis (PMD): Yeah, not, not really.

Bob (vis.): That's alright. That's okay. That's no problem. As long as
you're feeling good, you're feeling well, that's all we've got
to worry about.

However, perceiving lack of interest, Phyllis is left feeling frustrated. Her self-withdrawal into anxiety, creates a situation that Bob appears so keen to avoid:

Bob (vis.): I've got to do those, fix those two nails up. Remind me. *(He lets go of Phyllis's hand).*

Phyllis (PMD): Is there any-

Bob (vis.): -That'd be cold. *(He points to her cup).*

Phyllis (PMD): *(Looks at the cup).* Yeah. Both of them would be. *(Looks back at Bob).* Is there- *(Turns again to the cup, then back to him).*

Bob (vis.): -You've got to speak up a bit!

Phyllis (PMD): Is there, anybody else in this, this- *(Looking at Bob, Phyllis rotates her extended index finger in small circles. Looking briefly to the coffee cup, then back to Bob, she stops rotating her left hand and points at the wall).*

Bob (vis.): -facility doing this?

Phyllis (PMD): Yes. Yes. *(Nods twice, resting her left hand back on her left thigh).*

Bob (vis.): I'm not interested whether there is or not ... *(He points his index finger at Phyllis).* I've got to care about number one - *(He points his index finger at Phyllis) - you.*

Phyllis (PMD): *(She nods once ... looking away and upwards, shifting her body to her left, as she scratches her left elbow with her right hand).*

Feeling ignored before, Phyllis now responds with disinterest and appropriate annoyance. A window of previous life glimpse old patterns of irritation and the mundane:

Bob (vis.): What — will — I — have — for — dinner — tonight?

Phyllis (res.): *(Closing her eyes again, she pulls her head back, shaking her head from left-to-right).*

Bob (vis.): Go and get some tomato, couple of lettuce leaves and call in
at the fish mongers down there at Broad Beach ... get some
prawns eh?

Phyllis (PMD): *(Shakes head left-to-right, scratching her left eye).*
Yeah. I don't care. You eat them. I don't eat them.

At a conversational lull, but still seeking social engagement, interactions echo past negativity. A spouse trapped in past relational patterns misses present interactional opportunities. Bob's frustration gives way to guilty regret and Phyllis responds as if she feels minimised and rejected:

Bob (vis.): Oh dear. We talk too much don't we? *(Bites bottom lip)*. Well
I do anyway.

Phyllis (PMD): You what?

Bob (vis.): I said we talk too much! I do anyway. You don't.

Phyllis (PMD): Why?! Well?! What?!

Bob (vis.): You just sit there.

Phyllis (PMD): *(Pulling her head backwards, she looks downward, biting her
bottom lip).*

6.2.2 Results and analysis for interactions during severe dementia

For family interactions, inclusive of a family member in the severe stage of dementia, one superordinate theme: *Distinctive familial bonds* overarched two subordinate themes, *in-step* and *out-of-step*, describing positive and negative familial interactions. *In-step* interactions were noted within family groups reciprocating *social support, having fun together*, and willing to go *on the ride* with their family member who had a diagnosis of dementia. *Out-of-step* interactions were characterised by *social frustration, non-reciprocity*, and *sidelining* of family members with dementia. When visiting relatives sought to retain the familiar, *out-of-step* outcomes were observed.

However, *in-step* outcomes were observed when visitors were willing to optimise all communication possibilities. See Table 19. (Notations: Appendix 1).

Table 19

Superordinate theme: Distinctive familial bonds, overarching sub-themes:

In-step: positive communication during social engagement in families.

- *On the ride*: Visitors' spontaneous adjustment to developments, and willingness to optimise all harmonious communication possibilities.
- *Social support*: Reciprocity of emotional support (empathy, understanding, caring); esteem support (positive regard, encouragement, validating self-worth); and information support (information, advice).
- *Having fun together*: When immersed in fun, family interactions became energetic and almost automatic.

Out-of-Step: negative communication during social engagement in families.

- *Social frustration*: Negative communication patterns involving fast changing and difficult questions by visitors, social frustration, caregiver demands, and power plays.
 - *Non-reciprocity*: Unable to positively influence family interactions by the end of a family visit, those with dementia sought to reject and escape their visitors.
 - *Sidelining*: Verbal outpacing by visitors, restrictive care practices, and efforts to retain the familiar that unintentionally sidelined family members with dementia.
-

6.2.2.1 *In-step*

During *in-step* attempts at social engagement, resident family members show unique interpersonal levels of awareness and social interaction that are embedded in *positive* distinctive familial bonds. Visitors' responses indicate that they see the thoughts and behaviour of that person as aligned with their own. Although common patterns of *in-step* interactions are observed, how each family deals with the fluctuating interpersonal awareness and engagement is unique. *In-step* patterns in communication are observed in visiting family members as: (1) checking hearing-aids and glasses; (2) positive eye contact to gain focused attention; (3) introducing the family visit (e.g., reason for visit, name, relationship) and politely repeating this if necessary; and (4) inviting engagement rather than demanding it. In relation to speech interactions, *in-step* interactions included: (1) short simple sentences; (2) staying on topic; (3) avoiding

repeated questions, especially direct questions taxing upon short-term memory; and (4) allowing time for response. Also, engagement was encouraged through the senses, with family caregivers seen: (1) reciprocating positivity and spontaneity; and (2) validating thoughts and emotions as aligned with one's own. In response, positive speech and non-speech expressions and gestures are common patterns in family members with dementia. For example, *in-step* non-speech patterns of communication include: (1) frequent eye contact, including looking to the relative; (2) frequent head nods; (3) leaning-in towards visiting relatives or objects such as family photos; (4) touch and holding hands; (5) kisses; (6) eye-crinkling smiles, laughter, and laughter with the upper body shaking; and (7) relaxed and playful facial expressions and body gestures.

6.2.2.1.1 ON THE RIDE

Visiting spouses experience *on the ride* interactions as commitment underpinned by acceptance of social losses, flexible adjustment to developments, and positive approaches to engagement. Observed visitors are committed to reciprocity, and willing to optimise all communication possibilities.

Committed to an authentic connection with their partner, visiting spouses seek to invite their partner to engage, in way that is both respectful and accepting of social losses. For example, Joy makes her social presence felt in a positive way with partner Harry. Her desire to reciprocate is observed in attempts to gain answers to confirm her interpretation of his wishes:

Joy (vis.): I've brought you something. (... *kneeling in front of him she holds a lunchbox towards him, holding his gaze*). I've come to see you. And I've brought you something. Your favourite.
Well I think it's your favourite? Look.

Harry (PSD): (*Harry looks down into the container*).

Willing to follow Harry's social lead, Joy is rewarded with unexpected intimacy. Their dance is interpreted as a distinctive spousal bond that facilitates Harry's complex goal-directed behaviour:

Harry (PSD): *(Stands up).*

Joy (vis.): Oh, we getting up? *(Kneeling, she moves aside and stands to join him).* Where are we going? *(She holds his right hand).*

 Do you want to dance?

Harry (PSD): *(Places his left hand in her right hand).*

Joy (vis.): *(Starts to sing).*

Both: *(They start swaying from side to side. Harry prompts Joy to pirouette ... They both stop dancing, and in unison bend their knees once).*

For spouses continuing *on the ride* together, relational bonds were more important than the loss of short-term memory:

Pam (PSD): I don't know why I was late. *(She turns to look at him).* All I care about is you.

Doug (vis.): Is it darling? Well you're the love of my life.

Pam (PSD): Yeah. You're the love of my life too. *(She holds Doug's gaze).*

Doug (vis.): *(Holding her gaze he strokes the top of her fingers with his thumb. He swallows back tears and squeezes her hand).*

6.2.2.1.2 SOCIAL SUPPORT

Social support is observed as a reciprocal need between family members, encompassing emotional support (expressions of empathy, understanding, and caring), esteem support (positive regard, encouragement, and validating self-worth), and information support (providing information and advice). Positive responses by visiting family members validate and maintain interactions.

Still recognising his wife as a family historian, Doug seeks help to identify old family photographs. Pam's efforts to hide her social losses are validated positively and sensitively by Doug. His desire to reciprocate is observed in attempts to confirm his interpretation of Pam's level of interest:

Doug (vis.): I found some photos at home. I brought them down just for you to tell me what and where they are. *(He moves his right hand several times back and forth across the back of a photo).*

Pam (PSD): *(Nods several times at Doug).* Oh right. Good on you Doug. *(She looks slightly away).* Cause I was, I was going to, going to *(Pam stutters and looks towards Doug. He continues stroking her fingers with his thumb)* start to do that-

Doug (vis.): -Were you?

Pam (PSD): -but I didn't get around to it.

Doug (vis.): Yeah there's a couple there ... that you've written on the back.
— Happy about that?

For the remainder of the family visit, with encouragement, patience, and occasional prompting, Pam provides information on most photos as Doug records the details. In turn, they reconnect and experience happiness:

Pam (PSD): Ah-

Doug: (vis.) *(His face breaks into an eye-crinkling smile).*

Pam (PSD): -yeah. *(Her face breaks into a broad smile).*

Doug: (vis.) *(Chuckles with belly shaking, eye-crinkling smile, looking at Pam's face).*

Visiting spouses, now running all aspects of the household, continue to seek expertise from their resident partner. The commitment of resident members to reciprocate is observed in attempts to offer information and advice:

- Dawn (vis.): That new bull.
- Ross (PSD.): Yeah?
- Dawn (vis.): He's getting a bit aggressive.
- Ross (PSD.): That's the way they go.
- Dawn (vis.): I know, but the last one didn't ...
- Ross (PSD.): Some are placid and some aren't. ... The Black Pole comes out in them ... they get a bit toey.
- Dawn (vis.): He's pawing the ground.
- Ross (PSD.): You got the horns off him? ... You can't have him around.

Unfazed by Ross' upsetting and retrospective self-evaluation, Dawn and Lisa's empathic validation brightens his perspective on his social losses. This is interpreted from his relaxing facial expressions:

- Ross (PSD.): The last 12 months, I've been hopeless. *(Ross's voice is emotional and faint. He starts to cry).*
- Dawn (vis.): Oh but you couldn't help that. It was ... the illness. ... It's a hard slog isn't it? *(Dawn kisses Ross on his right temple. ... She squeezes him in her embrace and ... then drapes her left arm over his shoulder to hold and occasionally rub his shoulder with her hand, while she cups his right knee against her right hand).*
- Lisa (vis.): It's been really hard Dad, *(she extends her right hand to touch his left hand)*, but ... I'm really proud of the way you've handled this ... I really admire you Dad.
- Ross (PSD.): *(His face starts to relax).*

Lisa (vis.): Really; you've had an amazing life. And it's still continuing.
There's always change isn't there? You should be proud of
yourself. Are you? *(Lisa holds eye contact with him).*

Ross (PSD): *(His face relaxes further).*

6.2.2.1.3 HAVING FUN TOGETHER

Absorbed in shared memories or activity, familial bonds for having fun together present all family members with opportunities for reciprocal wellbeing. Meaningful memories are seen to encourage two-way and three-way chatty conversations:

Cathy (vis.): They had beautiful big pancakes.

Esther (PSD): Oh yes, yes.

Cathy (vis.): Yes, they had beautiful big pancakes there.

Megan (vis.): Chocolate for breakfast. *(Everyone laughs).*

Esther (PSD): Yes. Yes!

Cathy (vis.): Only on holidays. Look!

Esther (PSD): Oh, look at the whole family. *(Everyone laughs).*

Commitment to change familiar ways of interacting also presents opportunities for reciprocal wellbeing. Flexibly reciprocating Harry's energetic and playful expressions, Joy validates Harry's thoughts and behaviour and appears to see his responses as aligned with her own. Immersed in the moment, interactions between her and Harry become increasingly spontaneous and almost automatic:

Joy (vis.): Do you want to play ball?

Harry (PSD): *(Harry moves his left hand, palm perpendicular in a slow loping left-right-circular motion. He opens his eyes, looks at the ball and smiles. ... As they play his facial expressions become more animated and he starts to mumble with voice ... He smiles and throws the ball high).*

With increasing energy, Harry initiates a joke through his behaviour. Joy's reaction's and response appear to confirm this:

Harry (PSD): *(He leans forward from his waist, smiling, holding Joy's gaze, raises his eyebrows briefly, and moves in a way that suggests he will throw the ball high. Instead he quickly throws the ball low and straight to Joy).*

Joy (vis.): *Ooop! (Catches the ball, chuckling she quickly crouches down and then jumps up while stomping her feet, twisting her body around and leaning towards Harry with her arms outstretched).*

Harry (PSD): *(He leans back, raises his eyebrows, and with an eye-crinkling broad smile and his upper body shaking he chuckles, still holding Joy's gaze).*

Joy (vis.): You think that's funny!

As their playfulness gathers momentum, Harry starts to speak. This presents more opportunities for reciprocal wellbeing and validation of Joy's efforts to reciprocate:

Harry (PSD): That was a good one. *(Smiling, he holds Joy's gaze).*

Joy (vis.): *(Laughs).* That was a good one. Yes. ... It makes a funny noise doesn't it? Listen. *(Bounces the ball across to him).* Makes a funny noise; can you hear?

Harry (PSD): *(Tilts his head, and rotates his head left to right, smiling).*

Commitment to reciprocate is observed in Harry's self-reflection. His creative responses compensate for his difficulty finding words:

Harry (PSD): *(Looks at Joy's face, runs his palm across the top of the ball and raises his eyebrows).* It's a very nice colour. ... It's a very nice one.

Joy (vis.): (*Smiles at him*). It's a nice ball, yeah. ... Do you know what colour it is?

Harry (PSD): It's the colour I like.

However, reciprocity can go too far. Appearing to monitor both his actions and Shirley's negative response, Harry acknowledges his mistake. Positive closure comes in Joy's acceptance and validation:

Harry (PSD): (He rotates the ball in his hands and brings it to his mouth, licking the ball with his tongue).

Joy (vis.): Now, don't do that. (Joy approaches him).

Harry (PSD): (He looks at Joy and removes the ball from his mouth) ... I know. (He bites his bottom lip and looks downwards).

Joy (vis.): You know.

6.2.2.2 *Out-of-step*

Conversely, during *out-of-step* interactions, unique interpersonal levels of awareness and engagement in family members with severe dementia are embedded in what appear to be negative yet distinctive familial bonds. During *out-of-step* interactions, family interactions evoke a reciprocal sense of syncopated irritation, frustration, rejection, and escape. Each family group is unique in how they deal with the fluctuating interpersonal awareness and engagement, although common *out-of-step* interactions were observed.

Out-of-step patterns in communication are observed in visiting family members as few attempts to confirm interpretation of their family member's wishes, and demanding engagement rather than inviting it. When speaking, visitors were noted to: (1) use long complex sentences; (2) rapidly change topics; and (3) quickly pose questions, and pose difficult questions, especially direct questions taxing upon short-term memory or requiring complex comparisons. Furthermore, visiting relatives were observed: (1)

outpacing the in-resident member; (2) ignoring; (3) overlooking social cues of negativity; and (4) invalidating responses and reactions, including physically blocking the person from moving. In response, negative speech and non-speech expressions and gestures are common patterns in family members with dementia. As such *out-of-step* non-speech patterns of communication included: (1) infrequent eye contact, including looking away from a relative, and looking about the room; and (2) staring at visitors, frowning, and biting bottom lip; (3) scratching elbows, face, behind ears, back of head; and agitatedly rubbing hands together; (4) groans and sighs; and (5) frequent leaning away from a relative, withdrawing or retracting from touch, attempting to walk away, and eventual slumped posture while looking downwards.

6.2.2.2.1 SOCIAL FRUSTRATION

For family members with dementia, negative patterns of communication involving visitors' fast changing and difficult questions generate frustration. When frustration spills over to visitors as well, spousal authority and control issues are illuminated.

Anxious and impatient family members overlook social cues of negativity. As such, Ron becomes increasingly anxious and agitated as Betty continues asking questions that he cannot answer:

Betty (vis.): Listen, have you got a new mate in your bedroom have you?

Ron (PSD): (*Slightly turns towards Betty and groans*). Ohhh, I don't know.

Betty (vis.): Listen, did you have a good sleep? (*She looks at Ron*).

Ron (PSD): (*Ron looks at Betty*).

Betty (vis.): You don't know?

Ron (PSD): (*Looks downwards*). No I don't.

Betty (vis.): And have you been going for walks with Dianne? (*Places her left hand on his right hand and leans into him*).

Ron (PSD): *(Sighs, rubs his palms together, looking downwards)*. I don't know!

Feeling powerless to positively change communication patterns during family visits, agitation in resident family members gives way to sarcasm:

Betty (vis.): Who was your best friend?

Ron (PSD): I suppose not me!

Betty (vis.): Bill Hamilton?

Ron (PSD): Well you can find out from him!

Where sarcasm is reciprocal, attempt to control emerges. Feeling helpless to re-engage her resident husband, Dawn's frustration spills over to anger. Correctly sensing that his authority as husband is being challenged, sarcasm is reciprocated between husband and wife in a struggle for authority:

Dawn (vis.): *(Dawn raises her voice speaking to Ross)*. Well I'm here!

Ross (PSD): *(Turns to stare at Dawn)*. That's a rare occurrence. I can tell you.

Dawn (vis.): Oh does it seem rare does it? I was only here on Thursday. Today's Tuesday.

Ross (PSD): *(Still staring at Dawn, he twists his body to scratch his leg)*.
How many visits out of — four days though were you here?

Underpinned by what appears to be negative marital dynamics, efforts to impose authority reveal insecurity:

Ross (PSD): So who's — who's living out there?

Dawn (vis.): Me. Just me. — And Blue.

Ross (PSD): Blue what?

Dawn/Lisa: Blue, the dog.

Ross: (PSD) You still living there on your own?

Dawn: (vis.) Yes. Yes. Ye-up. That's fine.

6.2.2.2.2 NON-RECIPROCITY

Non-reciprocity describes missed cues by both visiting and in-resident family members. When visitors repeatedly miss cues of negativity, residents seek to reject and escape their visitors through social excuses, walking away, or psychological withdrawal. For example, Esther rejects her family towards the end of the visit, leaving her visitors appearing uncertain and on-edge:

Megan (vis.): Do you want to come and have a cup of tea now?

Esther (PSD): Oh I think I might have to go. ... I'll have to be in a hurry. I've got to go down to Geelong, um, a long time ago ... I've got to go to oh-oh dear-o-dear ... Oh my god I won't be able to do that!

Megan (vis.): How about we go and have a cup of tea first?

Esther (PSD): No! No! No!

During discord, touch does not resolve tension between some family members. Physically blocked from being himself, Ron seeks to both reject and escape his wife:

Betty (vis.): *(She reaches to touch his hand).*

Ron (PSD): *(He withdraws his right hand from her touch. Ron pushes back with both hands against the arm of the chair but is unable to stand up because of Betty's left hand against his chest).*

Betty (vis.): No sit down. Sit down. No. No. No. Sit down ...

Ron (PSD): *(Turns to look at Betty).* Oh what are you talking about?!

When physical escape is impossible, resident members appear to psychologically withdraw:

(Sitting at 45 degrees to Ron [PSD], Betty holds her left hand on Ron's [PSD] right shoulder, looking at his face as she continues asking questions. Responding little, Ron [PSD] sits with his shoulders slumped, hands on his knees, eyes cast downwards).

6.2.2.2.3 SIDELINING

Seeking to retain the familiar, visitors become caught up in frustrations that unintentionally sideline the family member with dementia. For example, seeking to retain familiar standards of dress for mothers in care, well-meaning but pushy adult-daughters unintentionally sideline their mothers:

Pam (PSD): Oh careful Tracy!

Tracy (vis.): Oh sorry. *(Tracy, bent at the waist, forcefully attempts to put a shoe on Pam's foot).*

Pam (PSD): Don't go too- *(Frowns, looking at Tracy who is bent-over adjusting Pam's shoe).*

Tracy (vis.): -Mum-

Pam (PSD): -rough! *(She frowns, watching her daughter bent-over adjusting Pam's shoe). ... Arrghh!! ... Oh careful!*

When at-home rituals of a late night drink of port collide with in-care routines of an early bedtime, the social rhythms of resident family members are sidelined by the system. Attempts by a wife to personalise care are disregarded by care home priorities that increase the shadow of dementia over all aspects of life. In turn, the resident is left feeling resentful:

Dawn (vis.): Have you been having some of your special port of a night?

Ross (PSD): No. ... I'm asleep before then.

Dawn (vis.): Because I bought some ... down for you.

Ross (PSD): Waste of time. ... Take it home.

When efforts to personalise care for a mother fail, regression briefly emerges in an adult-daughter. Not only sidelined by the system, the mother is left sidelined by the best intentions of her discordant visitors:

Tracy (vis.): Why don't we- *(Looking from the wall to Doug, oscillates her hand with thumb extended from her chest to the wall).*

Doug (vis.): *(Looking at Tracy, his mouth ajar).*

Tracy (vis.): -pretty this place up a bit? *(Crosses her arms, sighs)* .

Doug (vis.): Well how? *(Looking at Tracy, Doug shifts in his chair, frowns and holds his right hand up palm facing up. Then he holds his left hand palm-forward touching each finger as he speaks each point).* She doesn't like the TV; doesn't like the radio; doesn't want a fridge.

Pam (PSD): *(Leans back, looks away from her feet, settling into her chair. She adjusts her glasses, clasps her hands in front of her chest. Rubbing the top of her right hand against the palm of her left, she looks at Tracy).*

Tracy (vis.): Doesn't have to be a TV. Doesn't have to be any of those things, but what about a vase with flowers in it? ... Nothing can go up on the wall can it?

6.3 Discussion

As far as the researcher can ascertain, this chapter presents the first studies seeking to investigate video-recorded interpersonal levels of awareness and social engagement during family visits inclusive of a family member who is in the moderate or severe stage of dementia. Although awareness fluctuated in family members with

dementia, complex levels of awareness were observed during the moderate stage of dementia (e.g., complex goal-directed movement, performance monitoring, and self-evaluation, and continued ability to engage in family conversation and to react to and use humour). Observed levels of awareness ranged from sensory perception (e.g., Harry listening to the sound of the bouncing ball) and appraisals in the moment (e.g., Ron withdrawing his hand from his wife's touch) to complex goal-directed movement (e.g., Harry initiating dance), performance monitoring (e.g., Harry apologising for licking the ball), and retrospective self-evaluation (e.g., Ross' negative self-assessment for the previous 12 months).

Levels of awareness were also inclusive of expressions of self (e.g., positive and negative beliefs, comparison of past and present, and familial roles as manifest through family visitors). Within this chapter, awareness was accepted as accurate when the responses and actions of family members were considered reasonable in the context in which they were expressed (Magai et al., 1996; Clare et al., 2008a, 2008b; Walmsley & McCormack, 2014). Specific to these studies, the reciprocal responses of visiting relatives lent support to these interpretations when they appeared to treat the thoughts and behaviours of the resident family member as aligned with their own. Therefore, the levels of awareness and social interactions identified during the family visits were inconsistent with expectations set by the CDR (see Table 16, p. 181). Although the CDR is a well evidenced clinical staging tool, like most other staging tools, it was developed before the biopsychosocial view of disease, which may explain why none have received widespread acceptance (O'Bryant, Waring, Cullum, & Hall et al., 2008; Olde Rikkert, Tona, Janssen, & Burns et al., 2011; Power, 2014; WHO, 2002).

Indeed, the ongoing use of standardised assessments in care homes "decontextualises the person as a social being and places him or her in a clinical setting

that is controlled by a system of thought” (Voris, Shabahangi, & Fox, 2009, p. 46).

Although standardised tests provide useful information regarding disability, overall functioning, and estimated stage of disease, their overuse contributes to views that undermine a person until they become seen as “a series of discrete cognitive tasks” (Power, 2014, p. 43). By virtue, standardised staging tools are deficit and function focussed, rarely measuring awareness, conversational, or social abilities, but tending to assess functioning in relation to activities of daily living (Olde Rikkert et al., 2011).

Therefore, the real problem with standardised assessment tools may not be the tools themselves, but the idea that any one assessment can stage dementia severity for a person living with a complex condition. As a result, residents are considered to require certain activities, approaches to care, and living environments. Indeed, there are no other groups of people in western economies, besides prisoners, who are segregated both ‘for their own benefit and ours’ (Power, 2014). In extreme circumstances, individuals with dementia become seen as “zombies”, “fading away” and “dying twice” (Power, 2014, p. 46) and standardised assessments become a self-fulfilling assessment of qualities that reinforce medical model views at the expense of more holistic perspectives (Shabahangi, 2014). Furthermore, when a medicalised approach to care overrides a homelike environment within care homes, features (e.g., nursing stations, hospital beds, hospital call systems, hospital flooring, bed screen curtains, showers centred near thoroughfares, hospital food, and medication trolleys), which reinforce depersonalisation, dependency, and decline (Power, 2014).

Furthermore, the findings presented in this chapter indicate that *Relational Social Engagement (RSE)* was observed, whereby individuals display optimal engagement within family groups. Although *RSE* could occur despite whether interactions were positive or negative, *RSE* was evident when interactions were positive. *RSE* highlights

that embodied experiences, emotions, and sensory exchange become increasingly central to the social experiences of individuals in the severe stage of dementia. Similarly, family members with severe dementia were also more reliant on the willingness and ability of visiting family members to engage in creative non-speech ways.

Building on earlier themes (Walmsley & McCormack, 2014), it was observed that families could be both *in-step* when visitors were willing to optimise all communication possibilities, and *out-of-step* when visiting relatives sought to retain the familiar. During the moderate stage of dementia, *in-step* interactions were observed as attempts at social engagement when the in-care member appeared confident and energised in response to *connectedness, security, inclusion, and meaning* within their family group. Conversely, *out-of-step* interactions during moderate dementia, were characterised by *cover-up, control, indifference, and retrogression*. During the severe stage of dementia, *in-step* interactions were noted within family groups experiencing reciprocal *social support, having fun together*, and relatives willing to go *on the ride* with their family member with dementia. Moreover, a deep sense of knowing and natural ease between family members characterised *in-step* family interactions, which was underpinned by what appeared to be trust and familiarity. When *out-of-step* during severe dementia, carer concerns generated unintended negativity, and interactions that were observed as experiences of *social frustration, non-reciprocity, and sidelining* of those with dementia. However, despite *out-of-step* discord, residents sought to maintain aspects of personal history, exercise choice, and express their point of view during family interactions.

Indeed, the relationships in this chapter were unique, both in terms of their dynamics and duration, in comparison to other studies, where observations were made of the relationships between individuals with dementia and researchers, staff, and residents (Götell et al., 2009; Kontos, 2004; Sabat, 2001). These participants were

immediate family members with an extensive history that included up to 9 years of living with the impact of dementia. Furthermore, without researchers or staff present, engagement and awareness in the family members with dementia and the reciprocal responses and reactions of their visiting family members were likely to reflect *interactions as normal* as much as possible. Therefore, the relationships between the participants in this chapter differed from other studies, even where a shorter-term relationship has emerged between residents or between individuals with dementia and staff or researchers (Götell et al., 2009; Sabat, 2001; Kontos, 2004). Indeed *distinctive familial bonds* were observed within these families, that could be both positive (e.g., play, storytelling, social support, and intimacy) and negative (e.g., suspicion, mistrust, and frustration).

Even though interactions were positive or negative, this chapter identified *RSE* within families not previously expected during assessment. Although *RSE* was observed during *out-of-step* interactions, it was evident during *in-step* interactions. On one hand, this observation reinforces the view that individuals with dementia both flourish through positive person centred interactions and find it difficult to challenge others when unintentionally positioned in a negative way (Kitwood, 1997; van Lagenhove & Harré, 1999). On the other hand, it offers a qualitatively different perspective in that despite complex negative interplay, when either resident or visitor was ignored, challenged or criticised, the responses of the other member indicated appropriate hurt, retort, or annoyance.

Indeed, awareness studies involving interviewers and residents with moderate-to-severe dementia have demonstrated resident avoidance, in response to the interviewer and the direction of the conversation (Clare et al., 2008a, 2008b; Sabat, 2001). Examples include the resident changing the topic, humming, singing, or leaving the conversation

when the topic was seen as difficult, disinteresting, sensitive, or threatening to self-competence (Clare et al., 2008a, 2008b; Sabat, 2001). However, in this chapter, observed avoidance in response to visitors (e.g., changing the topic, looking away, looking about the room, retracting from touch, withdrawing, or walking away) was displayed alongside instances of problem-solving and assertive—and at times aggressive—efforts to reposition self positively. Such repositioning included residents seeking clarity through questions, expressing viewpoints, frowning, agitation, groans and sighs, raising voice and staring. Efforts were also interpreted as self-serving, when residents sought to restore the status quo if their sense of continuous-self appeared to be challenged (as interpreted when Pam excuses her failure to record family photographic history because she “didn’t get around to it”). As a result, residents were found not only to retain family membership but retain integrity as individuals. Therefore, it would seem that distinctive familial bonds within families offered a sense of security and familiarity in which to both enjoy common ground and express differences.

Although it has long been recognised that “the responsibility for effective communication between people lies with the listener as well as with the speaker” (Sabat, 2001, p. 39), opportunities for meaningful communication remain poorly supported within residential aged care. Despite the overriding mission to individualise care, practitioners may lack the authority to diversify a dominant and hierarchical medical model for the wellbeing of residents (Beck et al., 2012; Erickson-Lidman et al., 2013). Limited availability of care practitioners related to poor remuneration, inadequate training, time pressure, and emotional labour contribute to high staff turnover (Bailey et al., 2015; Beck et al., 2012; Erickson-Lidman et al., 2013; Sargent et al., 2008, 2009, 2010). Cumulative upon rotating staff rosters, it is likely that familiarity and trust is undermined within residents, leading to insecure resident-staff

relationships (Power, 2014). However, family visits would appear to present an important opportunity for residents to socialise in a personally meaningful way.

Within this chapter, when visitors overlooked the psychosocial needs of a family member with dementia, a reciprocal and commensurate response was observed in the resident. Hence, neither visitor nor resident experienced psychosocial needs fulfilment. However, family visits presented opportunities for residents to express both complex levels of awareness and aspects of self. Additionally, the momentary relational interactions depicted in this chapter suggest that family visits offer opportunities for all family members to restore psychosocial needs (e.g., desires to be taken seriously and feel useful, and experience spontaneous fun, belonging, and love).

6.3.1 Conclusions and recommendations

Therefore, this chapter addresses an important dimension of the lived experiences of individuals with moderate dementia and their family members. In particular, it offers a window into the creativity that families bring to the dementia experience to remain connected socially, emotionally, and physically. Within this chapter, awareness was retained beyond assessed levels in those with moderate or severe dementia during family interactions. *Relational Social Engagement (RSE)* was observed (whereby individuals display optimal engagement within family groups during negative to positive interactions). *RSE* highlights that embodied experiences, emotions, and sensory exchange become increasingly important to the social experiences of individuals as dementia progresses, and family members are relied on for their willingness and ability to engage in creative non-speech ways. Moreover, in the severe stage of dementia, the efforts of family members to support and restore interpersonal awareness levels and social interaction may be more important than ever before. As such, the findings in this

chapter present an opportunity for an individualised family focus to recover opportunities for *RSE*.

6.4 Chapter close

In this chapter, levels of retained awareness were found to exceed the levels at which the family member with moderate or severe dementia had been assessed. Despite whether interactions were positive or negative, this chapter identified *Relational Social Engagement (RSE)*, whereby individuals display optimal engagement within family groups. Conceptually, *RSE* integrates the ability to access retained awareness, relational and social engagement not previously expected during assessment. Situations where this can occur can be *in-step* or *out-of-step* and therefore positive or negative. The authors define *RSE* as a complex and accessible set of relational interactions between family members that is situated in distinctive familial bonds.

In this thesis, this chapter is central, in providing a theoretically rich and unexpected model of functioning in moderate and severe dementia when those with dementia are situated socially within their familiar family group. It encourages further exploration of the interpreted phenomenon of dementia additional to that of health care managers and the objectivity of the observing researcher. In the next chapter, the researcher seeks a broader lens into the systemic experience of families by exploring: (1) family carers' positive and negative interpreted experiences of supporting a family member with dementia prior to and during admission to a care home within a western health care system; and (2) their subjective insights and meaning making of the psychosocial impacts of dementia on the individual caregiver and family relationships.

CHAPTER 7 Family Caregivers

Navigating a hierarchical health care system, and the impact of dementia on family relationships

7.0 Introduction

Dementia presents challenging situations for families, especially when a member with dementia requires hospital and care home support later in the disease trajectory (AIHW, 2012, 2013; Callahan, Arling, Wanzhu, & Rosenman et al., 2012; Prince, Knapp, Guerchet, & McCrone et al., 2014). Indeed, the losses experienced by family members start early and accumulate over time (see chapters 4 and 5). Of their experienced losses, the progressive and fluctuating psychosocial loss of “missing the person” may be the most difficult (see Chapter 4, Boss, 2010; Santulli & Blandin, 2015, p. 87). Although a range of negative and positive aspects of caregiving exist (Folkman & Maskowitz, 1997; Kramer, 1997; Lawton et al., 1991), how this situation will impact on the psychological wellbeing of family members fulfilling the caring role, especially if those carers are themselves no longer young or several generations are involved in care, is a new area of research.

Therefore Chapter 7 aims to investigate the subjective interpretations of family groups supporting a member with dementia prior to and during admission to a hospital or care home in a hierarchical health care system, and their interpretations of the psychosocial impact of dementia on the individual family caregiver and their family

relationships. Both positive and negative subjective interpretations from family caregivers across the dementia trajectory are sought in this chapter.

7.1 Method

7.1.1 Participants

Following university ethics approval, family members with guardianship status were invited to participate, by the directors of aged care services at five care homes. Inclusion criterion was an in-resident relative with mild, moderate, severe, or profound dementia, as assessed by the directors using the Clinical Dementia Rating Scale (CDR: Morris, 1993). See Section 3.3.1, p. 112, for further details on participant selection and recruitment. For demographics, see Table 20. (Notations: see Appendices).

Table 20
Family groups at the time of data gathering

Resident, age (years), stage of dementia	Visitor/s, age (years), relationship	Caregiving (years)
Jack, 96, mild	Linda, 67, Daughter	3
	Stephen, 52, Son	
Rose, 83, mild	Gail, 55, Daughter	6
Frank, 82, mild	Danielle, 42, Daughter	10
Jessie, 73, mild	Kym, 52, Daughter	12
	Craig, 56, Son-in-law	
Edith, 93, moderate	Jan, 54, Daughter	4
	Lilly, 23, Grand-daughter	
Ruth, 76, moderate	Lori, 51, Daughter	7
	Kaye, 49, Daughter	
Phyllis, 80, moderate	Bob, 80, Husband	7
Alice, 84, moderate	Lucy, 61, Daughter	7
David, 76, moderate	Julie, 65, Wife	9
Don, 70, severe	Joan, 70, Wife	4
Ross, 72, severe	Dawn, 71, Wife	4
	Lisa, 48, Daughter	
Harry, 84, severe	Joy, 80, Wife	4
Esther, 80, severe	Cathy, 57, Daughter	5
	Diane, 53, Daughter	
	Megan, 27, Grand-daughter	
	Kayla, 26, Grand-daughter	
Ron, 84, severe	Betty, 76, Wife	5
Pam, 74, severe	Doug, 77, Husband	6
	Tracy, 51, Daughter	
Helen, 96, profound	Gary, 72, Son	10
	Susan, 64, Daughter-in-law	
Deborah, 69, profound	Richard, 72, Husband	10

7.1.2 Procedure

See sections 3.3.2, 3.3.2.1, 3.3.2.1.1 and 3.3.2.1.2, pp. 114–116 of this thesis, for further details on the procedures for interview data collection and analysis. For a copy of the interview schedule, see Appendix 4, p. 339.

7.2 Results and Analysis

In presenting the results and analysis for Chapter 7, the researcher first presents the findings in relation to aims of participants' subjective interpretations of supporting a member with dementia prior to and during admission to a hospital or care home in a

hierarchical health care system. Then he will present participants' interpretations of the psychosocial impact of dementia on the individual family caregiver and their family relationships. Both positive and negative subjective interpretations from family caregivers across the dementia trajectory are presented in these findings.

7.2.1 Results and analysis regarding families and the care system

Family members subjective interpretations of entering and navigating a hierarchical health care system revealed one superordinate theme, *Mistrust/Integrity*, describing each family's oscillating struggle with mistrust in the system and sense of personal integrity. Within this fluidity, two sub-themes, *Intrinsic-trauma*, and *Extrinsic-trauma* describe distress that caused self-withdrawal into sadness and guilty rumination, or externalised expressions of frustration and anger. Intrinsic trauma responses were dependent upon a perceived pressure to conform to the system, whereas extrinsic trauma occurred in response to perceived harm and injustice towards their family member. Motivated by mistrust that challenged moral integrity, *Growth* describes a redefining of self that nurtured hope, moral courage, gratitude, and further change through advocacy. See Table 21. (Notations: Appendix 1).

Table 21
Superordinate theme, Mistrust/Integrity, overarching sub-themes

<p><i>Intrinsic-trauma</i>: emotional responses directed inwards, by all members of the family, when situations triggered a retreat into submission.</p> <ul style="list-style-type: none"> ▪ <i>Unequals</i>: when practitioners adopted the expert stance, relatives were caught off-guard and left feeling inadequate, unprepared and disempowered as carers. ▪ <i>Guilty failure</i>: despite delaying the move into institutional care for as long as possible, guilty failure was experienced by relatives when home care was finally relinquished. ▪ <i>Guilty submission</i>: yielding to a hierarchical health system, relatives witnessed helplessly as a family member was subsumed by institutional care. ▪ <i>Rumination</i>: ruminative brooding in relatives about care decisions and inadequacy as carer. This appeared to perpetuate guilty worry and shame. <p><i>Extrinsic-trauma</i>: emotional responses directed outwards, by all members of the family, depending on situations that triggered a need for advocacy.</p> <ul style="list-style-type: none"> ▪ <i>Vigilance</i>: when relatives perceived threat within the medical system, it precipitated their mistrust and efforts to advocate for a relative with dementia. <p><i>Growth</i>: taking a moral stand, relatives experienced strengths of character and capabilities that came to positively redefine care and personal choices.</p> <ul style="list-style-type: none"> ▪ <i>Moral courage</i>: standing in the face of adversity or unpopularity, relatives discovered integrity, assertiveness, bravery, and perseverance. ▪ <i>Gratitude</i>: recognising that life cannot be taken for granted, relatives experienced wonder and thankfulness for life itself, positive acts and good people around them. ▪ <i>Hands-on advocacy</i>: moving beyond traumas and grim realities, relatives redirected their distress into problem-solving that spilled over from private to public domains.

7.2.1.1 *Intrinsic trauma*

For all family members, *intrinsic-trauma* represents responses directed inwards, when situations trigger a retreat into submission. Sadness, guilt, rumination, anxiety and shame are internalised by family caregivers in response to dementia care models that reduce their role in advocacy. Confusion, loss of appetite, and sleep disturbance are noted in family members with dementia when adversarial health encounters trigger submission.

7.2.1.1.1 UNEQUALS

Feeling inadequate, unprepared and disempowered as caregivers, relatives are caught off-guard when practitioners adopt the expert stance. Feeling inadequate, family members draw negative first impressions of the support that they receive:

I felt out of my depth ... like I wasn't on their level (Joy).

Forced into silence by time-poor doctors, family members feel unprepared as carers. A prognosis and its impact on family members remain undiscussed:

For me it wasn't fully explained ... I didn't ever think to ask "What will this mean?" (Kaye)
In astonishment, a wife witnesses adversarial care and a husband being devalued because of his dementia diagnosis. Conversely, when that partner is the sole focus of consultation, the carer feels disempowered. Nevertheless, family caregivers excuse poor treatment rather than challenge the status-quo:

David would sometimes interrupt ... Dr Wilson would say "I'm not talking to you, I'm talking to Julie." I thought "That's a bit mean, cutting David right out. He doesn't need that right now" ... but his time is so limited. [Whereas] Dr Grey wouldn't talk to me. She would only talk to David ... I couldn't tell her what was happening at home ... [but she] made him feel — good, like a person (Julie).

7.2.1.1.2 GUILTY FAILURE

Despite delaying the move into institutional care for as long as possible, relatives experience guilty failure when home care is finally relinquished. Unable to help his wife resolve guilty rumination, a husband describes frustration with delays seeking support:

I couldn't do it (Kym). For two years we talked about "she needs to go into care" (Craig). ... I didn't want to do it before she absolutely needed to. ... Guilty ... second-guessing whether we were making the right choice and going over it and over it and over it (Kym).

Daughters, like Kym, speak of a “heart rending” situation when a mother moves into institutional care, particularly when these daughters consider this to be “the end” for their mother. For other daughters, distress gives way to guilt when they recognise that their mother sees herself as being forcibly and hastily sent off to care:

Oh it was a terrible day (Lori). ... I thought I was going to vomit. ... I just wanted it to be over (Kaye). ... Then Mum seemed to be stalling, not moving along, and then she said in the end “What’s the hurry?!” ... you could feel the tension ... you could feel it ... we were all feeling terrible (Lori). ... I’d say the worst day of our life (Kaye).

For husbands, such as Richard, distress is experienced as guilt over broken promises:

You’re going against a promise that you’ve made to this person, you just make a rod for your own back, which makes it that much harder for you to emotionally cope with what really is an extremely difficult situation (Richard).

For wives, including Joy, guilt is experienced as failure.

I feel very guilty. ... I could have kept him that bit longer. You certainly feel as if you’ve failed (Joy).

7.2.1.1.3 GUILTY SUBMISSION

Yielding to a hierarchical health system, relatives witness helplessly as a family member appears defeated by institutional care. Cumulative upon their own distress, they witness a family member subsumed by an institutional approach to living.

A wife recounts the shock of witnessing a family member subsumed by an often adversarial health sector. In turn, they describe their struggle to make sense of new events and their expectations of care:

They had sedated him. When I went into see him, he was just a zombie. ... Oh it was traumatic. I’d lost him. I felt that they’d taken him and changed him — I had no say (Joy).

When the family chemist raises concerns about psychotropic medication, mistrust in a wife motivates her unpopular stance against hierarchical care:

“Is this for Harry?” ... This is the chemist where I go all the time. And they knew us well. ... “This medication says it shouldn’t be given to dementia patients...” ... So, I thought right ... I don’t care what they say ... I saw the Registered Nurse and he said “But Mrs Williams, I have to take my orders from the doctor”. I said “Yes, you do. But I don’t” (Joy).

Surrounded by unfamiliar practitioners, the participants observe that hospital stays exacerbate the confusion of dementia in a family member. Cumulative on the trauma of placement, spouses recognise that confusion, loss of appetite, and sleep disturbances are traumatic responses in their family member. Without any other option, there is resignation as wives, such as Betty, accept that institutional care is becoming their husband’s last refuge. Vicarious distress is noted in the helplessness of family caregivers. This is cumulative upon their own pain as they watch without hope the demise of sense making and adaptability to change in the family member with dementia:

It was trauma, trauma, trauma ... he didn’t know where he was ... he didn’t eat ... wouldn’t sleep ... it is one of the hardest things that you’ll ever, ever do ... that’s why I could never take him home (Betty).

Adult daughters note that in a parent with dementia, any positive expectations present on coming into care are replaced by frustration and despondency:

“I’m just a nuisance. I’m just a nuisance.” ... I think he gets frustrated that he can’t do what he used to do (Linda).

7.2.1.1.4 RUMINATION

Rumination describes ruminative brooding in family caregivers that appears to perpetuate their guilty worry. For a wife, unfair social judgement disregards her achievements as wife and carer:

I have a very bad guilty feeling ... that I've put him in a home and he's going to be here until he passes away ... that's final. ... She said "I'd never put my husband in a home" ... but her husband died at 50 ... that still plays on my mind (Betty).

Daughters notice that hope wanes in their mother with dementia. Guilt becomes the dominant emotion when that mother is in a "really bad mood" (Cathy). Those adult daughters responsible for the move to residential care express that ruminations of guilt are intrusive and keep them in a ponderous state of anxiety:

"Have I done the wrong thing?" "Have I increased the disease speed by putting her in here?" (Cathy)

Granddaughters' describe intrusive guilt ruminations triggered by their sad anticipation of a grandmother's death at some point in the future:

If she does pass away, you think "Those afternoons I sat on the lounge and watched TV, I should've gone and seen her" (Megan).

7.2.1.2 Extrinsic trauma

Extrinsic-trauma represents angry and frustrated responses of family members directed at others, depending on situations that trigger a need for advocacy.

7.2.1.2.1 VIGILANCE

Vigilance describes perceptions of threat, by family caregivers, within a medical system seen as adversarial. Precipitating mistrust, family caregivers are motivated to become advocates for family members with dementia.

For daughters, disappointment gives way to anger and mistrust when fathers are seen as a set of symptoms rather than a “whole person” (Lisa). Over time, they see an overreliance on medication:

I don't trust doctors! ... They don't treat people as a whole person. ... A pill for that ill! (Lisa)

Rather than place their mistrust in institutional approaches to care, a husband alert to possible harm, becomes a covert advocate for his wife with dementia:

It's made me more observing. ... I'm Phyllis' eyes and ears. ... I'm not abusive or demeaning ... I just point things out (Bob).

Describing hypervigilance, like walking on eggshells, a wife learns to rehearse strategic approaches in advocating for their husband. Their sense of powerlessness in the face of a threatening and powerful system is evident:

It took a lot of effort. ... I had to think a lot before I went in ... about what I was going to say and how I was going to say it (Joy).

Often, advocacy for the individual family member with dementia becomes the only outlet for relatives amidst waves of routine and depersonalised care. When disregard of individual care is inconceivable to wives, their commitment to advocacy is amplified:

He just thought “Here's another one”. Well I'm not just another one. I'm an individual. I treat people individually. ... I wasn't asking for anything special. I was asking for consideration for my husband (Joy).

Sarcasm in residents who are trying to stay abreast with the care system, reveals perceptions of threat that precipitate mistrust. Powerless and angry, they seek advocacy from trusted sources:

“Bullshit, the doctors don't know what they're doing. I shouldn't be taking this tablet ... this is how it makes me feel.” He was so tuned into his body and the medication ... he was trusting us ... we were advocating for him (Lisa).

7.2.1.3 Growth

Within the family groups, a reverse mirroring of advocacy and submission commences between family members and the member with dementia. By embracing personal integrity and hope rather than misplacing trust to a health sector that had reduced their role in advocacy, family carers begin to redefine self, relationships, and outlooks on life. As family caregivers continually bring meaning to their health sector experiences, distress inevitably declines. Despite distress, they describe positively re-evaluating their life story, goals, values and priorities, and growth within themselves that allows them to re-engage with support and health-sector care.

7.2.1.3.1 MORAL COURAGE

Standing in the face of adversity or unpopularity, relatives discover and witness integrity, assertiveness, bravery, and perseverance. Over time, this positively redefines care and personal choices.

With satisfaction, wives including Joy recognise unexpected capabilities in themselves as caregivers:

I've had to become more strong in every shape and form, and I fight tooth and nail ... I think I surprise myself really. There are some things that have happened that I didn't think I was capable of (Joy).

However, newfound personal strength can present a downside. Younger siblings describe family dynamics disrupted by more authentic interactions:

I've got a lot more forceful ... (Kaye). I've got less. I've given her my forcefulness (Lori). I always felt I had to give into the 'big sister' Rhonda ... I started to say "no" ... it's hard because you've got those dynamics (Kaye).

Nevertheless, family caregivers recognise that adversity can be a catalyst for courage, moral integrity, and perseverance that come to positively redefine care and personal choices:

It can produce good in people that never would have stretched themselves ... they've got to move out of their comfort zone if they're going to feel they're acting with integrity... it pushes you to persevere with things that you wouldn't normally want to push yourself to do (Jan).

7.2.1.3.2 GRATITUDE

Recognising that life cannot be taken for granted, relatives experience wonder and thankfulness for life itself, positive acts, and good people around them. For example, relatives describe new philosophies (e.g., Linda and Stephen: “life is short,” “make the most of every day,” “value family” and enjoy the “beauty in nature”). Others begin to positively redefine their work, through gratitude, as an opportunity to “learn new things,” “stretch my mind” “teach” and “keep active” (Cathy).

Daughters express gratitude for older people who volunteer care for their parent living with dementia. Although many daughters are mindful that they are “approaching that age” themselves (Lucy), gratitude makes way for positive redefinitions of ageing that encompass “viable people ... involved in a community and giving positive benefits” (Lucy).

If it wasn't for volunteers ... even 'Grey Nomads' [retirees with holiday-caravans who drive around Australia] travelling around the country actually keep country towns alive and help people. So I've changed my view from 'pensioners are a burden to society' ... They're volunteering. They're not all sitting at home doing nothing. ... They come out of the woodwork. I've met all these wonderful people ... little things people would say (Lucy).

Gratitude motivates an altruistic search for volunteering opportunities:

My husband is volunteering now. ... He just started driving for HIV transport.

My daughter has just volunteered for the Disability Games. ... So we see volunteers in a whole new light (Lucy).

Gratitude is also expressed by daughters for the quality care provided by the team at a care home for a mother with dementia:

Here she had the freedom to walk, and she did walk, and she — she was content for the first time in her *life*! And that was so good for us (Susan).

For a husband and father with dementia, relatives feel gratitude for a relational style of care:

Amazing staff. ... There is a rapport that goes on between some of the staff and Dad. ...Yes they get right into his face. They give him kisses. They stroke him (Lisa). I think the nursing staff ... in the hospital went through the university, not the old style of nursing, it's completely different. They don't have that same care (Dawn).

Daughters describe gratitude for friends who offer quality and peace, especially friends with a personal understanding of dementia:

It's made me reflect more on what is important ... quality time... some of my friends have had to just be shed ... but I've had some friends who've stayed with me through the journey ... we offload to each other and then get on with it. ... A little bit of peace (Lucy).

By acknowledging her true self, a wife describes a newfound sense of gratitude for their own health and wellbeing, which encompasses positive re-evaluation of values and priorities. They reject conditioned ideals of beauty and a life organised around possessions and status:

I don't care about my appearance as much. ... I don't care about having money or a new car because someone else has got a new car ... As long as I'm healthy (Julie).

7.2.1.3.3 HANDS-ON ADVOCACY

When relatives move beyond traumas and grim realities, distress is redirected into problem solving and support that spills over from private to public domains. For instance, by working through earlier trauma, spouses reinterpret their distress from an experience of loss to one that encourages purpose and meaning:

I am mostly over the traumatic part of Pam's admittance ... I am fully aware that she will never come home but I don't let that get me down ... I keep thinking how and what I can do to make her life more meaningful than what it is in the facility (Doug).

When self as 'carer' and self as 'dementia practitioner' collides for caregiving grand-daughters, existing systems of care no longer seem adequate. Viewing the world differently as a result of their personal dementia adversities, caregiving adult-grand-daughters discover newfound fulfilment, purpose, and meaning in their work:

[Before] I could walk away ... I didn't think about what I walked away from at the end of the shift. [Now] I think about how the family is dealing with it ... I tend to spend more time talking to them, and I say "You can cry. You can let it out" (Megan).

And when hands-on advocacy in wives and daughters spills over to everyday life, it offers hope for individuals living with dementia in their community and the ageing population in general:

It's just broadened my horizons not to be judgemental (Julie). ... I have more compassion for people with dementia and the ageing population. I see people even down at the supermarket ... I think "Do you need some help getting that?" or "Do they need help while waiting for a taxi?" (Gail)

7.2.2 Results and analysis regarding familial relationships

Now, the researcher presents the findings regarding the subjective interpretations of these family groups relating to the psychosocial impact of dementia on the individual family caregiver and family relationships, across the dementia trajectory. As such, one superordinate theme, *Lost and found*, describes family members oscillating between negative and positive change, as they struggled to make sense of ambiguous social awareness and engagement in a family member with dementia. *Lost and found* overarched three sub-themes: (1) *Aloneness*, (2) *Engagement* and (3) *Growth*. Within these sub-themes, participants became socially isolated when they accepted stigmatising views and felt shame as a result. Subsequently, appearing to turn inwards upon the family group, relatives rediscovered opportunities for intimacy and engagement rooted in familial bonds, trust and familiarity. Motivated by stigmatising views that challenged personal integrity, growth came through a redefining of self that nurtured hope, acceptance, meaning and advocacy. See Table 22. (Notations: Appendix 1).

Table 22

Superordinate theme, Lost and found, overarching sub-themes

Aloneness: stigma and shame that isolated those with dementia and families by association.

- *Isolation*: isolated at home, relatives with dementia sought security rather than the public embarrassment of declining social skills.
- *Unbelonging*: finding it hard to belong, relatives with dementia diverted social attention from their forgetfulness.
- *Abandonment*: frustration and depressing feelings of loneliness in relatives, when family/friends stopped contact and unsupportive friendships were let go.

Engagement: underscored by familial bonds, trust and familiarity, relatives examined opportunities for intimacy and engagement within their family group.

- *Familial retrospective*: for relatives, negative and positive appraisal of intra-familial memories came to explain present-day familial bonds.
- *Familial security*: situated in the connectedness, trust and familiarity of the family group, unmistakable identity and social skills re-emerged in those with dementia.

Growth: rejecting stigma and refusing shame, distressing losses nurtured relatives' search for self-integrity and hope, to positively redefine self and familial relationships.

- *Acceptance*: co-existing with distress, relatives reached acceptance of unpredictable, fluctuating, and irreversible social change.
 - *Meaning*: bringing positive meaning to their experiences, relatives accumulated wisdom for more flexible coping with developments.
 - *Voice of advocacy*: wisdom gained through experiences so far, motivated relatives to give an empathic voice of support for individuals and families experiencing dementia.
-

7.2.2.1 *Aloneness*

Underpinned by what appears to be community fears and misconceptions, stigma and shame isolate those with dementia and their relatives by association. As a result, the family caregivers within this chapter experience frustration, embarrassment, and in extreme circumstances depressing feelings of loneliness. In turn, they witness a family member with dementia seeking the security of home or striving to fit in socially through whatever means possible.

7.2.2.1.1 ISOLATION

Isolated describes family members living with dementia becoming isolated in their homes, when it would seem that their changing social skills and subsequent reactions in others threaten their sense of security. This brings embarrassment to them and frustration to their family members.

Rather than risk further social embarrassment, mothers with dementia isolate themselves from their local community:

She just didn't want to talk ... She'd be quite angry ... She didn't go out of the house ... hadn't had her hair cut for two years ... wouldn't go to the doctor (Gail).

Even in far-off communities, unlikely to be visited again, a husband with dementia choose security in isolation rather than risk social shame:

We were travelling around Australia ... he used to be the most social person ... then he started not wanting to go out ... not joining in. By the time we got back home that was really pretty evident (Julie).

For mothers with dementia, crankiness becomes a way to distance inquisitive daughters. These daughters find no clear turning point when negativity started to redefine familiar mother-daughter bonds:

It changed from the very beginning ... for me, crankiness and agitation because she was just not there? Or losing it? Or it was just like frustration? ... She was cranky ... I was cranky. ... I've always wanted to spend time with Mum ... It was real sort of change... At the time, I didn't know when it actually changed (Kaye).

Rather than feel overwhelmed by losses in awareness, self-withdrawal in mothers gives way to obsessional behaviour:

She was always sorting things... It was her way of staying in control (Kym).

7.2.2.1.2 UNBELONGING

Still wanting to belong socially but finding it increasingly difficult, relatives with dementia seek to divert social attention from their forgetfulness. For example, mothers/grand-mothers with dementia are seen to divert attention from their insecurities about forgetfulness, by striving to keep up social appearances e.g., "They

might think I'm weird? I'm a dumb bat" (Lucy). When that person perceives that their sense of self-competence is being challenged, internalised shame gives way to anger, and is witnessed by daughters/granddaughters such as Jan and Lilly:

She knows she hasn't got a good memory, so she's trying to make up for that by trying to come across as well kept ... (Lilly). That partly comes from Dad who used to say "Don't be such a Dill Weed, Edith." ... She'd think, "Oh, yes, I suppose I am" She'd take it. ... It's embedded in her memory. If she thinks she looks foolish [now], she's more likely to get angry (Jan). Yes, hostile (Lilly).

Insecurities are seen to resurface in mothers with dementia, when older siblings visit:

I think she's always felt because they were more academic ... she wants approval. I think it's been lying dormant for some years. ... Usually she wears a big hat (Lucy).

Mothers, recognised by daughters as just wanting "to belong" despite having "lost her social skills" are seen to disregard social norms. The symbolic meaning behind their creative responses to social exclusion is understood by observant daughters:

Mum undid the buttons on her cardigan ... She looked at her, and said "You didn't notice that I undid the buttons on my cardigan." That was her way of saying "You've left me out of the conversation" (Lucy).

7.2.2.1.3 ABANDONMENT

In extreme conditions, when unsupportive friendships are let go, or family and friends stop phoning or visiting, frustration and depressing feelings of loneliness overwhelm family caregivers. For instance, a husband, observing the minimisation of a wife with dementia, choose to end friendships that he now sees as insincere:

"She did this." "She did that." I decided that I didn't have to put her through that ... I was hurt more so for Marilyn ... [They] were like shadows — false people (Bob).

Disappointed and frustrated, daughters see family friends place their emotional discomfort ahead of a father's sense of support:

Some people don't know what to say ... and they feel like they're going to cry.

Well we all cry! At least he knows that they are there and that they care (Lisa).

When family and friends stop calling and visiting, depressing feelings of being alone emerge in the wives in this chapter. Spilling over to bitterness, wives struggle to make sense of social avoidance that envelopes a husband with dementia and extends to them as wife:

It's a very lonely feeling ... when ... people that used to come ... don't want to become involved. I feel very hurt ... cynical ... disappointed ... [less] patience with people. ... I'm starting to think maybe they're concerned that this might happen to them (Joan).

Inevitably drawn towards loss, daughters seeking familiar relational bonds find injustice and ambiguity:

Is she just 'yes-ing' and 'no-ing'? ... It's unfair. She's alive ... and we want her ... but it's like we can't have her (Kaye).

For some husbands, efforts to move past loss and distress give way to feelings of loneliness:

Even though I have immersed myself into the activities of the U3A [University of the Third Age] in a bid to move on, I know that most of these activities are those that Pam would also have enjoyed ... but I am doing them alone (Doug).

For some wives, depressing feelings of being alone give way to overwhelming panic and despair:

Depression has taken over my life ... I can understand, let me tell you, how people take their own lives ... panic attacks ... you're in this damned big dark black-hole ... you think you're never going to get out of it (Betty).

7.2.2.2 Engagement

Underscored by familial bonds, trust, and familiarity, relatives begin to redefine opportunities for intimacy and engagement within their family group. Appearing to turn inwards upon the family group, participants find what appears to be security within the family group and patterns of engagement rooted in familial bonds.

7.2.2.2.1 FAMILIAL RETROSPECTIVE

For family caregivers, negative and positive appraisal of historical interpersonal experiences with their family member with dementia, come to explain present-day familial bonds with that person. For example, daughters describe negative bonds reflecting poor maternal attachment. Unable to resolve past maternal rejection, daughters choose to replace their regressive views with maturity, compassion, and forgiveness:

I don't think Mum accepted me and I don't think I accepted her. ... I found it frustrating and annoying that I was put in that position when she hadn't been there for me, which is probably an infantile way of looking at it ... So I had to separate ... that sort of resentment ... and try and leave that behind (Kym).

Living in the moment, past differences between mother- and daughter-in-law give way to positive relational change. Familiarity promotes security:

We didn't get on well ... but when she came here and into care I was a familiar face who would talk to her and take her to things ... suddenly I was her very best friend (Susan).

When dementia disregards past maternal defensiveness, daughters experience long-awaited maternal recognition:

She's always had her defence up, never let anyone in ... now that's not there as much. ... I'll walk in with ... my grandkids and she'll be delighted to see them, whereas ... she was never delighted to see my kids. I think "At last!" (Kym)

Noted by a visiting wife, distinctive familial bonds of devotion disregard ambiguous interpersonal losses, even in severe stages of dementia:

He said to me today “You’re lovely. You’re really good and I love you” and I said “Well how about a kiss” So he gives me a kiss I don’t think he would give anybody else a kiss. He was so — it’s hard to say this — he was so devoted (Joy).

7.2.2.2.2 FAMILIAL SECURITY

Situated within the connectedness, trust, and familiarity of the family group, family caregivers witness unmistakable identity, and social skills momentarily re-emerge in a relative with dementia. Witnessed relaxation in that person gives way to noticeably greater interpersonal awareness and engagement:

I think it’s her mood ... if she’s feeling good ... she will be more aware of things ... Make her more relaxed ... casual (Lilly). It depends on her mood (Jan).

Sisters describe the re-emergence of their “old Mum” (Kaye):

It was humour. I was thinking “Wow! That’s old times. That’s the old Mum” (Kaye). It really depends on the day, a good day or the right conversation (Lori) ... It just happens. something might click (Kaye).

Symbolic expressions of former roles are recognised by a visiting husband. Recognising those aspects of identity allows him to witness the continuation of meaningful engagement in a wife with dementia:

As a mother and a person who understands little children ... I think ... that she’s sort of still got those inbuilt knowledge and skills ... buried pretty deep (Richard).

Familiarity is seen by supporting family members as a conduit for social engagement, as was distinctiveness: Recognition is seen to make an increasingly uncertain world more certain for family members with dementia:

Your voice, a thought, something you're wearing, a ring, something she looks at ... she recognises (Jan). She always reacted to our voices, always. I think she always knew that we were positive (Susan).

Discussing patterns of engagement, family members muse at the interpersonal awareness and engagement retained by a family member with dementia. Some participants believe that family members with dementia are unaware of historical relational bonds within their family:

She often doesn't know why she knows me, or who I am ... she just knows that she knows me (Jan). When she lost the ability to speak, we don't know who she thought we were, except that we do know that we're important to her (Susan).

Indeed, some participants disregard medical views that they are just familiar faces, and instead find validation of historical relational bonds through the love expressed by parents dying with dementia:

I got a beautiful smile every time I walked into my mum's. I was heartbroken to think that I'm only familiar. I just didn't believe them. ... She smiled at me at the end. All I wanted was a smile. That helped me. ... "I always thought she knew who I was" (Linda).

7.2.2.3 Growth

Rejecting stigma and shame that challenges both personal integrity and hope, *Growth* describes a redefining of self that nurtures *acceptance*, *meaning* and further change through *voice of advocacy*. For those families able to embrace the fluctuating

presentation of dementia, a positive redefinition of intimacy and relational engagement emerges.

7.2.2.3.1 ACCEPTANCE

Over time, most relatives accept the unpredictable, fluctuating, and irreversible social change in a family member with dementia. Despite ongoing distress, fluctuating interpersonal awareness and engagement are seen as an inevitable part of daily developments. Acceptance makes room for more flexible coping.

When a husband rejects stigma and refuses shame, acceptance of unusual social behaviour in a wife with dementia allows him to continue daily life with less disruption:

She started to see ... reflections ... in the car ... when we were in car parks ...

“Look as much as you like fellas” ... Because I’d accepted it, and that was Pam.

... “C’mon Pam let’s go and do our shopping” (Doug).

Conversely, pockets of acceptance are also found in the community. Daughters describe “safe places” without judgement and the subsequent “anxiousness” and “confusion” in a mother with dementia (Lucy):

I’ve found safe places. The Thai restaurant ... [The owners] give her a hug, and they sit her down ... all the other customers in there get the picture. So it is a safe place for Mum ... without all the judgment (Lucy).

Feeling accepted by a previously unwelcoming mother, daughters let their defences go. Moving beyond self-absorption towards common ground with a mother now living with dementia, daughters recognise that acceptance has come to positively redefine relationships in general:

Now ... she has to accept me ... and I have to accept her as she is ... “Why have that conflict?” You can pretty much translate that to anyone (Kym).

Daughters note ease when they focus on present developments rather than ruminating over past regrets:

You can only go along with the waves, really, go along with the tides, and deal with what you have on the day (Tracy). It sort of makes it easier for me ... you don't get bogged down on what has happened in the past ... every day is a new day (Kym).

7.2.2.3.2 MEANING

Family caregivers accumulate wisdom for more flexible coping with developments when they were able to bring positive meaning to their distressing losses. For some family members, storytelling is a powerful tool for positively integrating adversity into everyday life. New meaning allows them to move forward out of adversity:

Indigenous dreamtime stories explain in a mystical way, what is the unexplainable at the time. So therefore what I do is mainly look at those sorts of stories I can make stories up for myself to explain what is happening ... to give peace to myself (Lucy).

Through skilful words, daughters come to reinterpret problems as an opportunity for new perspectives that brings wisdom, acceptance, and flexible coping:

Adventure is never knowing where you are. So if I am lost in it all, it's an adventure (Lucy).

And:

The mind ... it's almost like a wind ... like a breeze. ... it sort of comes and goes (Tracy).

Inexorably drawn towards loss and grief, daughters seek familiar maternal bonds through story-based retrospectives of a mother's life. In positively redefining a mother, daughters find that continuity in maternal bonds can co-exist with loss and ambiguity:

I needed to put it down. ... A PowerPoint of "Mum's story" ... It's like meditation. It makes me remember Mum as she was; A very viable person. ... A viable person is one that still is positively involved in a community and giving positive benefits. We still get enjoyment from Mum, so I would still call her a viable person (Lucy).

7.2.2.3.3 VOICE OF ADVOCACY

Experiential wisdom gained to date motivates many relatives to give an empathic voice of support for others experiencing distressing social losses related to dementia. Redirecting their emotional pain into advocacy, a wife considers the value of their experiences for helping others:

I dearly would love to give a talk to people that are just starting out ... to tell them my idea and what I think would help (Joy).

When wives reject stigma and refuse shame, experiential knowledge spills over to advocacy focused on 'common-sense care', social inclusion and participation:

I do believe that you have got to do more things ... get them out ... do more to stimulate their minds ... I do think that that's important (Cathy). ... A lot of common-sense comes into caring ... They shouldn't be hidden away. They should be out in the public and doing things. ... Help them, but push them that little bit further (Joy).

For some wives, humour brings their message home:

He was a bit slow, but we went bowling, dancing, playing darts. ... He wasn't throwing the dart at anybody else. He was throwing it at the board (Joy).

For a young granddaughter, a personal search for integrity and hope gives way to positive new outlooks on essential human worth. This offers hope for a generational shift in thinking about people living with dementia:

She doesn't seem like the same Granny that she used to be. She used to be a really good buddy... we'd go out for coffee ... we'd talk ... now it's really hard to hold a conversation ... I feel like that's where I got a lot of meaning from ... placed value on that instead of they're just a person ... they should be loved and ... valued, no matter what ... We're human beings, we're not human doings (Lilly).

7.3 Discussion

This chapter presents a new perspective of 27 family caregivers (17 family groups). The studies within this chapter sought: (1) to explore both positive and negative interpreted experience of supporting a family member with dementia prior to and during admission to a hospital or care home within a hierarchical health care system; and (2) the subjective insights and meaning making of the psychosocial impacts of dementia on the individual family caregiver and family relationships. The meaning that each relative brought to their lived experience was unique, although patterns of meaning making highlighted convergent themes across the data set. Therefore, this chapter indicates that over time, relatives experienced intrinsic drives to reduce their distress through efforts to both avoid and bring purposeful meaning to their adversities. As such, they came to redefine their experiences of dementia care pathways, and their responses to the ambiguous social loss of a family member with dementia, as a mix of oscillating responses, both positive and negative.

Dementia care pathways left family carers struggling to adapt to a system that imbued mistrust when personal choice and control were constrained; yet could sooth

their distress by including them in the dialogue of care. Once able to accept the fluidity of experience i.e., that their particular vision of care could be at odds with the systemic carers; family caregivers more readily positioned themselves as advocates or conformists, as needed. As such, these family caregivers began to acknowledge that complex dementia care pathways could be navigated with the co-existence of psychological wellbeing and appropriate distress. By embracing personal integrity and hope, rather than misplacing trust in institutional care that had reduced their role in advocacy, family carers began to positively redefine self and relationships for adaptive flexibility. Despite distress, growth domains of *moral courage*, *gratitude*, and *hands-on advocacy* allowed these family caregivers to keep navigating complex dementia care pathways.

Moreover, stigma and shame left families struggling to adapt to a community where they were at times avoided, yet also where “certain safe places” (Lucy), offered inclusion without judgement. Once able to accept this uncertain social environment i.e., that their perspective of relational intimacy and social engagement could run contrary to public fears and misconceptions, family caregivers more readily positioned themselves as advocates for social inclusion. As such, they began to acknowledge that psychological wellbeing and distress could co-exist alongside experiences of relational intimacy and social engagement within their family group. By embracing personal integrity and hope, rather than accepting stigma or feeling shame, relatives began to positively redefine self and familial relationships for adaptive flexibility. Despite distress, growth domains of acceptance and meaning enabled these family caregivers to redefine *Relational Social Engagement* within their family and create further change as a voice of advocacy.

The findings indicate that stigma was one of the convergent experiences for family caregivers supporting a dementia consumer. Practitioners who adopted the expert

stance left relatives feeling inadequate, unprepared and disempowered as carers. This suggests that when relatives positioned doctors as standards of authority, those relatives counter positioned themselves as conformists. Unwilling to question treatment, it would seem that family caregivers considered their consumer needs and views as secondary to the doctor's time and expertise. In turn, when it appeared that doctors were fused to a specific model of care, whether biomedical or person centred, a more holistic yet individualised and familial approach to care was disregarded. In extreme times, when families perceived that care was harmful, it seemed that they feared retribution from a threatening and powerful system. In those situations, it was apparent that vigilance and surreptitious advocacy became an outlet for families witnessing a family member unable to advocate for themselves against overmedication, depersonalised views and treatment.

Indeed, in recent years, there have been concerted efforts to reduce anti-psychotic medications within care homes, which has resulted in prescriptions declining 15% to 50% in Europe and the USA (Gallini, Andrieu, Donohue, & Oumouhou et al., 2014; Health & Social Care Information Centre, 2012). However in Australia, up to 80% of residents with dementia are receiving psychotropic medications, which in some cases have been inappropriately prescribed (National Prescribing Service, 2013; Snowden, Galanos, & Vaswani, 2011), and almost a third are receiving antipsychotics for BPSD, despite awareness that BPSD has a variety of physical, environmental, and psychosocial causes (Chenowith, King, Jeon, & Brodaty et al., 2009). However, the use of antipsychotics varies widely between care homes according to differences in environmental and psychosocial factors (Rochon, Stukel, Bronskill, & Gomes, et al., 2007; Rodney, 2000; Snowden, Galanos, & Vaswani, 2011). Moreover, although antipsychotic use has increased over the past decade, the average dose has fallen (Snowdon et al., 2011). Nevertheless, only 20%

of residents receiving anti-psychotic medications for BPSD experience positive clinical outcomes (Chenowith et al., 2009).

Beyond perceived overmedication in the care home, it would seem that changing social skills and subsequent community reactions also threatened the security of those with dementia, motivating efforts to avoid public embarrassment or desperately belong. This highlighted the degree to which stigma was witnessed by family caregivers as internalised in family members with dementia, and awaiting activation when that person's sense of social competence was threatened. It would seem that this situation was maintained when relatives with dementia struggled to positively reposition themselves against stigmatising treatment and instead positioned themselves in shame or hostility.

Moreover, this research illustrates the impact of guilt and shame on the psychological wellbeing of families supporting a member with dementia in (what manifests as) a hierarchical system of health care. Cumulative upon a sense of guilt and shame at not being able to alleviate the losses of their family member, it would seem that both primary and vicarious traumatic responses were a possibility in these family caregivers. Their traumatic responses were recounted through the use of rich language to illustrate distressing separation (e.g., *I'd lost him; heart rending; hardest thing; worst day of our life; worst feeling; going to vomit; wanted it over*); intrusive rumination (e.g., *going over it and over it and over it; still plays on my mind*); despair (e.g., *out-of-my-depth, failed*); and trauma (e.g., *oh it was traumatic; trauma, trauma, trauma*). During the interviews, the participants repeated this language and re-experienced corresponding emotions. The traumatic responses recalled by these family caregivers evidenced *intrinsic-trauma* (inner directed) and *extrinsic-trauma* (directed at others) depending on situations that called for compliance or advocacy as appropriate. *Intrinsic-trauma* was

characterised by sadness, guilt, cynicism, and anxiety, whereas *extrinsic-trauma* encompassed emotions of sarcasm, impatience, irritability and anger. Additionally, some relatives interpreted responses of *intrinsic-trauma* in a family member with dementia during hospital residency (e.g., somatic complaints, sleep disturbance, appetite change, mood change, and social withdrawal).

The traumatic stressors experienced by these family caregivers, within health systems, appeared to be recurrent and cumulative following losses that compounded one after another with minimal time to process each one. This was evidenced when family caregivers described distressing losses using both past-tense or present-tense language, and sometimes future-tense language; suggesting sad expectation of the future death of their family member with dementia. Similarly, for these family members, the findings indicate that both primary and vicarious traumatic responses were a possibility, when their inability to alleviate the ambiguous social loss of their family member was cumulative upon social abandonment, shame and distressing losses that compounded in quick succession. In extreme circumstances, responses to the ambiguous loss of a family member whose interpersonal awareness and social engagement fluctuated encompassed traumatic responses of incomprehension and intense distress that gave way to frustration, anger, panic, and depressing feelings of loneliness and despair.

However, in these situations, growth domains of *moral courage*, *gratitude*, and *hands-on advocacy* were described by these participants indicating the nurturance of hope. Finding opportunities for relational intimacy and social engagement within their family group provided an outlet for families struggling to 'connect what was with what could be' or witnessing a family member unable to advocate against stigmatising views and treatment.

As such, the findings suggest that stigma and shame both undermined and motivated these family caregivers in their struggle for *acceptance, meaning* and eventual *voice of advocacy*. These findings indicate that ambiguous social losses bring both adjustment challenges to families and the opportunity for successful reintegration of distressing memories. Over time, family caregivers able to move beyond stigma and shame, were able to reconnect with a family member with dementia at a deeper, simpler level that was previously overlooked because of a preoccupation with the frustrations and devastation of losses and overemphasis on what the person cannot do. While growth domains were not evident in all interviews, when they were, participants describing growth were more likely to describe losses in the past tense. This suggests that for these family caregivers, as psychological wellbeing took hold, distress within the health care system and social experiences dominated by negative domains inevitably declined. Although there was no definitive tipping point between negative and positive change for participants, positive examination of self and relationships appeared foundational upon both time and receipt of good quality care. Similarly, positive examination of self and familial relationships appeared to rely on time and again finding “safe places” within the community (see Lucy).

Despite current limitations in dementia care, obstetric care—for example— is one model of care that has undergone change in recent years to more individualised care within a traditional system. It offers a framework that could be adapted for individuals living with dementia. However, dementia care pathways present specific challenges to families, with distressing losses complicated by inadequate care and compounding over time. Nevertheless, the oscillating experiences of mistrust and integrity in the families participating in this chapter illustrate the opportunity for psychological wellbeing despite distress. This supports a move towards relational models of care that encourage

collaboration with families, and the recovery of growth domains for individual family members.

Similarly, the importance of ‘dementia friendly communities’ is highlighted, as they emerge to help individuals with dementia feel more confident about asking for help with less embarrassment (Green & Lakey, 2013; Skladzien & Holdsworth, 2013). Dementia-friendly communities also offer families opportunities for meaningful community contribution through consultation on infrastructure improvements, public awareness, and improved dementia literacy within that community (Green & Lakey, 2013; Skladzien & Holdsworth, 2013). Furthermore, when social support is lacking, as experienced by these families, it is a known barrier to psychological growth (Bonanno, Brewin, Kaniasty, & Le Greca, 2010; Kaniasty, 2008). This highlights the need for relational models of care inclusive of families and the recovery of growth domains for individual family members. Thus, participants became individual experts in relational intimacy, social engagement, and triggers for unexpected levels of *Relational Social Engagement (RSE)*.

7.3.1 Conclusions and recommendations

Therefore, Chapter 7 addresses an important dimension of the lived experiences of family caregivers supporting a dementia consumer within hierarchical health systems and the impacts of dementia on family relationships across the dementia trajectory. It provides insights into family members fulfilling the caring role, especially if those carers are themselves no longer young or several generations are involved in care. Adaptive interpretations by family caregivers participating in this chapter allowed advocacy or compliance as appropriate, and similarly the rejection of stigma and shame facilitated positive redefinitions of self and familial relationships. This motivated positive redefinitions of self and relationships, and the emergence of psychological wellbeing concurrent with appropriate distress to facilitate ongoing *RSE*. Over time, growth

domains of *moral courage*, *gratitude*, and *hands-on advocacy* empowered these participants to re-engage with dementia care pathways.

Therefore, this chapter offers a qualitatively different perspective that supports a move towards relational models of care that encourage the recovery of psychological wellbeing for individual family members. Indeed, the perspectives of the relatives within this chapter highlight that they remain relationally and socially connected to family members with dementia, without which they might lose an important source of life-meaning. Further, the researchers recommend future investigation to enhance our understanding of *RSE* as a phenomenon and its estimation by standardised assessment of dementia severity.

7.4 Chapter close

For these family caregivers, perceived pressure to conform to the system generated intrinsic trauma responses of ruminative sadness, guilt, and shame, whereas perceived harm and injustice towards their family member provoked extrinsic trauma responses of hypervigilance, frustration and anger. Furthermore, rejection of stigma and shame allowed them to discover pathways for psychological wellbeing through *Relational Social Engagement (RSE)* in the family group. Indeed, their mistrust of the system motivated these family caregivers to move between moral integrity for advocacy or compliance as appropriate, which over time facilitated positive redefinitions of self and relationships. In fact, they positively redefined self through hope, acceptance, meaning, and advocacy. Importantly, their experiences within their own family group in the presence of dementia, and their navigation of an authoritative health system have offered new theoretical considerations, and opportunities for considering different and more collaborative care pathways in dementia.

In the last two chapters of this thesis, the researcher will reflect upon his experiences of using qualitative methodologies. Then, he will conclude the thesis with a presentation of the overall findings and recommendations.

CHAPTER 8 Critical Reflections

8.0 Introduction

In seeking to understand how individuals within the *triad of relational and social dementia expertise* experienced their world, and how they made sense of those experiences, the researcher chose a hermeneutic and phenomenological approach. In using qualitative methodology (encompassing IPA and Thematic Analysis), the researcher committed to certain underlying philosophies, subjective meanings, attitudes, and values. Therefore, it was not a case of adopting a qualitative approach while holding objectivist expectations, and as such, it was occasionally challenging for the researcher to apply qualitative constructs, given the dominance of objectivist paradigms throughout his psychology training.

Thus, in presenting Chapter 8, the researcher seeks to illuminate his own experiences in relation to using qualitative methodology in psychological research. The strengths and weaknesses of the studies within this thesis are discussed in Section 8.2 and throughout.

8.1 Personal reflections on using qualitative methodology

8.1.1 Bracketing biases and preconceptions

One challenge in completing a qualitative thesis was the underlying requirement to bracket my own theoretical interests and personal and professional experiences, before analysing the data. Indeed, the inductive cycle of continually returning to the data and revising interpretation could raise upsetting memories from my own experiences of living with the familial impact of dementia. On one hand, I recognised that my personal experiences gave me a level of empathy and insight for understudying the experiences of

participants, yet on the other hand, I acknowledged that my own views and preconceptions could eclipse the data. As such, my interpretations sometimes caused me to present themes not apparent to my supervisor. It may also have been that my roles as interviewer/observer, primary analyst, and manuscript writer brought me too close to the data.

However, to avoid obscuring clear links between the data and my interpretations, I sought repeated phenomenological enquiry and fresh bracketing of my theoretical interests, biases, and preconceptions. I also sought conceptual guidance, such as the need to expand and contract subjectivity to promote empathic understanding of the participant without eclipsing the data through own personal interpretation (see Conrad, 1987). However, in accepting that not all aspects of personal experience can be set aside during qualitative research (Heidegger, 1927/1962), I also sought to respond to unexpected disruptions during data gathering and analysis, due to my own internal dialogue as a researcher, therapist, and family member. Moreover, by engaging in self-reflexivity to delineate self from other in the common world, I was better able to achieve an insider's perspective on participant experiences (Conrad, 1987; Reeves, Kuper, & Hodges, 2008).

8.1.2 Using interviews to collect data

With little experience of interviewing, I noticed tensions in my interviewing technique. During my early attempts to interview participants I sought to both control the interview (e.g. using closed and directive questions) and let participants take the lead in generating novel insights. As such, I found myself almost competing with the participant for control of the research topic. I also became aware that I often rigidly questioned participants, which could shut down their valuable and rich exploration of the research topic. Furthermore, I noticed that I sought to build rapport with

participants through informal narrative, while attempting to meet formal interviewer requirements (e.g., establishing a double hermeneutic process of meaning making, and guiding participants back to the topic). Due to these tensions, I sometimes found it difficult to cover all interview questions in a timely manner.

I also found that these early interviewing experiences were hindered by my use of topic headings rather than pre-formulated questions. Topic headings were too unstructured for a novice interviewer. To address this situation: (1) I sought to develop a set of pre-formulated yet semi-structured questions; and (2) I found opportunities to practice interviewing through role-plays with my supervisor and other students. As a result, by later interviews, I was confident enough to use probing questions, which were adequate for gently guiding the interview between the anticipated topics of interest and exploratory diversions from negotiated domains. As my interviewing became more flexible and spontaneous, I realised that participants were subsequently more likely to reveal the phenomenon of interest in a rich and valuable way.

The richness of interview data could also vary considerably, not only due to ideographic differences between family members and family groups, but also depending on the participants' progress in bringing meaning to their adversities. For some interviewees, they were noted to be grappling for comprehension following some recent and cumulative adversity, whereas others were found to be able to focus on significance in their current or future lives. For the interviewees who I found to be struggling with recent events, it seemed that they could not move beyond their efforts to find comprehensibility, which might lead to significant meaning. As a novice researcher, I had to refrain from intruding upon their meaning-making efforts with my own views and experiences. In time, I learnt to protect the fragile double-hermeneutic that exists

between interviewer and interviewee, by gently seeking clarity through probing and prompting.

8.1.3 The making of video recorded observations

The making of video recordings was a novel methodological approach, seeking to capture phenomenological insights from naturalistic *family visits as usual* (see Walmsley & McCormack, 2014). Certainly, with the camera-recorder set to run in the privacy of the in-resident's bedroom, the video-recorded observations remained as unobtrusive as possible. This interpretation was supported by visitors who reported that they had quickly adjusted to the presence of the camera-recorder (e.g., "Oh, we've just been sitting here. We forgot about it to be honest" – Lucy).

However, several visitors did express concerns about participating in the video-recorded observations. In particular, they described worries about interacting in the *right* way, and the ability of their in-resident family member (and indeed themselves) to remain engaged throughout the 15-minute video recording. In response, I sought to allay their anxieties through rapport building, putting them at ease before commencing video recording, and explaining empathically that I was only interested in recording visits as usual. Additional to this preparation, I felt confident in making the video recordings, because I had piloted this approach with other families during an earlier Master's degree (Walmsley & McCormack, 2014).

However, the making of video-recordings and their transcription was not without further challenges. Despite the video-recordings being relatively easy and quick to complete, the transcription of speech and non-speech interactions was not. Indeed, the researcher found that transcribing the speech, vocalisations, facial expressions, and body gestures of multiple family members to be time consuming and intensive detailed work. Transcription was further complicated by environmental noise that occasionally

disrupted clear audio recording (e.g., staff talking outside the room, food trolleys being pushed down the corridor, metal food covers falling onto the linoleum floor, and public buses passing in the street). Similarly, in one situation, video recording was obscured when a visiting spouse inadvertently sat between the camera-recorder and her in-resident husband.

None the less, video-recorded observations provided rich and valuable data, inclusive of the participants with dementia. For further details on the strengths and weaknesses of this methodological approach, see Section 8.2 on page 259. For details on the practical and ethical implications of video and its analysis, see Section 3.3.2.2.3, p. 121.

8.1.4 Relational dynamics

Relational complications need to be considered before data gathering, as they can undermine equity, neutrality, and compromise data gathering. Where I perceived that a participant was holding hierarchical assumptions in relation to me (in either direction), I sought to strengthen rapport, reinforce a sense of collaboration, and clarify the research topic of interest. These factors were supported by multiple points of participant contact before data gathering, which also helped motivate participants' self-reflexivity in advance.

Similarly, I discovered that family dynamics and systemically connected relationships between participants could enhance or distort patterns of group discussion. This made it challenging for me, as the researcher, to bracket both compliant comments and domineering contributions during triad and focus group interviews. However, my concerns were alleviated by discussing: (1) my expectations with participants; (2) our roles as interviewer and interviewee; and (3) willingness of participants to engage beyond the boundaries of any pre-existing relationships.

Additionally, by remaining alert to the possibility of status differentials, and the stake that each had in the interview, I was less likely to accept participant responses at face value during data gathering (see Potter & Hepburn, 2012).

8.1.5 Non-reciprocal, person-centred stance

Semi-structured interviewing requires a non-reciprocal but person-centred relationship, underpinned by the double hermeneutic approach. On one hand, the participant offers their intimate thoughts and feelings, and in response, the researcher helps the participant feel heard and validated. For the researcher, this requires empathic and interested questioning to make sense of the interviewee's efforts to bring meaning to their experience. To facilitate this, the researcher must avoid imposing their values or views, offering guidance, or using directive questions. Furthermore, overriding pauses during participant responses, or shutting down the emotions of participants, should also be avoided. During interviewing, I noted that my non-reciprocal and person-centred stance was best supported when I was willing to follow the lead of participants as they explored each successive layer of meaning.

In exploring emotionally sensitive issues, memories can trigger distress in the interviewee. At such times, a skilled researcher can access rich and meaningful data while concurrently helping the participant bring meaning to their distress. However, when such situations provoke concerns in the novice researcher, participants may shut down, closing access to potentially rich data. During my early interviews, I sometimes intruded upon participant meaning-making by offering validation, normalisation, and empathic insights in response to participants' distress. All of these efforts represented a misunderstanding of my role as a researcher, and a blurring of the boundaries between self-as-researcher and my work as a therapist supporting families. However, in later interviews, I could contain my impulse to protect participants from their distressing

memories, and instead fulfil the role of researcher through exploration of their phenomenological interpretations.

8.2 Study strengths and weaknesses

The central focus of this PhD was capturing an insider's perspective from the *triad of relational and social dementia expertise* in their experiencing dementia, and the relational and social engagement that occurs within this triad. Therefore, an idiographic, hermeneutic, and qualitative approach based on phenomenology and interpretative psychology was selected. Although a mixed methodology could have provided nomothetic insights, it was not chosen because this thesis sought to enhance understanding of *RSE* by getting inside the lived experiences of participants. In hindsight though, I would have added a quantitative aspect to this thesis. For example, brief questionnaires such as the Impact of Events Scale – Revised (Weiss & Marmar, 1996) to measure subjective distress following traumatic events, and the Psychological Well-Being Post-Traumatic Changes Questionnaire (Joseph, Maltby, Wood, & Regal, 2012) to measure subjective wellbeing following adversity. Indeed, with 35 participants able to complete these questionnaires, this would have further enriched the data-set from another methodological angle.

However, by seeking insights on the experiences of a purposive sample, these studies did not seek generalisability to all people in a similar situation, but rather ideographic insights from a group of individuals for whom the research topic held personal significance (Harper & Thompson, 2012). Although it can be queried whether a purposive sample might be more positively engaged than a randomised sample, the studies did not restrict discussion of either negative phenomenology during interviews or negative interplay observed during family visits (see chapters 4, 5, 6, and 7).

Additionally, the semi-structured interviews encouraged reflexive dialogue, generation of new insights, and a double hermeneutic process of meaning making with participants (Heidegger, 1927/1962; Willig, 2013). Similarly, the 15-minute video recorded observations of family interactions provided rich data, inclusive of participants with dementia whose speech was impaired (see Walmsley & McCormack, 2016b). In particular, the video-recordings provided dense data, which I could watch and re-watch frame-by-frame, in slow motion, forwards, or backwards, for credibility and depth of phenomenological insights. Although the interpretation of participant responses and levels of awareness during the video-recorded speech/non-speech family interactions was challenging, the responses of visiting relatives lent support. Furthermore, despite qualitative research necessarily involving the researcher's subjective interpretations, independent auditing and other quality measures brought credibility to the findings (see Section 3.3.3, p. 122).

Chapter close

In presenting the challenges of qualitative analysis for the novice researcher, I recognise both strengths and weaknesses in the studies within this PhD, my experiential learning, and the rich data that was collected. In particular, my personal reflections highlight the importance of remaining committed to qualitative philosophies, subjective meanings, attitudes, and values. Otherwise, the novice researcher may gather data and complete analysis, directed by own biases, preconceptions, and interpretations. Above all, the qualitative researcher must commit to inquiry and analysis, based on their *stepping-into* the world of the participant as it is found in the data.

In the final chapter, the theoretical models describing *Relational Social Engagement (RSE)* are presented in the context of the key findings of stigma, traumatic loss, and psychological growth. The perspectives of the *triad of relational and social*

dementia expertise are also drawn to a close in Chapter 9. Opportunities for future research, with a focus on the implications for clinical psychologists working in dementia care, are presented throughout the next chapter.

CHAPTER 9 Thesis Conclusions and Implications

9.0 Introduction

This thesis sought to explore the relational, psychosocial, and systemic aspects of dementia by connecting the supporting, close-up, and contextual perspectives of a *triad of relational and social dementia expertise*. Family interactions were video-recorded during family visits as usual, inclusive of a member with moderate or severe dementia. Individual, dyad, and focus group interviews were conducted with health care managers and family caregivers. Therefore, the key questions of this thesis sought to understand how these individuals experienced unique interpersonal levels of awareness and social engagement across the dementia trajectory, and how comprehensibility and significance brought to their lived experiences of dementia impact from both primary and secondary perspectives. Phenomenologically, the research studies sought an unbiased understanding of purposive meaning making, rather than an explanation of psychological reactions and responses through an objectivist construct of disease and psychopathology.

9.1 Key research findings of this thesis

9.1.1 Informed by complementary pilot studies

Although complementary pilot studies informed this thesis, the first pilot study was completed during a Master of Clinical Psychology and submitted exclusively towards that degree in 2011 (see Walmsley & McCormack, 2014). However, those participants were re-contacted in 2013, and invited to participate in the pilot study that contributes towards this PhD (see Chapter 4; Walmsley & McCormack, 2016a). Thus, in

Chapter 4, the researcher presented findings that indicated that those family groups took *steps-backward* into adversity (e.g., when individual members hovered uncertainly, missed opportunities to engage due to advancing dementia, and felt regret) and *steps-forward* out of adversity (e.g., moments of unexpected rewards, acceptance, self-forgiveness, and empathic connection with others on a similar journey). Despite their frequent distress, positive aspects of caregiving were possible for these family members, as were opportunities for psychological wellbeing and growth (Walmsley & McCormack, 2016a).

9.1.2 Supporting perspectives of health care managers

Chapter 5 presented the supporting perspectives of health care managers through: (1) an exploration of their positive and negative interpretations of working within a systemic model of dementia care; and (2) their subjective insights from witnessing the impact of dementia on family relationships (Walmsley & McCormack, 2015a, 2015b). As such, Chapter 5 revealed the following insights:

- Interpreted experiences of caring within a hierarchical health system were ones of systemically entrenched stigma, including minimisation of health care staff through poor remuneration and training;
- Systemic invalidation offered the opportunity for these participants to positively redefine their professional practice and personal choices;
- Family functioning across the stages of dementia was witnessed by these participants as an experience of family members moving out of embarrassed shame towards maintaining hope and eventual positive redefinitions of relational and social intimacy; and
- These managers of health care saw themselves as facilitators of family adjustment, by modelling advocacy, integral care, and relational intimacy.

9.1.3 Close-up perspectives of family members with dementia

Through video-recorded observational studies, Chapter 6 sought the close-up perspectives of individual family members living with moderate or severe dementia. In doing so, the studies within Chapter 6 observed and described the unique levels of awareness in these individuals, and patterns of positive and negative interpersonal engagement between them and their visiting family members. These studies found:

- Retained awareness was expressed at levels higher than expected for the assessed severity of dementia;
- Awareness extended to complex familial relational and social interactions that could be both positive *in-step* and negative *out-of-step*;
- *Relational Social Engagement (RSE)*, whereby individuals displayed optimal engagement within family groups, was possible regardless of whether interactions were positive *in-step* or negative *out-of-step*. However, *RSE* was most evident during *in-step* interactions; and
- Distinctive familial bonds underpinned *RSE* to provide security for in-resident family members to spontaneously enjoy common ground and express differences within their family group.

9.1.4 Contextual perspectives of family caregivers

Chapter 7 directs the thesis towards the personal experiences of family caregivers. Hence, the studies within Chapter 7 sought the contextual perspectives of individual family caregivers: (1) to explore both their positive and negative interpreted experiences of supporting a family member with dementia, prior to and during admission to the health care system; and (2) to gather their subjective insights and meaning making of the psychosocial impacts of dementia on the individual caregiver and family relationships.

The studies in Chapter 7 found that for these participants:

- An oscillating struggle with systemic mistrust and personal integrity promoted a withdrawal into sadness and guilty rumination (dependent upon a perceived pressure to conform to the system), or externalised expressions of hypervigilance, frustration, and anger (in response to perceived vulnerability and injustice towards their family member);
- Adaptive interpretations facilitated advocacy or compliance as appropriate, and subsequent positive redefinitions of self. Thus, adaptive wellbeing could co-exist with appropriate distress;
- Oscillating positive and negative assessment of changing interpersonal levels of awareness and social interaction at different stages of dementia facilitated personal significance and comprehensibility in current life;
- Increasing interpersonal levels of awareness and social interaction at different stages of dementia were attributed to distinctive familial bonds;
- Stigmatising views and treatment were both experienced in the hierarchical medical model and directed from their cohort; and
- Rejection of stigma and refusal of personal shame positively redefined care and provided opportunities for optimal engagement as defined by *RSE*.

9.2 Research conclusions

As in earlier research from Ryan & Deci (2001) and Joseph (2011), it may be that health care managers can facilitate growthful adaptation for families supporting a member with a diagnosis of dementia, by promoting agency and relational opportunities. Indeed, these managers were uniquely positioned to recognise negative and positive meaning-making in families struggling with dementia, as they witnessed families moving through three stages of change, from those dominated by negative

change towards growthful domains. In particular, these managers of health care facilitated the movement of families through these stages by modelling a solutions-focused mindset and ways of *connecting what was* and *what could be*.

Furthermore, observed family interactions highlighted in-care members as individuals situated within a familial relational context, which was unique in both intimacy and duration when compared to previously researched relationships (e.g., resident–researchers, –staff, or –residents: see Götell et al., 2009; Kontos, 2004; Sabat, 2001). The family interactions revealed the novel ways that each family group reacted and responded to changing communication pathways in a member living with dementia. For those family caregivers able to connect through alternative communication pathways, these studies indicate that despite distress, psychological wellbeing and growth were possibilities.

Therefore, the hermeneutic and phenomenological investigations in the presented studies progress the unravelling of the social, relational, and systemic challenges of dementia that are currently poorly researched. In particular, it highlighted gaps in our existing knowledge of dementia care, relating to observed retained awareness, and examples of optimal engagement, which revealed several key conclusions. First, that these family members with dementia were more aware than previously recognised when social cues optimised communication pathways. Second, within a medical model superimposed upon care homes, a hierarchical approach to dementia care restricted efforts to provide holistic care developed in collaboration with families for the individual needs of residents. This created distrust and hypervigilance in family caregivers, especially when care was impersonal or medication changes were made without consultation. Third, hypervigilance in family caregivers generated an unstable foundation for their mediation of care, and ability to recognise and appropriately

respond to expressions of retained awareness and social engagement in an in-resident family member. Concurrent with psychological distress and traumatic responses, psychological wellbeing and growth were possible for family caregivers who were able to bring positive redefinitions to the changing psychosocial landscape of dementia pre- and post-systemic care, and their role within that landscape.

Characterising the dementia experiences of family members, this research provides evidence for family members' vulnerability to primary and vicarious distress in relation to the caregiving, systemic, relational, and social adversities they experience. Underpinned by integrity (moral decision-making and authenticity) and experiences of *RSE* within their family group, these participants sought positive change for their family member with dementia, often at considerable cost to themselves. Negative outcomes felt by family caregivers included stigmatised social isolation and invalidation, and both anticipation of trauma, and traumatic losses and betrayal. These negative experiences were cumulative upon a sense of abandonment, shame, or guilt at not being able to alleviate the losses and distress experienced by their family member (see Figley, 1998). However, through ongoing purposive self-appraisal in response to these cumulative losses and distress, all of these family caregivers came to positively reconstruct their place in the world, to varying degrees.

This suggests resilience or relative resistance to adversity (see Rutter, 1999). When individuals are resilient, they bounce back comparatively quickly, remain psychologically and emotionally unaffected, and hence without need to re-appraise life views, priorities, goals, or actions (Lepore & Revenson, 2006; Levine, Laufer, Stein, & Hamama-Raz et al., 2009). However, this does not describe the narratives of family members within the *triad of relational and social dementia expertise*. Psychologically, the lives of family caregivers were put on hold and shaken-up by traumatic and

compounding losses across the course of dementia. These losses were cumulative and frequently occurring, with minimal time for appraisal between each one (see chapters 4 and 7).

However, through a *synthesis of meaning* that drew upon past and present cumulative adversities, family caregivers' adaptive interpretations—through their vulnerability to distress—stimulated a continued search for meaning (Linley & Joseph, 2004; Tedeschi & Calhoun, 1996). According to the literature, the degree that psychological growth can be realised depends on a socially supportive environment (Bonanno et al., 2010; Joseph & Linley, 2008; Kaniasty, 2008). Although in varying degrees these participants described support from health care managers and other families, most had not experienced a socially supportive environment. For many, theirs was a social experience of isolation and invalidation over an extended period, with little evidence of systemic support or support from other families. For many family caregivers, growth eventuated in the face of social isolation and invalidation. This raises questions about factors, both extrinsic and intrinsic, which motivated psychological growth out of adversity. As in other literature (see McCormack & Joseph, 2013; 2014), in the absence of social networks, or in the presence of adversarial negative support, other factors may motivate growthful change. In these studies, it would seem that *Relational Social Engagement (RSE)* within the family groups, was the key factor for positive change.

Therefore, central to the research studies, the concept of *Relational Social Engagement (RSE)* refers to a complex and accessible set of relational interactions between the person with dementia and their family members, situated in distinctive familial bonds. It is manifest through family interactions, whereby individuals with dementia display optimal engagement within family groups and can be positive (*in-step*)

or negative (*out-of-step*). *RSE* was particularly evident when family members were engaged in positive *in-step* interactions. This highlights the centrality of person centred and individualised approaches within families for supporting levels of awareness and speech/non-speech communication beyond assessed expectations. It indicates that distinctive familial bonds offer security and comfort for those with dementia to spontaneously enjoy common ground and express differences within the family group.

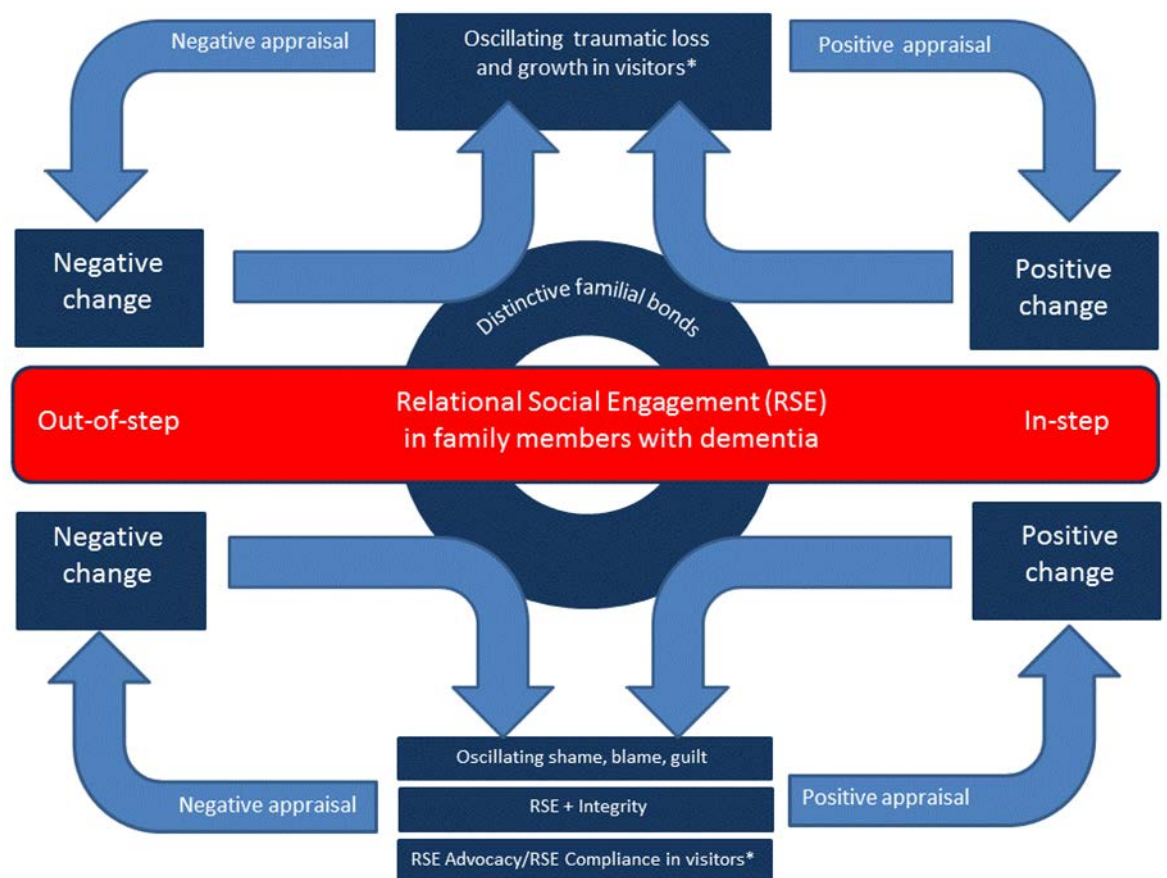
RSE highlights complex psychosocial challenges, which if not considered an essential part of dementia care, may limit opportunities to preserve and optimise retained awareness and interpersonal skills at any level of impairment in residents with dementia. Observed *RSE* highlights that embodied experiences, sensory exchange, and emotion become increasingly important for maintaining social experiences for individuals in the later stages of dementia. Where this is overlooked within busy care homes, residents who require a more creative approach to communication may be assumed less aware and communicative, than is the case. However, private manifestations of *RSE* between family members, inclusive of those with dementia, can present a very different picture.

As such, *RSE* indicates that focusing on family members is important and beneficial within dementia care, particularly when it becomes harder for residents to satisfy their psychosocial needs. Therefore, *RSE* has implications for family visitors who could benefit from new perspectives on retained awareness, for the attainment of psychosocial needs in their in-resident family member and opportunities for psychological wellbeing and growth despite ongoing distress in themselves. In particular, *RSE*, regardless of whether it is *out-of-step* or *in-step* supports the maintenance of distinctive familial bonds. However, it would appear that *RSE* during *in-step* family interactions revealed psychological wellbeing and growth in family members

who were able to move beyond negativity, towards positive reappraisals of the care system and self-as-carer for *RSE* advocacy or compliance as appropriate. Indeed, it was through their alternating positive and negative appraisal of changing interpersonal levels of awareness and social interaction at different stages of dementia that they came to realise personal significance and comprehensibility in current life. Thus, adaptive wellbeing and domains of growth were found to co-exist with distress, and it would appear that as positive change and *in-step* interactions took hold, distress and *out-of-step* interactions inevitably declined. See Figure 2.

Figure 2

Relational Social Engagement (RSE) in context of stigma, traumatic loss, and psychological growth



*When assimilation occurs, i.e. pretrauma world view retained, family members are likely to disconnect and stop visiting.

9.3 Future research

This thesis has implications for clinical psychologists seeking to facilitate *RSE*, and psychological wellbeing and growth in families. In this thesis, it was through the independent efforts of health care managers and family caregivers that both systemic care and self-as carer were positively redefined. Although systemic issues must be addressed (e.g., stigmatising views and treatment of those who live with dementia, remuneration and training for health care assistants), the researcher would argue that positive change in dementia care and *RSE* within families will occur when a *turning point* of individual thoughts and views come to regard existing ways of caring and interacting as unacceptable. To leverage and facilitate this anticipated turning point, these studies indicate that in partnership with health care managers and their staff, clinical psychologists can play a role in facilitating family adjustment by: (1) modelling opportunities for *RSE* in families who are uncertain about retaining relational and social connection with a family member who has dementia; and (2) helping families access their own *synthesis of meaning* from past and present cumulative adversities for their positive redefinition of care and self-as-carer.

Hence, following this thesis, the researcher intends to write a book for families, and test that book with families as a bibliographic intervention within a randomised controlled trial. Based on those study findings, he intends to publish the book with a supporting website. In authoring the book and website, the researcher will draw upon the published studies from this thesis, and other dementia literature, to offer a guide on dementia for families. The content will be foundational upon concepts developed in this PhD. Therefore, the book and website will seek to provide insights and skills for practical application within families, encompassing: (1) negative and positive psychosocial impacts of the current health care system from the perspectives of health

care managers and family caregivers; (2) negative and positive psychosocial impacts on the individual family caregiver and their family relationships from the perspectives of managers of health care and family members; and (3) *in-step/out-of-step* communication and opportunities for *Relational Social Engagement (RSE)* within families.

9.4 Chapter close

Insider perspectives from the *triad of relational and social dementia expertise* revealed the possibilities surrounding interpersonal awareness and engagement, the psychosocial struggle, the impact of dementia on psychological wellbeing, and the opportunity for psychological growth in these participants. The construct, *Relational Social Engagement (RSE)* has been identified through this thesis as a complex and accessible set of relational interactions between the person with dementia and their family members, situated in distinctive familial bonds. Although theories of growth regard social support as an essential condition for growth following adversity, when social support was limited or even adversarial for family caregivers, findings of this thesis would suggest that families seeking *RSE* with an in-resident member, foster meaning making for psychological wellbeing and growth. *RSE* presents opportunities for future research hypotheses, with interventions focused on preserving and optimising retained *RSE* at any level of cognitive and functional impairment, and opportunities for psychological wellbeing and growth in families.

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Appendices

1. Transcript extract notations

—	A pause in speech.
...	Removal of nonessential material.
(PMD)	Person with moderate dementia
(PSD)	Person with severe dementia
(vis.)	Visitor

2. References for Table 4

References numbered below correspond with the numbered items in Table 4, on page 47 of this thesis:

1: Fratiglioni, Wang, Ericsson, & Maytan et al. (2000); Holwerda et al. (2014); Steptoe, Shankar, Demakakos, & Wardle. (2013); 2: Comijs, van den Kommer, Minnaar, & Penninx et al. (2011); Greenberg, Tanev, Marin, & Pitman (2014); 3: Boyle, Buchman, Wilson, & Schneider et al. (2012); Lachman, Neupert, Bertrand, & Jette (2006); Lachman, Agrigoroaei, Murphy, & Tun (2010); Preussner et al. (2005); 4: McDowell, Guoliang, Lindsay, & Tierney (2007); Sando, Melquist, Cannon, & Hutton et al. (2008); Stern (2012); 5: Anstey, Mack, & Cherbuin (2009); Anstey, von Sanden, Salim, & O'Kearney (2007); Gudala, Bansal, Schifano, & Bhansali, (2013); Loefer & Walach (2013); Lopes Furtado, Ferrioli, & Litvock et al. (2010); Nilsson & Nilsson (2009); Pendlebury & Rothwell (2009); Rusanen, Kivipelto, Quesenberry, & Zhou et al (2011); Sabia, Nabi, Kivimäki, & Shipley et al. (2009); Tolppanen et al. (2014); Vagelatou & Eslick (2013); Xu et al. (2011); 6: Järvenpää, Rinne, Koskenvuo, & Räihä et al. (2005); 7: Laitinen, Ngandu, Rovio, & Helkala et al. (2006); 8: Lye & Shores (2000); McKee & Robinson (2014); Monti, Margarucci, Tosco, & Riccio et al. (2011); Plassman, Havlik, Steffens, & Helms et al. (2000); Smith, Johnson, & Stewart (2013); 9: DeKosky & Gandy (2014); 10: Fratiglioni et al. (2000); Holwerda et al. (2014); Seeman, Miller-Martinez, Stein-Merkin, & Lachman et al. (2011); Steptoe et al. (2013); 11: Boyle et al. (2012); Lachman et al. (2006); Lachman et al. (2010); Preussner et al. (2005); 12: Alladi, Bak, Duggirala, & Surampudi et al. (2013); Woumans, Santens, Sieben, & Versijpt et al., (2015); 13: Fitzpatrick et al. (2004); Kukull et al. (2002); Lachman et al. (2010); Sando et al. (2008); Small & McEvoy (2008); Stern (2012); Wilson, Boyle, Yu, Barnes, & Schneider et al. (2013); 14: Dufoir, Pereira, Chêne, & Glymour et al. (2014); 15: Barnes & Yaffe (2011); Di Marco, Marzo, Muñoz-Ruiz, & Ikram et al. (2014); Lautenschlager et al. (2012); 16: Ahlskog, Geda, Graf-Radford, & Petersen (2011); Colcombe & Kramer (2003); Defina, Willis, Radford, & Gao, et al. (2013); Dik, Deeg, Visser, & Jonker (2003); Geda, Roberts, Knopman, & Christianson et al. (2010); Lachman et al. (2006); Xu, Park, Huang, Hollenbeck, & Blair et al. (2011); 17: Fotuhi, Mohassel, & Yaffe (2009); Gu & Scarmeas (2010); Laitinen et al., (2006); Lourida, Soni, Thompson-Coon, & Purandare et al. (2013); Morris, Jacques, Rosenberg, & Selhub (2007); 18: Elwood, Galante, Pickering, & Palmer et al. (2013).

3. University ethics approval

HUMAN RESEARCH ETHICS COMMITTEE

Notification of Expedited Approval

To Chief Investigator or Project Supervisor:	Doctor Lynne McCormack
Cc Co-investigators / Research Students:	Mr Bruce Walmsley
Re Protocol:	Staying connected: In-Step and Out-of-Step communication pathways in families living with dementia.
Date:	21-Jun-2013
Reference No:	H-2013-0067
Date of Initial Approval:	13-Jun-2013

Thank you for your **Response to Conditional Approval** submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under **Expedited** review by the Chair/Deputy Chair.

I am pleased to advise that the decision on your submission is **Approved** effective **13-Jun-2013**.

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research, 2007, and the requirements within this University relating to human research.

Approval will remain valid subject to the submission, and satisfactory assessment, of annual progress reports. *If the approval of an External HREC has been "noted" the approval period is as determined by that HREC.*

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal *Certificate of Approval* will be available upon request. Your approval number is **H-2013-0067**.

If the research requires the use of an Information Statement, ensure this number is inserted at the relevant point in the Complaints paragraph prior to distribution to potential participants
You may then proceed with the research.

For noting: With regard to participant information statements/consents, the inclusion of reference to specific institutional policy documents is unlikely to be particularly helpful or informative to potential participants.

Conditions of Approval

This approval has been granted subject to you complying with the requirements for *Monitoring of Progress, Reporting of Adverse Events, and Variations to the Approved Protocol* as detailed below.

PLEASE NOTE:

In the case where the HREC has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University's HREC.

Monitoring of Progress

Other than above, the University is obliged to monitor the progress of research projects involving human participants to ensure that they are conducted according to the protocol as approved by the HREC. A progress report is required on an annual basis. Continuation of your HREC approval for this project is conditional upon receipt, and satisfactory assessment, of annual progress reports. You will be advised when a report is due.

Reporting of Adverse Events

1. It is the responsibility of the person **first named on this Approval Advice** to report adverse events.
2. Adverse events, however minor, must be recorded by the investigator as observed by the investigator or as volunteered by a participant in the research. Full details are to be documented, whether or not the investigator, or his/her deputies, consider the event to be related to the research substance or procedure.
3. Serious or unforeseen adverse events that occur during the research or within six (6) months of completion of the research, must be reported by the person first named on the Approval Advice to the (HREC) by way of the Adverse Event Report form (via RIMS at <https://rims.newcastle.edu.au/login.asp>) within 72 hours of the occurrence of the event or the investigator receiving advice of the event.
4. Serious adverse events are defined as:
 - Causing death, life threatening or serious disability.
 - Causing or prolonging hospitalisation.
 - Overdoses, cancers, congenital abnormalities, tissue damage, whether or not they are judged to be caused by the investigational agent or procedure.
 - Causing psycho-social and/or financial harm. This covers everything from perceived invasion of privacy, breach of confidentiality, or the diminution of social reputation, to the creation of psychological fears and trauma.
 - Any other event which might affect the continued ethical acceptability of the project.
5. Reports of adverse events must include:
 - Participant's study identification number;
 - date of birth;
 - date of entry into the study;
 - treatment arm (if applicable);
 - date of event;
 - details of event;
 - the investigator's opinion as to whether the event is related to the research procedures; and;
 - action taken in response to the event.
6. Adverse events which do not fall within the definition of serious or unexpected, including those reported from other sites involved in the research, are to be reported in detail at the time of the annual progress report to the HREC.

Variations to approved protocol

If you wish to change, or deviate from, the approved protocol, you will need to submit an *Application for Variation to Approved Human Research* (via RIMS at <https://rims.newcastle.edu.au/login.asp>).

Variations may include, but are not limited to, changes or additions to investigators, study design, study population, number of participants, methods of recruitment, or participant information/consent documentation. **Variations must be approved by the (HREC) before they are implemented** except when Registering an approval of a variation from an external HREC which has been designated the lead HREC, in which case you may proceed as soon as you receive an acknowledgement of your Registration.

Linkage of ethics approval to a new Grant

HREC approvals cannot be assigned to a new grant or award (ie those that were not identified on the application for ethics approval) without confirmation of the approval from the Human Research Ethics Officer on behalf of the HREC.

Best wishes for a successful project.

Professor Allyson Holbrook

Chair, Human Research Ethics Committee

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4. Interview schedules for family members

1. Can you please tell me your age; and the length of time you have been caring for your family member with dementia?
2. Broadly, can you tell me about your experience of caring for your family member with dementia? Or: Broadly, can you tell me about your experience of using the health care system for your family member with dementia?
3. In general, how do you interpret its impact on your life both positively and negatively? Or: In general, how do you interpret the impact of the health care system on your life both positively and negatively?
4. More specifically, how do you interpret:
 - a) your thoughts, feelings, priorities that may have changed through this experience?
 - b) your worldviews that may have changed?
 - c) its impact on your relationships and communication skills?
5. How you make sense of being caught up in those human dynamics?
6. How you make sense of your spiritual beliefs, if any, in relation to your experiences?
7. How you see your life going forward from these experiences?

5. Interview schedules for health care managers

1. Can you please tell me your age; the length of time in your current role; and the length of your overall health care career?
2. Broadly, can you tell me about your experience of working in dementia care? Or: Broadly, can you tell me about your experience of witnessing the impact of dementia on family relationships?
3. In general, how do you interpret its impact on your life both positively and negatively? Or: In general, how do you interpret the impact of this witnessing on your life both positively and negatively?
4. More specifically, how do you interpret:
 - a) your thoughts, feelings, priorities that may have changed through this experience?
 - b) your worldviews that may have changed?
 - c) its impact on your relationships and communication skills?
5. How you make sense of being caught up in those human dynamics?
6. How you make sense of your spiritual beliefs, if any, in relation to your experiences?
7. How you see your life going forward from these experiences?

6. Examples of suggestive extracts from transcripts

Chapter 4: Extract from the focus-group interview

- Researcher: So, can you tell me how do you interpret the impact on family relationships?
- Richard: I guess a negative in that sort of area for me (his voice breaks and he tears up) was to see that Jeanette cannot [he breaks down] any longer interact with her grandchildren.
- Susan: Hmm.
- Gary: Yeah.
- Researcher: That's a tough, that's difficult.
- Susan: Very difficult. Yep.
- Richard: Ah. That hurt our youngest son (he clears his throat) she doesn't even know that I've got children (his voice almost breaks).
- Susan: Yeah (her voice almost breaks).
- Gary: The children themselves, she interacted with exceptionally well.
- Richard: Yeah.
- Susan: But she didn't connect those children with their parents. That's what (her voice almost breaks) broke his heart wasn't it?
- Gary: Aaah.
- Susan: Cause she was talking to him the day that Dad died and he was just chatting to her about general things, and then she turned to him and said "Do you have any children?", and his face (her voice almost breaks).
- Richard: Yep.
- Susan: And I explained to him, that he needed to see her reaction to his daughter, and he said "She doesn't even know Jade", and I said "She does know Jade but she doesn't connect you and Jade".
- Susan: She connects Jade with us, because we take her to see her while you're at work, and then ...
- Richard: Yeah, yep
- Susan: ... when he actually saw her with his daughter, he realised that his daughter was important to her, because they had been used to this very strong woman who played golf and ran the household and they didn't see the decline, because we visited, they, our kids were working when they she came here to live our oldest son brought his boys to see her a number of times, and because we minded our youngest son's kids and brought them here, he didn't come to see her till after, I think they were married and he brought them, everybody came in in their wedding gear to show her, and

he was so shocked, and he just said (her voice almost breaks) “Mum I can’t see her. I can’t see Nanna like that”.

Chapter 5: Extract from the interview with Peter

Researcher: How do you make sense of the family dynamics that you observe and experience?

Peter: I think the staff have come a long way, I mean we basically in each of the facilities in this town, we have a micro-palliative care unit where the staff are trained and up-to-scratch to deal with things, that are not expected of them, but that works so well, and complement the whole place of the nursing home environment is really working to our favour, up to a point where some of some of the family members think oh it’s not good enough that the nurses I want to see a palliative care specialist, it’s just, you know it’s human because it’s really hard to deal with loss, you know human nature is I don’t accept loss, so to prepare them to say this is the reality you know, dementia is not going to go away, it has this and that problem so, we need to deal with it you just can’t get another specialist to come and tell you it’s dementia, it is dementia, or get another specialist to say it’s difficult behaviour, and we need to be doing that and that, so um, and I think as time goes and they read the testimony of other people and family and you know personal reference of when they make a decision to put somebody in the care of you know we know what we’re doing and we’re doing it very well, there is no way that you know for every palliative care patient or every advanced dementia case we can involve the geriatrician, or psychogeriatrician and this stuff yeah we wait six months for the geriatrician appointment for the old person so we don’t have six months! So you know a lot of the things um that that the local specialist’s know me and they know my capacity and the know my knowledge base and we sort a lot of things out over the phone and they say you’re on the right track, do this, do that, and we get on, but that in a way is good enough for the family to say yes he’s spoken to the specialist and you know they’ve found this and that, so, so it’s good to have that backup um because you know dementia is multifaceted, it affects so many things and it presents so differently, um, and the pre-morbid um personality is important too. If people have been, we’ve got a sailor in here, and he is rude and rough and he’s still rude and rough but now without any inhibition.

Researcher: How do you make sense of that?

Peter: Well, I think that's a really one of the biggest challenges in living with dementia or a patient with dementia is to accept what is happening their behaviours and understanding, because you know our biggest challenge is to say that the dement is world is separate world, you basically when you get into that door, you climb, like climbing out of your car and you're leaving that vehicle and you're climbing into this vehicle and you live this year you know it's a different journey and when you go out of this door you sort of climb out of this vehicle and go along with your normal life. It's not compatible, and once they sort of snap back, it's a lot easier, because they constantly want to pull the patient up to the standards of living and vision and whatever they wear, and that's the biggest challenge, so you know it's difficult because things like a family member have said um you know when they were both well "don't put me in a nursing home – ever" you know so the poor woman can't look after her husband, she try her best and you know wear herself totally down before eventually she puts the old man into a nursing home, then she lives with this guilt because she deserted him and has broken her vows and whatever and then when they come in and see they still constantly want to drag him. I had a patient that was really advanced dementia and the family constantly drag him out into town to have a coffee because he likes coffee, but he has not a clue what coffee is you know he is so demented you don't know, but just because you always loved it they think well he still loves it but just getting him into the car, getting him out of the car, getting him in a busy street, he is totally lost.

Researcher: How do you make sense of that?

Peter: I think it's human to always try your best, but you need to you know focus it in the right direction, they they still committed to the family member but committed totally in the wrong direction and that's where we spend a lot of time with the families. Look you need to come in here, you need to establish what's the things here in his little dementia world that gives him comfort, that's giving him um you know that he can still understand, that he still can enjoy, and then you focus on that and you do that. It doesn't matter what your needs are, when you come into this tiny little world this is what you focus on, you don't tell him about the cat and the dog that died, and the aunty that is sick, you just focus on their little world, you do things that comfort them and support them.

Chapter 6: Extract from a video-recorded observation

Joy: Hello Harry. (Joy leans forward in her chair, facing Harry. Her eyes hold his.) Hello.

Harry: Heeh (He moves his head from left to right and then faces Joy. He smiles.)

Joy: How are you today?

Harry: Me? (He taps his belly once with his left hand,)

Joy: Yes.

Harry: I dinni thi din tho (He faces Joy. His eyes hold hers. Occasionally his eyebrows rise and fall as he speaks.)

Joy: Oh?

Harry: I've been trying for ever.

Joy: You've been busy?

Harry: Yeh.

Joy: You have. What were you doing?

Harry: He stretches his left arm straight out and moves it slowly to the left in a horizontal line. His hand is perpendicular to his arm and the back of his hand faces outwards. His movement is slow, gentle and rhythmic like an orchestra conductor. He then moves his arm back to the centre in the same fashion. He smiles as he does this and his eyes hold Joy's eyes. He then holds his hand still for a second.)

Joy: Hey? What were you doing? (Joy smiles and holds her eyes on Harry's eyes.)

Harry: (Still smiling, still holding his gaze on Joy's eyes and continuing to hold his left hand in the same position, he now stretches his left hand straight out with his palm facing downwards and fingers curled as if playing a piano. He now moves both arms to the right in a slow rhythmic way. He holds them to the right for a second. He moves his right hand perpendicular to his arm with the back of his hand facing outwards and moves his left hand palm to face downwards. Now more quickly he moves both arms rhythmically to the left. His left hand still held straight forward with palm perpendicular

Joy: You're not talking to me again. You've been busy today. You've had breakfast.

Harry: (Mumbles.)

Joy: Haven't you. You've had breakfast.

Harry: (Mumbles.)

Joy/Harry: What did you have for breakfast? ... What did you have for breakfast? ...I've brought you something. (Harry places both hands on the arms of his chair and leans forward.) No you sit still. Look (She leans forward and extends her left arm to tap him several times lightly on his right knee.) I've brought you something. (She gets out of her chair, walks to him, and

kneels in front of him holding a lunchbox of fruit and custard. As she speaks she holds eye contact with Harry.) I've come to see you. And I've brought you something. Your favourite. Well, I think it's your favourite. (She opens the box and Joy mixes the contents with a spoon) Look. (Harry looks down into the container.) It's a bit messy. It's started to leak. Do you want a piece of this? (As she lifts a spoon of the fruit towards his mouth, Harry opens his mouth. He eats. As Joy speaks to Harry she holds close and clear eye contact with him. He chews the food.) It's a pear. It's pear. It's good isn't it? Aye. It's good. Can you hear me alright? Is your hearing aid working? (Joy offers him spoons of pear which he accepts and eats.)

Chapter 7: Extract from the interview with Joy

- Researcher: Broadly, can you tell me about your experience of using the health care system for your family member with dementia?
- Joy: The first time that I put him into hospital and I really think, ah, the amount of sedation they gave him um considering, this is another thing, they didn't know who he was they didn't know what he was like and so he was maybe frightened. I think, I think what they should have done was send for me even though it was night time. I would have gone; I would have, done anything I could to calm him down, which was I think what they were trying to do. I have no idea how he reacted when he got into that hospital. I can imagine and I think they went round it the wrong way. They gave him sedation. He was like a zombie. I'm not exaggerating for four whole days and fortunately I went in when the doctor was coming round, on his rounds, and I said to him "What have you done to my husband?" Considering Harry ran to get into the ambulance you know (she chuckles). It was a bad night. It was pouring with rain blowing a gale, and as soon as he got out the door, he said "Oh! It's raining" and off he went, and ran to get into the ambulance and when I went into see him, he was just a zombie. He couldn't, he couldn't pick his head up, he, the next day they put him in a chair, but he was just, sitting... and the doctor said, he said "Oh we're not going to give him anything else" He said "we can't understand this" but Harry never had as much as a Panadol, in all those years, we've been married 60 years.
- Researcher: So, um medication wasn't something that you used when you were unwell?

Joy: No. No. No. Never-ever. He wouldn't take Panadol. He never, very, oh I can't remember when he had a headache. He only had a really heave cold; you might say the flu in 60 years, he only had it twice.

Researcher: Ok. Yeah. Yeah.

Joy: So he didn't need medication. However, that's gone and I try and forget it. Um, but until then, you know I could take him out, and people could talk to him. He was a bit slow but we went bowling ...dancing ...playing darts. I mean he was playing darts and he wasn't throwing the dart at anybody else. He was throwing it at the board. That was OK.

Researcher: What did it mean for you when he entered hospital?

Joy: Oh it was traumatic! It was terrible!

7. Published journal abstracts relating to this thesis

Chapter 4

- (1) Walmsley, B. D., & McCormack, L. (2016). Synthesis of meaning: Negative and positive change in family members following the adversity of dementia. *Journal of Humanistic Psychology*, 56(2), 122–143.
<http://dx.doi.org/10.1177/0022167814557547>

Abstract

A paucity of research explores both negative and positive changes for family members supporting a loved one with dementia, especially when communication by speech and awareness of others diminishes. This qualitative study sought the views of family groups concerning their experiences over the past 10 years supporting a loved one with dementia. A focus group sought negative and positive subjective interpretations of this phenomenon. One superordinate theme: *Synthesis of Meaning* emerged from the data using interpretative phenomenological analysis. This overarched two subordinate themes: (a) *Steps backward* encompassing those times when relatives hovered uncertainly, missed opportunities to engage due to advancing dementia, and felt regret and (b) *Steps forward* encompassing moments of unexpected rewards, acceptance, self-forgiveness, and empathic connection with others on a similar journey. This study highlights that although often fraught with distress, positive aspects of the dementia journey are possible and offer opportunity for psychological growth and well-being.

Chapter 5

- (2) Walmsley, B. D., & McCormack, L. (2015a). Stigma, the medical model, and dementia care: Psychological growth in senior carers through moral and professional integrity. *Dementia*, 1–18. Online 12th March:
<http://dx.doi.org/10.1177/1471301215574112>

Abstract

Minimal research explores the impact of a career in dementia care on senior health professionals. This study sought positive and negative subjective interpretations from seven senior health professionals regarding their experiences in dementia care. Data from semi-structured interviews were analysed using interpretative phenomenological analysis (IPA). One superordinate theme, *Honouring stigmatised self*, overarched four sub-themes: *Systemic stigma*, *Invalidated*, *Self-respect* and *Moral integrity and Growth*. Stigma was interpreted as systemically entrenched minimisation of aged care and the aged-care workforce, including poor remuneration and

training. Participants experienced peer invalidation particularly when attempting to resolve complex professional and moral challenges in dementia care. These often occurred in the context of efforts to individualise care, constrained within a medical model. Paradoxically, external invalidation motivated a search for redefining 'self' and moral integrity. By wisely acknowledging career experience, growthful domains of self-respect, optimism, humility and innovation defined professional practice and personal choices. Implications are discussed.

- (3) Walmsley, B., & McCormack, L. (2015b). Shame, hope, intimacy, and growth: Dementia distress and growth in families from the perspective of senior aged care professionals. *Dementia*, 1–19. Online 27th February: <http://dx.doi.org/10.1177/1471301215573676>

Abstract

Minimal research explores the impact of dementia and a dementia diagnosis on families from the unique vantage of senior health professionals. The participants of this study, eight senior aged care professionals, provided unique interpretative insights into family dynamics and sense-making on the journey with dementia, and their own role in that journey. Both positive and negative perspectives were sought. Data from semi-structured interviews were analysed using Interpretative Phenomenological Analysis (IPA). One superordinate theme, *Dementia naiveté and redefined intimacy*, overarched *Embarrassed shame*; *Maintaining hope*; *Redefining a model of intimacy*; and *Redefined relational intimacy and growth*. Within these themes, the participants shed light on hurtful embarrassment and shame experienced by families associated with the diagnostic label given to a loved one. This label was perceived to either trigger separation, hurt and immobility through ignorance, or precipitate a frenzy of naive yet hopeful energy for seeking that elusive cure. The participants saw their role as one of enacting a new way of connecting what was with what could be. Thus, they modelled advocacy, integral care and relational intimacy. Validation came in witnessing a redefining of intimacy in many families who were able to embrace that holistic and empathic approach to the shifting presentation of dementia. Psychological well-being was observed to occur when families embraced growthful domains, e.g., acceptance, hope, relational closeness and altruistic concern for other families. Implications for future care models are discussed.

Chapter 6

- (4) Walmsley, B. D., & McCormack, L. (2016b). Severe dementia: Seeking *Relational Social Engagement* during family visits. *Aging & Mental Health*: <http://dx.doi.org/10.1080/13607863.2016.1220923>;

Abstract

Few studies have utilised observation to investigate retained awareness when individuals with severe dementia interact with family members. Seeking evidence of retained awareness in those with severe dementia, interactive family visits in care homes were observed and analysed. Five family groups (14 individuals) completed 10/15-minute video recorded family interactions. Speech and non-speech interactions were analysed using Thematic Analysis. One superordinate theme: *Distinctive family bonds*; overarched two subthemes, *in-step* and *out-of-step* describing positive and negative familial interactions. *In-step* interactions revealed family groups reciprocating *social support, having fun together*, and willing to *go on the ride together*. *Out-of-step* interactions characterised *social frustration, non-reciprocity*, and *sidelining* of members with dementia. Although awareness fluctuated, complex awareness was observed in the speech/nonspeech expressions of those with dementia. In response, visitors appeared to treat those expressions and behaviours as understandable. Observed outcomes were *out-of-step* when visitors sought to retain the familiar and *in-step* when visitors sought to optimise all communication possibilities. Video recorded family interactions and analysis revealed: (a) awareness was retained in the participants with severe dementia beyond assessed levels; and (b) *Relational Social Engagement (RSE)* occurred within family groups despite positive or negative interactions. Implications are discussed.

- (5) McCormack, L., Tillock, K., & Walmsley, B. D. (2016). Holding on while letting go: Trauma and growth on the pathway of dementia care in families. *Aging & Mental Health*, 1-10. Online 16th February: <http://dx.doi.org/10.1080/13607863.2016.1146872>

Abstract

Limited research explores the medical model of residential care in dementia from the family caregiver's perspectives. This study sought subjective interpretations of nine family caregivers who experienced relinquishing their status as primary caregiver to a medical model, dementia care residential setting. Following semi-structured interviews and transcription data was analysed using interpretative phenomenological analysis. One superordinate theme, *navigating 'system' control*, overarched three subordinate themes: *connecting/disconnecting, windows closing*, and *capacity for sensation*.

Navigating system control reflected participants' experience of circumnavigating a medical system fraught with hierarchical challenges inclusive of a complex maze of contradictions that appeared threatening, yet appeared comforting; authoritarian, yet often humane. For them, care of self, while advocating for a family member with dementia, required vigilance to manoeuvre a system of care that imposed its uninvited authority at will. *Connection/disconnection* highlights the enduring struggle for inclusivity in caregiving despite the omnipresent trauma of *windows closing*. Psychological growth came to these participants through an unexpected *capacity for sensation* which offered a unique lens to communication with the family member with dementia primarily through sensory exchange. Models of dementia care and therapeutic interventions could inclusively involve dementia family caregivers who may be experiencing traumatic distress, and associated guilt, stigma, loss, and grief. Co-existing psychological wellbeing, however, is possible when family members are encouraged to transition communication to sensory awareness and exchange as *windows close*.