“What she used to do, now I have to do it”: *A collaborative autoethnographic approach to an Italian-Australian family’s experience of dementia*

Honours thesis submitted in partial fulfilment
of the requirements for the award of the degree
BACHELOR OF COMMUNICATIONS AND MEDIA STUDIES
(HONOURS)
from
UNIVERSITY OF WOLLONGONG
by Giverny Witheridge
School of the Arts, English and Media

2017

Abstract

Dementia is a disruptive and difficult experience for families, and yet its impact on families is not as well documented as might be expected. There is a relatively widespread tendency in the literature on dementia to describe family as a single individual designated as “family caregiver” rather than the larger family unit or system. In this study, I adopt a family systems approach to explore the impact of dementia on my own family. Using both collaborative autoethnography and collaborative ethnography as research methods, I conducted interviews with five family members to understand the meanings that they individually and collectively ascribe to changes associated with my Nonna’s dementia. Given our Italian-Australian background, I also consider the influence of Italian culture on family caregiving and draw on the experiences of two non-family participants, one Italian and one non-Italian, who both had a loved one with dementia. Taken together, their accounts reveal seven overarching themes and provide some ways of thinking about how other families might respond to dementia. Overall, this study offers rich insights into the methodological and ethical issues involved in researching family experiences of dementia. It also offers some thoughts and reflections on my experience of being both an insider and outsider and how the positionality of the researcher impacts the research process. The thesis closes with a call for further research on the naturally occurring process of family storytelling and how it unfolds as an everyday and potentially transformative communicative practice.

Declaration

I certify that this thesis is entirely my own work except where I have given full documented references to the work of others, and that the material contained in this thesis has not been submitted for formal assessment in any formal course and the word length is 18,836.

Giverny Witheridge
4 October 2017

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Acknowledgments

This thesis represents a collaborative effort. My greatest debt of gratitude is owed to my supervisor, Dr Kate Bowles, who encouraged, advised and assisted me every step of the way. It is through Kate’s guidance and support that I have grown as a writer, thinker, and as a person.

My appreciation also extends to Dr Siobhan O’Dwyer and Dr Laura Béres for their valuable suggestions and to my fellow Honours student, Angus, for his comradeship.

During my research, I have been privileged to meet two lovely women who trusted me with their stories. To both Paola and Penny, I offer a sincere thank you for sharing your experiences with warmth, frankness and generosity.

Finally, I would like to express my deepest and heartfelt thanks to my family for being part of this research journey and for the love and care you have always given me.

I dedicate this thesis to my adored Nonna and Nonno, with all my love.

I had envisioned opening this thesis with an evocative and heartfelt story about my Nonna and the inroads dementia has made upon her life. However, when I started to write it, I found myself spilling out the clichéd dementia narrative that constructs a reductionist view of the person before cognitive impairment and the person after. Like many others have before me, I could paint a vivid picture of the Nonna I remember fondly from my childhood, and then describe the devastation of loving someone who is no longer, and will never be, the same. But to do this would rob Nonna of the canvas of her life and impose some form of "narrative foreclosure" (Freeman 2000, p.90) upon her, despite the fact that she is still storying her world. So, to preserve Nonna's personhood and respect her continuing narrative development, I have left these things unsaid and hold space for an identity still in motion.

Chapter 1: Introduction

One of the largest public health and social care challenges facing the global population in the 21st century is the increasing prevalence of dementia (ADI 2015, p.1). Worldwide, around 47 million people have dementia, and this number is predicted to rise to 131.5 million by 2050 (ADI 2015, p.1). This has profound implications not only on a societal level, but on a family and individual level as well.

Dementia is not a single specific disease; it is an umbrella term for a wide range of symptoms related to the impairment of language, memory, perception, personality and cognitive skills (AIHW 2012, p.2). The most common types of dementia are Alzheimer's disease, vascular dementia and dementia with Lewy bodies (AIHW 2012, p.2). While the course of dementia varies substantially, it is often characterised as occurring in three stages: mild (early-stage), moderate (middle-stage) and severe (late-stage) (AIHW 2012, p.3). Dementia mainly affects older people, although onset can begin before the age of 65 (WHO 2017).

This thesis is the story of my family's journey with dementia. In this work, I turn to collaborative autoethnography to explore and describe our experiences since Nonna developed Alzheimer's disease. This approach provides the opportunity to speak from the 'inside' about the many changes, losses and adjustments that have taken place in my family with the progression of the disease.

My initial decision to research this topic emanated from witnessing my Nonno's daily caregiving struggles and my desire to give voice to his suffering. Family caregivers of people with dementia play a vital, yet often unrecognised and undervalued role in society (Gitlin & Hodgson 2016, p.1177). As a neglected, vulnerable and at-risk population, family caregivers are appropriately called the "invisible second patients" in dementia care (Brodaty & Donkin 2009, p.217).

Notwithstanding this, there has been extensive research over recent decades on the issues experienced by family caregivers of people with dementia. Much of this research treats the family caregiver and the person with dementia in isolation from the family context in which they are embedded (Keady & Harris 2009, p.6). However, caring for a person with dementia is a family issue, having an impact on the entire family system (Celdrán, Triadó & Villar 2009, p.244). Yet, few studies have examined the perspectives of family members other than the primary caregiver and the impact of dementia on the wider family (La Fontaine & Oyebode 2014, p.1245). This is problematic because it can be difficult to develop a relational understanding of dementia and improve services and interventions without hearing from all those directly affected (Merrick, Camic & O'Shaughnessy 2016, p.35).

While searching for literature on families and dementia, I formulated a research question: "How does dementia impact on individual family members and on families as interactive units?" To address it, I interviewed five members of my family from three different generations, focusing on how they negotiate changes associated with dementia and manage its effects in everyday life. In doing so, I provide insight into the nuance, complexity, emotion and meaning of their experiences in a manner only an insider can describe.

This study adopts a family systems perspective to investigate these experiences. From within this theoretical framework, individual family members are interdependent, exerting a continuous and reciprocal influence on one another (Cox & Paley 1997, p.246). Hence, any individual family member can never be fully understood independent of the larger family system (Cox & Paley 1997, p.246).

Given my family's Italian-Australian background, another objective of this study is to consider the impact of Italian cultural factors on the ways in which dementia is experienced and managed within families. In order to enrich this companion inquiry, I interviewed two non-family participants, one Italian and one non-Italian, who both have experience with dementia. My engagement with these participants can be viewed as counter to the collaborative autoethnographic family systems approach taken in this study. This offers a pathway for exploring the potential value added by this approach in research focusing on the dementia experience.

At its heart, this is a communications thesis concerned with the methodological, emotional and ethical issues attendant in chronicling other people's rich and complex experiences. The practice of asking for people's stories, listening and making sense of them and retelling these stories as part of one interconnected narrative is central to this work. Like any narrativist, I grapple with issues of power, representation, voice and privilege and the questions they raise: Who is telling the story? Who speaks for whom? Who has the right to represent whom and for what purposes? Whose voices are included and whose are excluded?

Previous research has been criticised for not actively involving people with dementia as study participants (Ablitt, Jones & Muers 2009, p.506). Unfortunately, I was unable to interview Nonna due to practical and ethical challenges. As such, Nonna's voice is not heard in the discussion. At several points throughout this work, I draw attention to Nonna's absence as a reminder that her side of the story will never be told. This thesis should be read with this limitation in mind.

The methodological elements of this study are crucial not secondary. This study combines the practice of collaborative autoethnography with the principles of collaborative ethnography. Grounded in postmodern philosophy, both these approaches subvert traditional norms of scholarship in which the researcher speaks authoritatively about the lives and experiences of other people and undercuts conventions of writing that foster hierarchy and division. They also open up possibilities for honouring different voices and perspectives and for reaching wider audiences that traditional research usually disregards. In this regard, they offer a valuable vantage point from which to empower the people ethnographers aim to understand. This study is further guided by what Ellis (2017, p.438) calls a "relational ethics of care".

While this research project is a direct result of my desire to obtain my Honours degree, I reject the notion that it is principally for my benefit and education progression. The "gift" of autoethnography takes many forms and can be transformative for participants and readers alike (Bochner & Ellis 2006, p.111). I am in agreement with Barbara Myerhoff who wrote that "a kind of fundamental healing takes place when a story is told and heard" (eds Kaminsky, Weiss & Metzger 2007, p.19).

The stories presented here may function as "equipment for living" (Burke 1974, p.293) and inspire personal connection rather than analysis. Ultimately, I hope that this thesis provides a space where others might see themselves, evoking identification and offering companionship to those who also struggle under the impact of a loved one's memory loss. If you have not had experience with dementia, then this thesis offers you a chance to become a compassionate observer of something unfamiliar. In either case, I invite you to engage with this work in an effort to learn more about the lived reality of dementia.

In saying this, however, it is important to understand that my family's narrative is not meant to represent the experiences of all families of people with dementia. This collaborative autoethnographic account is intended "*to stand with*, not to *stand in for*, others' stories" (Park-Fuller 2003, p.219, emphasis in original). I acknowledge the unique story each family lives; ours is one of millions.

Finally, to help guide you as a reader, I provide an outline of each chapter below.

Chapter 2 is a review of the literature. I begin by examining dementia caregiving in an Italian-Australian context before exploring current understandings of family experiences of dementia.

Chapter 3 details the theoretical framework and methodology for the study. In this chapter, I discuss the ethical complexities of doing "ethnography on my doorstep" (Hall 2014, p.2180) and reflect on my dual position as both an insider and outsider in the course of the study.

Chapter 4 presents the major themes that emerged from the interview data. I have not titled this chapter as the "findings" as this label implies that the data was "found" and subsequently that I claim some ownership over it. The stories shared in this thesis belong to the tellers. It has been an honour to re-present them here.

Chapter 5 draws the thesis to a writing close. It is an opportunity for me to consider the overall implications of the study. I am reluctant to suggest a "conclusion" as this denotes a closure, an ending. The thesis provides insights rather than clear and precise conclusions. This is because bringing voice to the voiceless and making the invisible visible are inevitably unfinished and unfinishable agendas.

Chapter 2: Literature Review

The aim of this literature review is two-fold. Firstly, I seek to summarise the existing research base concerning family caregiving for dementia within an Italian-Australian cultural context. Secondly, I attempt to illuminate what is currently known about the impact of dementia on families.

Much of the initial work in the field of dementia focused on its biomedical dimensions (Hellström, Nolan & Lundh 2005, p.7). However, since the early 1990s, increasing attention has turned to a subjective, emotional and experiential understanding of dementia (Gilles 2000; Gilliard 2001), with accounts becoming less “technological” and more in tune with the “meaningful context of lived experience” (Phinney 2002, p.70).[1]

A family’s response to a chronic disease such as dementia can be understood by examining it within a cultural context (Dilworth-Anderson & Gibson 2002, p.56). Cultural norms and values are recognised as having a particularly pervasive influence on people’s values, beliefs and attitudes toward caregiving, specifically because it influences their perceptions on health and illness, their experience of caregiving, their caregiving role expectations and their approach to accessing support networks (Botsford, Clarke & Gibb 2011, p.447).

Research examining dementia care among non-Anglo populations in English-speaking countries has only emerged in the last 30 years (Boughtwood et al. 2011b, p.366). Previous work on this topic has been conducted in North America and has focused predominantly upon Asian, Hispanic/Latino and African American populations (Boughtwood et al. 2011b, p.366). Within an Australian context, there has been limited research focusing on dementia within culturally and linguistically diverse (CALD) communities (Boughtwood et al. 2011b, p.366).[2] Researchers have acknowledged the

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[1] A key development in this major paradigm shift came with the influential work of Tom Kitwood (see, for example, Kitwood 1997a; 1997b), who applied the concept of ‘personhood’ to people with dementia and advocated for person-centred dementia care (Smebye & Kirkevold 2013, p.2).

[2] The term ‘culturally and linguistically diverse’ is commonly used in Australia to refer to groups and individuals who differ according to religion, race, language and ethnicity – except for those whose ancestry is Anglo-Saxon, Anglo-Celtic, Aboriginal or Torres Strait Islander (Community Relations Commission for Multicultural NSW n.d., cited in Nichols, Horner & Fyfe 2015, p.2). Internationally, the term CALD is not used, rather racial and ethnic minority groups are considered (Cheng et al. 2009, p.2).

difficulties in including older CALD persons in studies (Low et al. 2009; Shanley et al. 2013).[3] This knowledge gap is especially troubling as people from CALD backgrounds constitute a significant and increasing proportion of the population living with dementia.[4] CALD caregivers also tend to carry an additional burden as they may hold opinions and beliefs about their responsibility for caring for a family member with dementia that differ from those of the mainstream culture in which they reside (Benedetti et al. 2013, p.139).

The studies by Boughtwood et al. (2011a; 2011b; 2011c; 2012) and Shanley et al. (2012) provide valuable insights into the experience of dementia within CALD communities. The studies each report on a research project targeting Arabic, Chinese, Italian and Spanish-speaking communities in south-western Sydney that was conducted with family carers, bilingual/bicultural community workers, bilingual general practitioners and geriatricians. The overall findings include: the different understandings of dementia that may be held in CALD communities; carers' lack of familiarity with and knowledge of dementia support services; cultural beliefs about caregiving within the family that means people often do not seek services until the needs are critical; carers' difficulty accepting residential care; the important linking role played by bilingual health professionals; and preference for care within ethno-specific services (Boughtwood et al. 2011a; 2011b; 2011c; 2012; Shanley et al. 2012).

It is important to recognise, however, that there is much diversity within CALD populations (Low et al. 2009, p.145).[5] Boughtwood et al. (2011b, p.370) identified that of all the four communities, Italians were the most reluctant to discuss dementia outside the family. Italian multicultural workers attributed such reluctance to a fear by

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[3] One noted challenge is the recruitment of CALD participants (Shanley et al. 2013, p.279). A methodological advantage of insider research is in gaining natural access to CALD groups that are otherwise difficult-to-reach.

[4] The prevalence of dementia within the population of older people from CALD backgrounds in Australia is projected to increase more than three-fold, from approximately 35,000 in 2010 to 120,000 by 2050 (Access Economics 2009, p.30). Additionally, the prevalence of Mild Cognitive Impairment among people from CALD backgrounds is two-to-threefold higher than for those from English-speaking backgrounds (Low et al. 2012, p.866). These projections highlight the need to better understand, develop services for and manage dementia from a CALD perspective (FECCA 2015, p.17).

[5] According to Low et al. (2009, p.145), there may be as many differences between individual CALD groups as there are in comparisons between CALD and non-CALD populations, so treating different CALD populations as homogenous might be problematic.

the family of how the person living with dementia and their broader family would be perceived by other community members (Boughtwood et al. 2011b, p.370).

A similar finding was reported in Benedetti, Cohen and Taylor's (2013) study which examined the experiences of nine Italian-Australians caring for a family member with dementia. A barrier to negotiating early dementia care assistance was the caregivers' fear that if they did not provide the type of in-home aged care that is expected of them, then they would be harshly judged by the wider Italian community (Benedetti, Cohen & Taylor 2013, p.158). The authors also found that there is a strong cultural basis for the Italian-Australian belief that caregiving is a family responsibility, with the Italian community's core familism values (duty, obligation, respect, filial piety) underpinning participants' motivations for adopting a caregiving role (Benedetti, Cohen & Taylor 2013, p.157).

However, in a study conducted by Cole and Gucciardo-Masci (2003, p.38) into the beliefs and values of carers from six ethnic groups residing in Melbourne, the interviewees of Italian background found it difficult to identify any significant community expectations relating to their roles as carers. This is also noted by Boughtwood et al. (2011b, p.375) who suggest that few CALD families understand the term 'carer' or the implications of the term; caring for a family member who needs help is just seen as a normal part of family life. These circumstances have a number of significant consequences, including a tendency for carers to be overburdened and stressed as well as developing their own health problems (Boughtwood et al. 2011b, p.371).

Care provision in many CALD families is drawn along gender lines (Boughtwood et al. 2011, p.294). Boughtwood et al. (2011a, p.294) revealed that not only is female caregiving an accepted social norm within many CALD communities, but it is also considered culturally inappropriate for males to conduct certain caring tasks (e.g., for a son to bathe his mother). In the same study, male CALD caregivers additionally revealed that their assumption of a caring role often placed them in the difficult position of having to transgress their community's traditional, well-defined gender boundaries (Boughtwood et al. 2011a, p.294). Similarly, Italian female carers of elderly family members in McCallum and Gelfand's study (1990, p.9) received limited support from their husbands, with caring seen as a gendered role specific to women.

Strong cultural expectations of family care are reported to play a significant role in whether or not formal services are accessed. For Italian-Australian caregivers, the use of or request for formal services is viewed as both inappropriate and unacceptable (Berisic 2008, p.12), with religion used as an important source of strength and support (Benedetti, Cohen & Taylor 2013, p.156). This was the case for the carers of Greek, Italian and Polish background in Barnett and Cricelli's (1990, p.42) study, most of whom could not contemplate any option but providing in-home care to their family member. Boughtwood and Gava (2010, p.8) reported that Italian family caregivers of people with dementia disagreed with the concept of residential care but were equally concerned their children would not adhere to the Italian tradition of providing in-home elder care. While older Italian-Australian parents resist nursing home placement, for many second-generation families with both partners working, this is often the only option (Vasta 1995, p.160). These findings have, however, been contradicted.[6]

Comparisons can also be made between CALD and Anglo-Australian carers. Like Anglo carers, CALD families struggle with managing changes in the person with dementia and worry about being unable to cope with the demands of dementia caregiving (Boughtwood et al. 2011a, p.296). Furthermore, the CALD carers in Boughtwood et al.'s (2011a, p.296) study reported stress, as have Anglo caregivers (Bruce & Patterson 2000).

Our developing understanding of the experience of dementia, therefore, highlights the importance of examining the specific cultural context surrounding caregiving. However, experiences of dementia, exemplified in the words of Carey Henderson, a man with early onset dementia, also draw attention to the context of the family: “One of the things about this – it's in the family, and the family has not only me and my wife, but we have our children and our children have their spouses. In other words, this thing about Alzheimer's is not just about two people. It's about a whole mess of people” (Henderson & Andrews 1998, p.65). In essence the message is clear – dementia

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[6] In one study comparing the caregiving experience of 461 Anglo-Celtic and 48 Italian carers of elderly family members, it was surprisingly found (given previous literature) that more of the Italian respondents in the study had used community support services than had Anglo-Celtic carers (Carrafa, Shultz and Smyrnios 1997, p.709). Similarly surprising was that the Italian respondents experienced significantly less trait anxiety than their Anglo-Celtic counterparts (Carrafa, Schultz & Smyrnios 1997, p.709). However, caution is required in interpreting these findings as the unequal sample size of the comparison groups detracts from their reliability.

affects the whole family. Yet, Henderson's words also raise an important question: who is family?

Most often, the word "family" in the literature regarding dementia, as well as in clinical practice, has come to be represented by a single individual often described as a family or primary caregiver (Purves & Phinney 2012, p.285). Studies addressing family dynamics tend to focus methodologically on one subsystem within the unit; typically the person with dementia and his or her spouse or the person with dementia and a son or daughter (Purves & Phinney 2012, p.286). Following an extensive review of the literature, Roach and Keady (2008, p.690) reported that they could only find one study which explored the experience of dementia as part of a family system. As Keady and Harris (2009, p.6) note, "people with dementia have become separated from their family systems within research, practice and policy attention with the weight of these resources being targeted at individual or dyad based methods of support/understanding."[7]

More recently, there have been studies that have addressed the concept of family analytically as a unit (Purves & Phinney 2012, p.286). However, with a few exceptions (e.g., Purves 2010), those studies that have included multiple family members have discussed their findings across many different families (Purves & Phinney 2012, p.286). This has resulted in broad and descriptive analyses which fail to take into consideration how each family is an independent unit with a unique character and construction of reality (Reiss & Klein 1987, p.203). To date, there are relatively few published accounts of single case studies that take a systems approach to understanding the family experience of dementia (Purves & Phinney 2012, p.296).[8]

Research into living with other health conditions supports the suggestion that a focus upon families is necessary and beneficial. This is evident in chronic illness (e.g., Walsh

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[7] It is worth noting that the way in which "family" is defined in these domains appears to based on the idea of the normal "nuclear" family. La Fontaine and Oyebode (2014, p.1247) recognise the need for further research into the experiences of dementia in different types of families, such as single-parent households and blended or step-families, and across different types of family relationships, such as gay relationships.

[8] The family systems approach will be discussed further in the next chapter.

1996; Fisher 2006) and in mental health difficulties such as psychosis, where it is recognised that families influence and, in turn, are affected by the impact of mental illness (Fadden & Smith 2009). Specifically, Arrington (2005) described how men's post-prostate cancer stories illustrated changes in their family roles, communication and relationships. Furthermore, family interventions in psychiatry have been found to reduce the relapse rate, aid in recovery and increase wellbeing (Heru 2006, p.962). However, it is important to recognise that research and interventions from other chronic and long-term conditions cannot necessarily be applied wholesale to the experience of dementia, as the condition involves distinctive challenges such as changes in cognitive abilities, relational functioning and roles, and an unpredictable, lengthy and changing course (La Fontaine & Oyebode 2014, p.1244).[9]

While there is a knowledge gap on families and dementia, it is nevertheless of value to critically consider how current research can inform us further. Garwick, Detzner and Boss (1994) reported on 38 multi-generational family interviews where the primary caregiver nominated the family members to be part of the interview process.[10] Through this approach, the authors found that families spoke little about the medical symptoms associated with dementia and, instead, focused their attention on "how the disease disrupted the fabric of everyday family life" (Garwick, Detzner & Boss 1994, p.8). The study showed that dementia can have a disorganising influence on family roles and boundaries and requires a reallocation of responsibilities within the family system (Garwick, Detzner & Boss 1994, p.9). This upheaval of steady state can be viewed as a crisis (Garwick, Detzner & Boss 1994, p.9).

Perry and Olshansky (1996) incorporated a family systems approach to explore the interactions among five members of one family in coming to terms with dementia. Their findings reveal that each member of the family experienced a similar process of coming to terms with changes in the person who had dementia (Perry & Olshansky 1996, p.12). This process consisted of three stages: identifying how the person was the same

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[9] Blandin and Pepin (2015, p.69) apply the term 'dementia grief' to "the unique role the disease process plays while implying pre-death status." The notion of 'ambiguous loss' is also useful for understanding the experiences of family members witnessing the multiple, unpredictable and unexpected losses associated with dementia (Large & Slinger 2015, p.165).

[10] In the study this ranged from between 3-11 people, although it appears that the person with dementia was excluded from the family interview process.

and different as he was before; redefining the identity of the person; and rewriting one's relationship with the person (Perry & Olshansky 1996, p.12). Although the process was similar for each family member, the experiences of each individual made the outcome unique for each (Perry & Olshansky 1996, p.16). The study also highlights the interaction between individual and family levels of experience, showing how differences in the ways that each family member defines and makes meaning of the situation have consequences for the family as a unit (Perry & Olshansky 1996, p.12).

Vizzachi et al. (2015) examined the family dynamics of two families who had a member with Alzheimer's disease at home. Their findings also reveal that the diagnosis of Alzheimer's is a threat to the stability and homeostasis of the family, because it brings successive losses of independence, generating fears and consequently, sensations common to the grieving process such as feelings of anxiety, sadness and irritation (Vizzachi et al. 2015, p.934). The processes of construction, (de)construction and (re)construction were experienced daily by the families, leading them to recognise themselves, readapt and adjust to a new reality (Vizzachi et al. 2015, p.935). An example of this is the role reversal in the parent/child relationship, which was described by relatives as bringing much suffering and difficulty of acceptance and coexistence (Vizzachi et al. 2015, p.935). The interactions between family members, and their behaviour and attitude toward the events related to Alzheimer's disease, were found to be influenced by the transgenerational values transmitted by the family, which remain present throughout the family history (Vizzachi et al. 2015, p.934).

While the impact of dementia has been shown to ripple throughout the entire family network, there are still notable differences in how individual family members are affected and their understanding of the crisis. Kjällman-Alm, Norbergh and Hellzen (2013) explored what it means to be an adult child of a person with dementia. They found that the adult children's existence and reality are threatened not only by the loss of the parent but also by the possibility that one day they too may inherit the disease (Kjällman-Alm, Norbergh & Hellzen 2013, p.1). This fear of inheriting the disease is not found in other research regarding spousal caregivers but rather is a unique trait for the adult children (Kjällman-Alm, Norbergh & Hellzen 2013, p.5).

Allen, Oyebode and Allen (2009) interviewed 12 participants aged 13 to 23 years, whose father had younger onset dementia. Young people in this study described feeling lost in the chaos of what family life had become; they could not talk with their fathers, were fearful of overburdening their mothers and found their wider family and friends stayed away due to stigma or were held at arm's length due to a sense of shame (Allen, Oyebode & Allen 2009, p.475). The authors drew on Doka's (1989) concept of 'disenfranchised grief' to note that the interviewees felt "unnoticed because they were neither the patient nor the main caregiver" (Allen, Oyebode & Allen 2009, p.475).

Globerman's (1994) research on balancing tensions in families coping with Alzheimer's disease incorporated a time dimension.[11] Family members with a relative at home indicated that they experienced dementia as a "constant crisis" which forced them to put their own lives endlessly on hold, while family members of institutionalised and deceased relatives spoke about the difficulties reconnecting and resuming their lives (Globerman 1994, p.221). This indicates that the stage of dementia is a key variable influencing family members' experiences.

In a separate study conducted with 38 families, Globerman (1995, p.7) found that caregiving children and non-caregiving involved others struggled with apportioning care. They returned to family-of-origin reputations and, because of the crisis nature of the disease, found it difficult to negotiate new ways of being with their relatives (Globerman 1995, p.7). They evaluated and criticised each other for what they each did and monitored each other's responsibilities (Globerman 1995, p.7). Children who were in some way different and excused from family responsibilities in childhood because they were, for example, "spoiled", a "problem child", "the intellectual", or "flaky", appeared to be unencumbered as adults when faced with caregiving responsibilities for a relative with Alzheimer's disease (Globerman 1995, p.1). Whereas the other family members described their burden and the overwhelming pulls and demands made on them, the "unencumbered child" described the effect of their relative's dementia in terms of their own loss of identity and selfhood (Globerman 1995,

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[11] The sample consisted of six families at different stages of the caring process who had a relative with dementia either at home, institutionalised or deceased. These stages represent turning-point experiences for many families (Pearlin 1992, p.647).

p.1). In this study, birth order and gender were not explanations for unencumbered status or protection from responsibility, but rather family legacy influenced who was the primary caregiver (Globerman 1995, p.9).

Schaber et al. (2016) explored the dynamic changes that occur in family interaction patterns when Alzheimer's disease is present. Contrary to Globerman's (1995) research, their findings demonstrate that families reorganise and restructure based on many factors, including geographic proximity, task competence, gender, other family responsibilities, past relationships within the family, and assigned roles from the primary caregiver or person with Alzheimer's disease (Schaber et al. 2016, p.29). The primary caregiver moved into a dominant style while other family members changed to a collaborative style to keep the family functioning (Schaber et al. 2016, p.30). While Alzheimer's disease caused a permanent suspension in normal reciprocity between the member with the disease and other family members, family members altered their own methods of communication, interaction styles and lifestyle to achieve intimacy and to preserve the personality or identity of the person with the disease (Schaber et al. 2016, p.30).

A more recent multi-generational study by Purves (2010) explored positioning in everyday talk in the family of a woman with Alzheimer's disease. This study included the person with dementia as an active participant, a voice which has largely been absent from such research (Ablitt, Jones & Muers 2009, p.506). Findings from the study revealed family members' struggle, individually and collectively, to come to terms with their relative's dementia in ways that could integrate their constructions of her as wife, mother and grandmother with their constructions of her as a person with Alzheimer's (Purves 2010, p.52). Family members attempted to negotiate the changes that dementia had brought by supporting the woman's competence in conversation, such as maintaining her role as family cook, despite others now doing most of the cooking (Purves 2010, p.49).

MacRae (2002, p.405) writes of "identity maintenance work" of the family members of the person with Alzheimer's disease. While some view the person as "already gone", others continue to hold on to the former self of the loved one (MacRae 2002, p.406). Family members developed ways of protecting their relative's social and self identity by covering up the memory loss, keeping the diagnosis a secret, blaming the disease not the person, managing appearance and finding glimpses of former selves through eye contact, a smile, a kiss or a squeeze of the hand (MacRae 2002, p.414).

In their study with children and young people who have or have had a parent with dementia, Sikes and Hall (2016, p.14) revealed challenges occasioned by the narrative that people with dementia are ‘still’ the same person they were prior to the onset of their condition. Their findings suggest that the construction of their parent as the same person is not helpful and that, furthermore, expectations that they will behave and feel towards that parent as they did before are a source of distress in what is already a challenging situation (Sikes & Hall 2016, p.1). Thus, Sikes and Hall (2016, p.14) have identified a need for honest portrayals of the lived experience of dementia: “To lock people and their family and friends who are living with dementia into how things were pre-diagnosis is both limiting and unrealistic.”

In their synthesis of qualitative research examining family relationships in dementia, La Fontaine and Oyebode (2014, p.1267) argue the need to explore both positive and negative themes in this area. This is accomplished by Alm, Hellzen and Norbergh’s (2014) study with people diagnosed with dementia and their spouses; and other adults with a parent diagnosed with dementia. The impact of dementia resulted in participants experiencing longing, lost closeness, loneliness and changed sibling relationships (Alm, Hellzen & Norbergh (2014, p.523). However, participants also described the formation of supporting relationships within their families in which family members not only adapted but found meaning in the situation (Alm, Hellzen & Norbergh (2014, p.524). Rather than dementia being a one-dimensional, negative experience as previous studies and common social (mis)conceptions purport, these findings introduce the possibility of positive outcomes for affected family members such as personal and relational growth.

Hellström, Nolan and Lundh (2007, p.383) also contend that many couples look to create a “nurturative relational context” in which their relationship can flourish. They carried out interviews over a period of five years and advanced three broad relationship phases following a diagnosis of dementia: “sustaining couplehood”; “maintaining involvement”; and “moving on” (Hellström, Nolan & Lundh 2007, p.383). Keady and

Nolan (2003, pp.29-30) developed relational notions of “working together / alone / separately / apart” to describe the temporal experiences of people with dementia and their family carers.

Jones (2015) explored the role in which communication (and its degeneration) plays in family relationships. She analysed 70 telephone calls recorded over a two-year period between a woman with Alzheimer’s and her daughter and son-in-law and found that the real communicative difficulties people with Alzheimer’s experience are interactional – they may arise, in part, from their cognitive deficits but challenges are occasioned by, or are contingent on, the other’s contributions in interaction (Jones 2015, p.567). As such, Jones (2015, p.568) suggests that family members can play an active part in co-managing interactions with their relatives who have Alzheimer’s in the hope that conversations will be more rewarding for those involved, and that important relationships can be maintained for longer.

Maintaining longstanding family rituals, routines and traditions allows families living with dementia to preserve their family identity and continuity across generations. Phinney, Dahlke and Purves (2013) examined how two men and their families negotiated changing patterns of everyday activity in the months after receiving a diagnosis of dementia. They concluded that conducting everyday activities that were meaningful for the family as a whole (e.g., gardening, attending a baseball game, regular family gatherings at a local café) contributed to sustaining family identity (Phinney, Dahlke & Purves 2013, p.366). Similarly, Genoe et al. (2010, p.181) found that families experiencing dementia used mealtimes as a way of honouring and preserving their family identity amidst uncertain changes and losses.

However, in Kindell et al.’s (2014) study of the experiences of a wife and son caring for a husband/father with semantic dementia, living with routines had a different meaning and perspective. It was not a strategy chosen by the care partners that helped them cope, but a challenge thrust on the family and, as a result, they had to assimilate this experience within their everyday lives (Kindell 2014, p.406). This research also indicates that generalising the experience of people with dementia and their family members without considering the type of dementia, or assuming that dementia is always synonymous with Alzheimer’s disease, might mask some of the particular experiences that arise from living with a given condition (Kindell 2014, p.406).

Studies have also examined the relationship between grandchildren and grandparents who have dementia (Celdrán, Triadó & Villar 2009; 2011; 2012; Hamill 2012). These studies suggest that having a grandparent with dementia can have a strong impact on grandchildren due to the deterioration of previous bonds, the emotional impact of witnessing grandparent’s decline, and the stress on the family system (Celdrán, Triadó & Villar 2011, p.333). This impact may be even greater on adolescent grandchildren because it coincides with normative adolescent changes (e.g., physical changes, the redefinition of family and peer relationships, identity construction), which sometimes cause tension and stress among teenagers (Celdrán, Triadó & Villar 2011, p.333). However, evidence is far from one-sided, as some studies have indicated the potential for positive changes. This is mainly related to the ability to keep emotional contact, learn important lessons from the family situation about the value of life and the complexity of the life-span, and develop new personal characteristics such as patience and responsibility as a result of the experience (Celdrán, Triadó & Villar 2009, p.243).

In summary, this synthesis indicates that the role of culture is crucial in understanding experiences of dementia family caregiving. It also lends strength to the need to focus on the psycho-social consequences of dementia for the family as a whole. The way in which relationships are negotiated, roles are defined and challenges are managed are important factors in influencing how family members, including the person with dementia, live with dementia.

When I first presented my research to my fellow students, I could tell from their expressions that they were taken aback by the profoundly personal nature of my work. I had been traversing through autoethnographic literature for seven months, so I felt confident to defend its rigour. Yet, a growing sense of unease swept over me as I tried to explain an approach that does not fit neatly into social scientific traditions. As I sat back in my chair, I began to think about the challenges autoethnographers face in bringing their private lives into the academy. For the first time, I felt a deep apprehension about laying bare my family's struggles with dementia for the world to see.

Chapter 3: Methodology

Family systems theory, developed in the fields of social work and family therapy, provides a useful theoretical base for understanding the impact of dementia on individual family members and on families as interactive units. Family systems theorists view families as systems of individually developing members who are connected through relationship bonds (von Eye & Kreppner 1989; Whitchurch & Constantine 1993). Hammer (1998, p.6) draws on the work of Becvar and Becvar (1988) to identify four assumptions of family systems theory that: 1) the individual is part of a family system in which all members are interdependent; 2) patterns of behaviour are circular rather than linear, with the behaviours of all members influencing and being influenced by those of others; 3) change and development are ongoing and inherent in family systems; and 4) failing to communicate or to act is as much a form of communication as choosing to communicate or act.

Hammer (1998, p.7) adds that a family is characterised by multiple perspectives, with different members giving different meanings to the same situation. A family systems approach lies in the exploration of how the multiple perspectives held by individual family members intersect and overlap in ways that are sometimes congruent and sometimes conflicting (Purves & Phinney 2012, p.295). While Hammer's review is oriented to early language intervention, it is applicable to dementia research, practice and policy which can begin to address the needs of the greater constellation of those affected by a loved one's diagnosis. A family systems approach can inform our understanding of how changes associated with dementia are experienced within a family (Purves & Phinney 2012, p.287). Such studies can provide a starting point for highlighting issues that might warrant further investigation in research while also suggesting possible questions for clinicians to address in their interventions for particular families (Purves & Phinney 2012, p.287).

This study adopts a collaborative autoethnographic family systems approach to explore the experience of dementia within my family. Communication scholars Carolyn Ellis, Tony Adams and Art Bochner (2011, p.273) delineate the autoethnographic method as "an approach to research and writing that seeks to describe and systematically analyse personal experience in order to understand cultural experience." The aim is to produce accessible and evocative texts that "make personal experience meaningful and cultural experience engaging" (Ellis, Adams & Bochner 2011, p.277). Contrary to the supposedly objective, neutral, impersonal and detached nature of traditional forms of social scientific research, autoethnography treats research as a socially-conscious act, embraces value-centred inquiry and "acknowledges and accommodates subjectivity, emotionality, and the researcher's influence on research" (Ellis, Adams & Bochner 2011, p.274).[12]

Autoethnography has captured the attention of an increasing number of scholars from a variety of academic disciplines within the last two decades (Wall 2016, p.1). Adams and Manning (2015, p.356) outline four qualities which make it especially suitable for conducting family research. They describe how autoethnography can allow researchers to: 1) offer insider accounts of families; 2) study everyday, unexpected experiences of families, especially as they face unique or difficult situations; 3) write against limited extant research about families; and 4) make research more accessible to non-academic audiences (Adams & Manning 2015, p.356).

Collaborative autoethnography takes this paradigm of inquiry one step further. Chang, Ngunjiri and Hernandez (2016, p.11) describe it as "engaging in the study of self, collectively; it is a process and product of an ensemble performance, not a solo act." They add that collaborative autoethnography "offers us a scholarly space to hold up mirrors to each other in communal self-interrogation and to explore our subjectivity in the company of one other" (Chang, Ngunjiri & Hernandez 2016, p.26). Collaborative autoethnography is the appropriate method for this study because, in conjunction with family systems theory, it recognises there is no one shared or consistent reality. The intent of collaborative autoethnography is to present multiple voices within a text and to encourage readings from diverse perspectives (Lapadat 2017, p.11).

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[12] Since autoethnography invites and honours researcher subjectivity, it can provide a methodological corrective to one of the problematic aspects of family systems theory. Yerby (1995, p.346) challenges an underlying assumption of family systems theory that the researcher is able to "stand outside" the family being observed (as though one were viewing it from above) and describe its reality and problems. However, it is difficult to legitimately claim that one can position himself or herself "outside" or "above" that which is being observed (Yerby 1995, p.346). This highlights the promise of autoethnographic inquiry for advancing the family systems approach. Using this method, the researcher is viewed not as an objective observer but as part of the family system that is being observed.

Following this approach, I conducted individual interviews with my Nonno, mother, father, brother and aunt to uncover how dementia is experienced by different family members in separate and overlapping ways.[13] In order to supplement our views, I also interviewed two female non-family participants who have experience with dementia in an Italian and non-Italian context. These participants were strangers to me, but colleagues of my supervisor. They were originally recruited to extend the scope of the research and test whether Italian culture influences family caregiving experiences.[14] However, their involvement ended up providing valuable methodological insights into what it means to study family narratives of dementia from both an insider's and outsider's perspective, which I will discuss shortly.

Interviews were semi-structured, allowing participants to address issues and experiences which they perceived as important and central to the broader research question (Mason 2002, p.62). I developed the interview guide after gathering information from existing literature and through consultation with my mother and father.[15] Open-ended questions relating to participants' everyday life, roles and relationships; family functioning; cultural factors; and residential care decisions were included. Before conducting the interviews, approval was obtained from the relevant ethics committee of my university. Each interview lasted approximately one hour and was audio-recorded, transcribed and checked for accuracy.[16] Transcripts were shared with participants for review, comment and correction. Field notes were written to describe the details of the interviews.

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[13] These family members were selected because they have a close relationship with Nonna. A limitation of this study is that it does not include the voices of Nonna, my uncle and cousins. Consequently, it does not present a complete and whole view of the experience of dementia within my family.

[14] This companion inquiry addresses another limitation of family systems theory. Family systems theory has been criticised for obscuring the importance of cultural differences that influence families' behaviours and views of the world (Rosenblatt 1994; Yerby 1995). Leslie and Glossick (1992, p.258) argue that family systems theorists too often describe family functioning as though the family were a "here and now" self-contained unit and fall short in demonstrating an appreciation for the broader historical/cultural context of family interaction. They suggest that we do more "to look beyond the boundaries of the family to understand presenting problems" (Leslie & Glossick 1992, p.258).

[15] Some of the interview questions were adapted from those made by Globerman (1994) and Schaber et al. (2016).

[16] I recognise that audio-recordings cannot capture non-verbal communication. Therefore, many of the more subtle but important aspects of the interviews such as participants' gestures of compassion or movements of discomfort may have been missed.

Interview sites produce “micro-geographies” of socio-spatial relations and meaning that impact the interview experience and material collected (Elwood & Martin 2000, p.649). My family members were interviewed in their homes, a location that is conducive to eliciting difficult stories because it is a safe, comfortable and familiar environment (Hämäläinen & Rautio 2013, p.22). As the site of much of family life, homes are also imbued with meaning, memories and stories that may speak to participants of past and present experiences (Starkweather 2012, p.291). On the other hand, my researcher accessories of pen, notebook and recording device were an intrusion into the home setting and significantly impacted the extent to which some family members opened up about their experiences.

The two non-family participants were interviewed at their workplace. These interviews were more formal than those held at homes. While an office space provided privacy, the workplace setting was less suited to discussing sensitive family issues. For one participant who had a meeting straight after the interview, the transition back into a work headspace was difficult. She commented that it would have been better to schedule the interview later in the day so that she could have “gone home to reflect silently” (2017 pers. comm, 26 June). By conducting the interviews during work hours, I also felt like I was impeding on the participants’ time.

The research process entailed a delicate negotiation of my position as both an insider and outsider. In interviewing family members, my insider status was advantageous in that it granted me access and legitimacy in the field. The underlying trust between myself and the family participants meant that I was able to delve into the nature of our family dynamics and pick up finer nuances of meaning shared only between family members. At the same time, my family membership created various challenges. For instance, our desire for family talk and interaction undermined the intention of interviewing. As a researcher stepping into established hierarchical relationships based along generational lines, it would have been disrespectful to take over the control of the discussion. I also found that my closeness and familiarity posed a barrier to eliciting detailed responses. Similar issues have been noted by other insider scholars (Chavez 2008; DeLyser 2001; Miller 1997).[17] The issue of distance raised by

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[17] To avoid getting deferring responses (e.g., “You know what I mean”) from her family members, Chavez (2008, p.485) developed the strategy of beginning interviews with this disclaimer: “I know that

Alvesson (2003) and Eriksson (2010) was another complication as I had to remain alert to the blind spots generated by intimacy.

Interviewing the two non-family participants from an outsider perspective introduced a whole different set of considerations. Whereas my family members described what I already knew, I was learning about these participants' experiences for the first time. There was a lot to take in all at once and I needed to pay close attention to piece together the details of their stories. I also found that how I related to and interacted with these participants varied in interesting and significant ways. The Italian participant and I shared common experiences, particularly in having our loved one placed into the same aged care facility. For this reason, I felt comfortable discussing my family's experiences with her and I often posed questions from within my family context. The danger of this was that I risked making assumptions and imposing our experiences on her. In comparison, I did not talk about my family with the non-Italian participant. This was due, in part, to our cultural differences, but also because she had much to say and I wanted to give her space to talk about her personal story. Overall, these interviews were an eye-opening experience for me. At times, I became so engrossed in their lifeworlds that I forgot about my questions. In retrospect, my interaction with these women was one of the most rewarding parts of this project.[18]

When it comes to analysis, autoethnographers pay varying levels of attention to the narration/description and interpretation/examination of autobiographical data (Ngunjiri, Hernandez & Chang 2010, p.3). According to Ellis and Bochner (2000, p.740, emphasis in original), "autoethnographers vary in their emphasis on the research process (*graphy*), on culture (*ethno*), and on self (*auto*)." Some scholars categorise these differences as "evocative" versus "analytical" approaches, where evocative autoethnography foregrounds the writer's personal stories and analytical

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we have probably talked about some of the things I might ask. But I want you just to pretend as if we were talking about them for the first time, so we can make sure we get the information right." While I did not adopt this technique, I used a number of probing strategies (e.g., "Do you remember when…") to solicit additional information. I also used photo elicitation techniques with my mother, father and brother to trigger their memories, promote reflection and stimulate discussion.

[18] Through interviewing the two non-family participants, I discovered the need to listen actively and to enter into other people's stories as if their experiences are our own, because, as Benjamin (1973, p.101) suggests, "this stranger's fate by virtue of the flame which consumes it yields us the warmth which we never draw from our own fate."

autoethnography connects to “some broader set of social phenomena than those provided by the data themselves” (Anderson 2006, p.387).[19]

As this thesis resembles a conventional research report and is grounded on data collection, analysis and interpretation, my autoethnographic approach can be likened to the analytical tradition. However, in this thesis, I seek to avoid the language of analysis and theorising (e.g., ‘generalisation’, ‘sampling’, ‘triangulation’) to prevent “sacrific[ing] the story at the altar of traditional sociological rigor” (Ellis & Bochner 2006, p.440). Instead, my intention is to present a reflexive and poignant family account of dementia that “elicit[s] emotional identification and understanding” (Denzin 1989, p.124) in the spirit of evocative autoethnography.

Autoethnography has been criticised for being self-indulgent, narcissistic, introspective and individualised (Atkinson 1997; Coffey 1999; Delamont 2007). Although autoethnography has its own limitations (see Méndez 2013), such outright rejections of the approach may be ascribed to positions anchored in traditional understandings of research. The critics fail to recognise that autoethnography was instigated to move ethnography away from “the gaze of the distanced and detached observer and toward the embrace of intimate involvement, engagement, and embodied participation” (Ellis & Bochner 2006, p.433-434). Consequently, when positivist labels such as reliability, validity and generalisability are applied to autoethnography, the context, meaning and utility of these terms are altered.[20] Furthermore, the focus on self does not necessarily mean “self in a vacuum” (Ngunjiri, Hernandez & Chang 2010, p.3). As the theory at the cornerstone of autoethnographic inquiry confirms, the personal story is connected to universality; the self is a construct of the social and the social a construct of the self (Reed-Danahay 1997, p.9).

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[19] For debates between evocative and analytical approaches to autoethnography, see the special issue of *The Journal of Contemporary Ethnography* in 2006.

[20] As Ellis, Adams & Bochner (2011, p.282-283) observe, in autoethnography reliability is understood in terms of the credibility of the narrator and validity means that a work seeks verisimilitude. Moreover, generalisability, though important to autoethnographers, is not understood in the traditional sense, but the focus shifts to readers and the extent to which they think the autoethnographic writing is meaningful to them. The autoethnographic narrative has no claim of mainstream generalisability “but it has the potential to act as a stimulus for profound understanding of a single case and, moreover, act as a stimulus to open new intellectual vistas for the reader through a uniquely personal meaning and empathy” (McIlveen 2008. p.5).

This thesis connects to other reported experiences of grief over a family member's loss of memories. The stories I tell have resonance with the autoethnographical work of Fox (2010) as he writes about his father's dementia. Fox suggests and models constructing a "mosaic" from the scattered fragments of memory of the loved one to help family members make sense of the loss. As well, I find companionship in the work of Malthouse (2011) who engages a "wide angled lens" to capture the shifting and complex relationships revealed in her experience as a daughter whose mother has Alzheimer's disease. In addition, Alemán and Helfrich (2010) use autoethnographic methods to co-author and jointly construct the meaning of living a family history of dementia, discovering how grief, a sense of loss and the need for self-care emerge for a daughter when a mother enters dementia. I also carry with me Bakan's (2016) scholarly and artistic autoethnography *The Fountain Pen*, which weaves prose, music and video to explore the multiple and complex issues that emerged while he coped with the dementia and subsequent passing of his mother.[21]

This thesis is further informed by other narratives of dementia family caregiving. Salmon (2006) conveys the strangeness both of having dementia and caring for someone with dementia. Her stirring autoethnography, *The Waiting Place*, uses diary excerpts, reflective writing and poetry to evoke the limbo she found herself in awaiting her mother's nursing home placement, flipping the viewpoint of a caregiving daughter who is also a health professional. Similarly, in her prize-winning autoethnography, *On Recognition, Caring, and Dementia* (2008), medical anthropologist Janelle Taylor describes caring for her mother with dementia, and the nagging question asked by many around her: "Does she recognise you?" She elaborates on how her mother enacts, practices, expresses and receives care beyond the cognitive acts of remembering. Evidently, my family is not the only one that has struggled with this situation. This is the power of autoethnographic work, for as I tell our story I cast light on the stories that others have and might live.

I would be remiss not to mention some of the risks in writing autoethnography, both to oneself and others. Autoethnographers can make themselves vulnerable by sharing their private stories (Tullis 2013, p.52). Allen and Piercy (2005, p.156, emphasis in

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[21] The song/video rendering that accompanies Bakan's (2016) autoethnographic article can be viewed here: https://www.youtube.com/watch?v=NXo9MghXtA4&feature=youtu.be.

original) state, “By telling a story *on* ourselves, we risk exposure to our peers, subject ourselves to scrutiny and ridicule, and relinquish some of our sense of control over our own narratives.” Yet, conventional research ethics and research ethics committees tend not to be concerned with the impact that the research process can have on the researcher, both within qualitative research in general and within autoethnography specifically (Dickson-Swift et al. 2008; Tullis 2013).[22] Ethics committees also rarely consider the ethical issues relevant to presenting autoethnography to audiences (Tullis 2013, p.54). The feelings evoked in readers may be unpleasant since the connections readers make to narratives cannot be predicted (Bochner & Ellis 1996, cited in Méndez 2013, p.282).

In autoethnographic research, the relationship between the researcher and his or her significant others also becomes a primary locus of ethical action (Poulos 2008, p.46). Tolich (2010, p.1608) contends that “the word auto is a misnomer” and Turner (2013, p.216) posits that autoethnography is “a relational pursuit”. In using personal experience, autoethnographers not only implicate themselves in their work, but also close, intimate others (Ellis, Adams & Bochner 2011, p.281). Furthermore, autoethnographers often maintain and value interpersonal ties with their participants, thus making ethics processes more complicated (Ellis, Adams & Bochner 2011, p.281).

Pace (2015) describes the various “sticking points” encountered in undertaking insider research with close relatives. These include dealing with issues of anonymity and informed consent (Pace 2015, p.341). For example, my family members are, by association, recognisable, even if I had changed their names. Pseudonyms also overlook the threat posed by internal confidentiality (Tolich 2010, p.1606).[23] Moreover, my family members may have given their consent on the basis of my best interests rather than their true preferences.

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[22] In light of this, I urge qualitative researchers who are studying emotional topics to consider the practical “self-care” strategies proposed by Rager (2005). Particularly helpful to me were journal writing, peer debriefing and member checking.

[23] In internal confidentiality, the relationship at risk is not with the researcher exposing confidences to outsiders, but confidences exposed among the participants themselves (Tolich 2010, p.1606). Internal confidentiality is a foundational guideline for autoethnographers, but often goes unacknowledged in ethical codes (Tolich 2004, p.101).

The issues of anonymity and informed consent are, of course, not unique to insider research. A pertinent consideration of this study was how to respect the rights of the people included in the two non-family participants' stories. Although these 'others' were given pseudonyms, it is worth mentioning that this thesis still violates their rights, for they have not given their permission and they do not have the right of withdrawal or refusal that informed consent provides (Morse 2002, p.1159). Ellis (2007, p.4) describes this predicament as "a quagmire in ethnographic research". Ultimately, I deemed it important to adhere to her suggestion, "Assume everyone in [a] story will read it" (Ellis 2007, p.25).

Another key ethical issue encountered in this study was obtaining the informed consent of my Nonna who is the subject of my family's dementia narrative.[24] For advice, I contacted dementia researcher Dr Siobhan O'Dwyer from the University of Exeter who introduced me to the concepts of assent and dissent. Assent has been defined as "the agreement to participate in research based upon less than full understanding" (Keyserlingk et al. 1995, p.340). Assent may be expressed verbally (e.g., saying "yes"), behaviourally (e.g., acting agreeably) or emotionally (e.g., having a positive facial expression) (Black et al. 2007, p.81). Dissent is the opposite of assent and has been equated with refusal to participate even when proxy consent has been obtained (Cacchione 2011, p.225).

Obtaining assent and respecting dissent are widely adopted safeguards when conducting research involving individuals who lack consent capacity (Black et al. 2007, p.77). However, there is no consensus on how assent and dissent should be defined for dementia research or what procedures should be used regarding them (Black et al. 2007, p.78). There is also a lack of guidance available on how to obtain assent in a personal context.[25] Following the assent procedure outlined by Black et al. (2010,

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[24] Obtaining my Nonna's informed consent is more a question of respect for her right to privacy than because it is required. This builds on the principle of "nothing about me without me" that is used frequently in the disability rights movement (Richards 2008, p.1717). Only a few studies have focused on ethical challenges other than the procedural ones when conducting qualitative dementia research (Heggestad, Nortvedt & Slettebø 2012, p.31). This was noted by Dr Siobhan O'Dwyer (2017 pers. comm, 22 March) "[…] lots of dementia researchers I know have written about their family members without ever exploring the ethical problems associated with that, so I think it's a really important & interesting discussion to have in your thesis."

[25] Slaughter et al. (2007, p.32) argue that objections of people with dementia are typically conveyed by indications of frustration, discomfort, unhappiness or passivity. Such indicators could not be relied upon

p.83), I obtained proxy informed consent from my mother who has an enduring power of attorney. I also explained my research project to my Nonna, asking how she feels about being mentioned and referred to by other family members.[26] This assent procedure, like all parts of the project, was approached from a relational ethics of care.

Ellis (2007, p.1) argues for a relational ethics of care in autoethnographic and personal narrative research. She writes that relational ethics requires researchers "to act from our hearts and minds, to acknowledge our interpersonal bonds to others, and initiate and maintain conversations" (Ellis 2007, p.4). Relational ethics recognises and values mutual respect, dignity, connectedness between researcher and researched, and being true to one's conscience (Ellis 2008, p.308). Central to relational ethics is the question "What should I do now?" rather than the statement "This is what you should do now" (Bergum 1998, cited in Ellis 2007, p.4). The practice of relational ethics comes with an ever-vigilant and rigorous self-reflexivity and mindfulness as we relate to our participants moment to moment, situation by situation (Metta 2010, p.59). Relational issues are, however, not the normal focus of institutional ethics applications (see Denzin 2003). The operations of ethics committees tend to be based on the assumption that the research participants will be strangers to the researchers (Henderson & Midgley 2010, p.104).[27] This is not the case in autoethnography, and often not the case in ethnography (Ellis 2007, p.5).

Gaining the approval of an ethics committee also suggests that the proposed research activity is ethical (Henderson & Midgley 2010, p.106). Yet, despite the relatively straightforward official approval I received for my project, I was persistently confronted with contesting issues of authority, representation, voice and method. In particular, I

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in my research as our close personal relationship meant that my Nonna responded warmly and happily to my request for her assent.

[26] Appendix A shows the script used to obtain my Nonna's assent, which was reviewed by Dr Siobhan O'Dwyer and Dr Laura Béres, Associate Professor at the School of Social Work, King's University College. In developing this script, I confronted many questions such as: How should the study be introduced in a way that is simple yet sufficiently informative? Would using the term 'dementia' cause unnecessary harm and distress? How do I approach the topic of dementia when my Nonna is unaware of her diagnosis and the condition itself?

[27] The National Statement on Ethical Conduct in Human Research emphasises situations when participants "enter into a relationship with researchers whom they may not know but need to trust" (National Health and Medical Research Council et al. 2007, p.3).

faced tensions in “working the hyphen” (Fine 1994, p.70) of self-other as I enacted an identity that was equally family member and researcher.[28] Thus, I have come to realise that the insider standpoint raises more fragile and complex issues than those that are typically addressed through institutional oversight measures.

I also encountered a difficult interview situation in which one of the non-family participants became vulnerable. When this happened, I stopped taking notes as I recognised that it was imperative as the story-listener to be fully present and engaged wholeheartedly.[29] This reveals how, as risk management for qualitative research, the ethics review process lacks depth and foresight (Tolich & Fitzgerald 2006, p.72). Ethics committees can only approve the known; they cannot monitor and support qualitative researchers in the unpredictable, often subtle, yet ethically important moments that come up in what McLean and Leibing (eds 2003, p.1) term “the shadow side of fieldwork”. As Tullis (2013, p.244) argues, the dynamic research environment requires a type of ethical engagement that is highly contextual, contingent and primarily relational.[30]

Collaborative ethnography presents one way to engage in contextual, relational ethics. Luke Eric Lassiter (2005, p.16, emphasis in original) defines collaborative ethnography as “an approach to ethnography that *deliberately* and *explicitly* emphasises collaboration at every point in the ethnographic process, without veiling it – from project

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[28] According to Fine (1994, p.72), “Working the hyphen means creating occasions for researchers and informants to discuss what is, and is not “happening between”, within the negotiated relations of whose story is being told, why, to whom, with what interpretation, and whose story is being shadowed, why, for whom, and with what consequence.”

[29] In doing so, I tried to practice “compassionate interviewing” (Ellis 2017, p.437) in which researchers and participants “listen deeply to, speak responsibly with, feel passionately for, share vulnerably with, and connect relationally and ethically to each other with care.” Instead of viewing the participants’ vulnerability as a tangential interruption in the interview, I treated it as opportunity to be present and acknowledge a personal loss that needed retelling, reinterpreting and deep listening (Ellis & Patti 2014, p.392).

[30] The need to adopt an ethical stance of “permanent vigilance” (Zylinska 2005, p.59) became once again apparent when I went to submit my thesis to Turnitin, a software tool for checking plagiarised content. This set my ethical alarm bells ringing as my consent/assent documentation did not account for the storage of participants’ interview material in an external system. This is an instance where the moral principle of caring for the words of others can be overlooked. What this example also illuminates is how easily the otherwise sacrosanct notion of informed consent and the safeguarding of participants’ rights can be disregarded and overridden in the digital environment.

conceptualisation, to fieldwork, and, especially, through the writing process." According to Lassiter (2008, p.74), collaborative ethnography is founded on four main commitments: ethical and moral responsibility to "consultants"; honesty about the fieldwork process; accessible and dialogic writing; and collaborative reading, writing and co-interpretation of ethnographic texts with "consultants".[31] These served as guiding principles throughout this study.

Firstly, I have strived to act in a "humane, non-exploitative way" and honour, care for and respect my participants (Ellis 2007, p.5). Secondly, I have openly discussed, explored and evaluated what the research journey has meant, both for myself and my participants. Thirdly, I have carefully considered the use of any disciplinary-specific jargon to ensure that my participants can engage with and respond to my work. I have also tried to adhere to Alzheimer's Australia's dementia language guidelines.[32] Finally, while the participants did not take any role in the writing process, I acknowledged my "narrative privilege" (Adams 2008, p.181) by inviting them to comment on the use and interpretation of their quotes.

In the feedback I received, some of my family members expressed concern that their statements were too critical of my Nonno. As a result, I worked closely with them to deal with the "grey areas between revealing and concealing" (Ellis 2007, p.9). Like other autoethnographers, I confronted ethical questions about what ought to be left missing and how to "honour [my] relational responsibilities yet present our lives in a complex and truthful way for readers" (Ellis 2007, p.14). While I have strived to present an account that is as nuanced and truthful as possible, my family's narrative is characterised by silences and absences that reside in between what is articulated. This type of "mindful slippage" (Medford 2006, p.853) is important for autoethnographers

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[31] Instead of participants appearing to only inform the production of knowledge, they take on the role of "consultant" or "co-intellectual" in the ethnographic process (Lassiter 2005, p.13).

[32] The guidelines can be found at: https://www.fightdementia.org.au/files/NATIONAL/documents/language-guidelines-full.pdf. They were developed to promote the consistent use of accurate, respectful, inclusive, empowering and non stigmatising language when talking about dementia and people with dementia (Alzheimer's Australia n.d., p.1). Terms such as "sufferer" and "victim" contribute to the stigma surrounding dementia and "demented person" places the condition before the person (Alzheimer's Australia n.d., p.2). Thus, such terms have been avoided in writing this thesis. For more information about the power of language in discussions about dementia, see various postings in the blog written by Kate Swaffer: http://kateswaffer.com.

who “continue to live in the world of relationships in which their research is embedded after the research is completed” (Ellis, Adams & Bochner 2011, p.282).

In conclusion, I believe that to better understand the diverse nuances of experiences with dementia, we need to hear from those involved *in* the experience rather than *outside* of it. Using a collaborative autoethnographic family systems approach enables me to attend to the dynamic interplay among self, family and culture. This research was woven with many challenges, dilemmas and ambivalence. However, Lassiter’s model of collaborative ethnography provided an ethical framework for engaging relationally with the participants and creating what Poulos (2009, p.134) calls a “narrative conscience” *or* a “knowing together”.

Once this thesis is submitted, my inner family life becomes public, visible, vulnerable; a story that is set free upon the handing over to others to read. What happens to it after that no longer remains within my control. This thought scares me. All I ask of you is that you take with great care the stories in this telling, and extend this care to how you reflect on and respond to the lives of the people mentioned here who you may or may not know.

Chapter 4: Communicating Our Stories

Background

My Nonna, Antonietta, is 79 and was diagnosed with Alzheimer's disease six years ago after she had a colon cancer operation. Nonna's primary caregiver is my 84-year-old Nonno, Antonio. Nonno migrated to Australia in 1957 to work in the burgeoning steel industry. Both their families had known each other for many years and after some nudging by his sisters, Nonno proposed to Nonna and she migrated in 1963. They have been married for 53 years and have two daughters: my mother, Silvana, and my aunt, Pina. Silvana is 52 and performs home duties. Pina is a 48-year-old casual teacher and is married with two children. My father, Ian, is 56 and manages the finance function at a bank. Ian is non-Italian and has known Nonna and Nonno for over thirty years. My brother, Matt, is a 24-year-old PhD student.

The timing of the interviews coincided with Nonna's placement into the aged care facility, San Giorgio.[33] As Nonno was reluctant to commit to long-term residential care, Nonna spent two months in respite care and has now returned home.

The Italian non-family participant is Paola. She is 52 and works at a university. Paola's mother was not diagnosed with Alzheimer's but some form of dementia. Paola's mother lived with dementia for approximately four years and was deteriorating rapidly over the time. Paola's mother's dementia was undiagnosed for eighteen months to two years. Paola and her sister were the primary caregivers for their mother until she was also placed into San Giorgio.

The non-Italian non-family participant is Penny. Born in Kenya, Penny is 52 and works at a university. Penny's mother lived with Lewy body dementia for approximately thirteen years and was deteriorating gradually over the time. Penny's mother's dementia was undiagnosed for approximately eight years. Penny did not play a role in

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[33] San Giorgio is a pseudonym. San Giorgio was established in the early 1980s by the local Italian community. Although its residents come from diverse cultural backgrounds, San Giorgio is predominately Italian-based and provides culturally and linguistically appropriate facilities and services (e.g., Italian-speaking staff, Italian food, Catholic services and Italian cultural events). San Giorgio has over 160 residents receiving low or high level care. The facility is a secure, single-story building with separate male and female bedroom wings and common dining, lounge and outdoor areas.

caring for her mother because her parents lived interstate. Most of the caregiving was provided initially by Penny's sister in between her work and home commitments, "My sister is a very caring person and it's her natural tendency to be a carer. She's our eldest of the siblings and she took that responsibility very seriously." When she could no longer manage and their mother moved into an aged care facility, Penny's brother gave up his job as a Chief Financial Officer in a NGO to care for their father and be there every day for their mother. Penny's brother also used all his superannuation to allow their father to move into the aged care facility and be closer to their mother. Meanwhile, Penny's brother stayed in the family home in case their parents ever wanted to return.

Roadmap

In this chapter, I present seven overarching themes derived from the interviews: *impact on relationship with the person with dementia*; *impact on the family*; *impact on carers*; *coping strategies*; *experience of residential placement*; *Italian cultural influences*; and *advice and wisdom*.

Before you start reading further, several points need to be mentioned and briefly reflected upon. First, it should be noted again that Nonna has been placed at the centre stage of discussion, yet she did not have any agency in the storytelling process. Without Nonna's voice, there is a void in the narrative. While Nonna's voice is textually absent in this work, her narrative presence is nonetheless invoked and inscribed through other family members' accounts. These accounts assemble a portrait of Nonna as a wife, mother, grandmother and person with dementia. Certainly this portrait leaves out much more than it includes.

Second, I feel it is important to acknowledge where I am in this chapter. As Saldaña (2003, p.222) points out, "A problematic choice is the researcher's inclusion as a character in the ethnodrama. Does the principal investigator have a role to play […] is he or she a major or a minor character?" Given this is a collaborative autoethnography, I deliberately cast myself as a minor character in an effort to shift the spotlight onto my family members and give voice to their experiences and stories. However, as the researcher, I played the most powerful part in shaping the narrative, both in its presences and absences. Thus, due to my authorial agency, my positioning within the narrative is far from minor.

Third, I am conscious that my claim to ‘give voice’ is problematic, if not impossible. Although I provide a space for the participants’ experiences and stories to be heard, their voices are still mediated and filtered through my own perspectives, motives, emotions and interpretations. While this is a prominent methodological issue faced by all qualitative researchers, it raises particularly troubling questions for me about my chosen methods and whether they live up to their objectives of redressing the power imbalances between researcher and researched.

Fourth, it is important to remember that Paola’s and Penny’s experience with dementia has concluded, whereas my family is currently embedded within the dementia journey under investigation. This had an interesting effect on how the participants constructed their stories.[34] My intention in writing this chapter has been to interweave my family’s storied lived experiences with the personal accounts of Paola and Penny. This allows for deeper layers of meaning and, in keeping with the autoethnographic tradition, extends our reflections to “others of similarity” and “others of difference” (Chang 2016, p.444).[35]

Lastly, I recognise that, inevitably, the unitisation of data through the search for connections, similarities or divergences across cases obscures the contextualised, unfolding and sequential accounts of individuals (Collins & Nicholson 2002, p.627). Riessman (1993, p.4) renders narratives as “essential meaning-making structures” and advises researchers to “preserve not fracture” participants’ stories. However, the method of analysis adopted in this study is aimed at conveying a sense of participants’ personal experiences within a framework of themes. These themes are not fixed but

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[34] My family members’ stories are still being constructed and capture a transitional moment in time. They came out in a quite clumsy and fragmented form, displaying a sense of uncertainty. In comparison, Paola’s and Penny’s stories had clear beginning, middle and ending points and conveyed a sense of coherence and closure. This parallels Becker’s (1997, p.6) finding that “people organise stories of disruption into linear accounts of chaos that gradually turns to order.” Given dementia is a progressive trajectory, a longitudinal approach would be best to illustrate how people’s stories change with the passage of time.

[35] In the writing process, one of the challenges I faced was working out how to balance the presence of multiple voices. While I tried to ensure that no one perspective is privileged over another, some participants – most notably my brother – are less heard in the narrative.

possess a certain flexibility in the way in which they uncover multiple overlapping and intersecting experiences. On this note, I will now begin to elaborate on the seven overarching themes that emerged from the analysis.

Impact on relationship with person with dementia

The relationship between the person with dementia and their children and grandchildren is subject to change in face of the condition. These two subthemes (*parent-child relationships* and *grandparent-grandchild relationships*) are expanded upon in the following sections.

Parent-child relationships

Dementia has a significant impact on parent-child relationships. Paola described the fundamental change that occurred in her relationship with her mother, “when she was sick she became more of the child I think and I became more of a parent.” This role reversal was particularly upsetting for Penny, “my mum went from being my mum to somebody that I needed to relate to as the grown up and she was the person that was more dependent than me. Sorry it makes me sad still.” Penny indicated that this marked the beginning of her grieving process, “you start the grieving from the time you realise they are not the same and you grieve from the time that they become your care and responsibility.”

Silvana commented on the change in her relationship with Nonna, “Even though she’s still alive, it will never be the same.” Silvana described experiencing strong feelings of loss of a parent, “It’s a huge loss to have one’s own mother stop calling. The chatter and the banter is no longer there anymore.”

Conversely, positive relational effects were also reported. Pina described experiencing enhanced closeness to Nonna due to having more regular contact, “In the fact that she has dementia I’m making a concerted effort to see her due to this issue. It has brought us closer.” Paola also reflected that she formed a closer relationship with her mother through the experience of dementia.

Grandparent-grandchild relationships

The impact of dementia extends to grandparent-grandchild relationships to varying degrees. Matt explained that his relationship with Nonna has changed, although this is not due to dementia but because he has grown older and no longer requires nurturing, “Grandparent-grandchild relationships will typically evolve as the child grows and enters adulthood. So, I believe my relationship would have changed anyway as a result of the course of time, regardless of the impact of dementia.” Matt stated that Nonna’s warmth and affection remains the same, noting that it is only his interactions with Nonna which have changed, “It’s still enjoyable to see her. It doesn’t matter that she has dementia. She’s still very loving and caring and close like when I was a kid but she just forgets everything you tell her.”

My cousins have demonstrated patience and care towards Nonna, however, as teenagers, are sometimes reluctant to visit. Pina commented, “when I discuss it with Sophie, there’s sympathy. It’s like “aw poor Nonna”. So, there’s feeling there and I think there’s understanding and then they too also at times find the visits good for a while and then tedious.”

Penny’s children, nieces and nephews had a similar reaction, “everyone just thought […] oh poor granny.” Penny provided a vivid account of her daughter’s experience:

> My daughter came in a couple of times to the dementia unit and found it really mindboggling. The smell […]. There was a lady sitting in the corner saying, “Please don’t do that Daddy, please don’t do that Daddy” and that’s all she said. […] other people just sort of catatonic. And then […] my mum was sleeping and she’d woken up and she was in the middle of a hallucination […] that was Emma[36] finished. So, she didn’t go back.

Penny also described the impact on her siblings’ children:

> My mum had a very difficult relationship with my sister’s five children and so they were quite detached and didn’t really come by. My brother’s two daughters were quite close

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[36] Emma is a pseudonym.

> to my mum and they were quite distressed but tended to avoid – I can't judge […] But the younger of the two would take my mum to church and take time to be with her. But they were also going through teenage years and were having a bit of a tough time.

Impact on the family

The effects of dementia ripple throughout the entire family network. This section interprets the subthemes, *changes in family life*, *sibling relationships* and *impact on adult children,* as to how they add to our understanding of the impact of dementia on families.

Changes in family life

Dementia results in significant changes across several domains of family life. As Nonno remarked, "When someone in family is sick, everyone get a portion." There is now more reliance on Silvana to run errands for Nonno, take Nonna to doctors' appointments and arrange medications. However, Silvana has recently been unwell and Pina stated that she could "step up a bit more".

Ian visits Nonna and Nonno on weekends as Nonno is seeking company, often stating that "it's like a graveyard here". With Nonno's siblings living in Italy, many of his friends having passed away and Nonna with dementia, Nonno experiences feelings of loneliness and isolation. When my uncle visits, he tries to impart positive advice and provide moral support. Thus, as Pina noted, "the family is pulling in."

Paola mentioned that her husband also helped in multiple ways when she was busy with caregiving, "Angelo[37] took it on the chin that he would have to do something or he would do some house chores that I would probably have done."

Dementia can also lead to changes in family dynamics. Silvana commented, "I've seen the family breakdown. The happiness and joy of everyone being well […] It's not like it used to be." This was reinforced by Ian, "We get together less now and you realise how family gatherings were centred around the family meal prepared by Nonna." In

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[37] Angelo is a pseudonym.

contrast, Paola maintained family mealtime routines and traditions through cooking at her mother's and having the whole family congregate.

Although we feel obliged to regularly visit Nonna and Nonno, visiting can be overwhelming. As Silvana commented, "It's depressing to go there. You can see what a struggle it is for them living day-to-day and you leave knowing that things can't pick up." It is also emotionally daunting when Nonno vents his anguish to us. Silvana stated, "It feels futile because there's little you can do to change his position. You cannot fix it. You feel helpless."

Another reason it is overwhelming to visit Nonna and Nonno is due to the difficulties communicating with Nonna. Pina noted, "it became a little bit challenging because you'd go into five minute cycles of the same question. So, admittedly it's always joyful seeing your mum but then it's also tedious as well." For the non-Italian speaking members of my family, there is an additional difficulty in understanding Nonna as she reverts to her native tongue. Ian pointed out that communicating is equally challenging for Nonna, "When you visit, Nonna will often sit quietly and just listen and is sometimes frustrated by her inability to take part in the conversation."

Sibling relationships

Dementia can strengthen or strain sibling relationships. The distribution of the caring responsibility among siblings is an important determinant of relationship quality.

Paola spoke about how she and her sister bonded through their shared caregiving experience, "We got closer." Paola also had a brother who was not involved in the caregiving, "he was in and out. […] He was living with her for a period of time but he wasn't really looking after her."

In Penny's family, conflict evolved between her and her siblings about the care situation:

> […] because I was far away there was tension in so much as I wasn't caring. […] There was I think resentment, which is perfectly understandable, that I was removed from the

> situation. […] I wasn't giving up hours and hours and hours to be with her and they were. The best I could do at my end was to say to my brother that I would fully support whatever decision he made […]. But that's not to say there wasn't emotional distress or at times thinking I wasn't kept involved.

It is important to understand the family dynamics underlying this tension. Penny is the youngest of her siblings by ten years and reported that there was a very different value system in Kenya when they were growing up. Penny's sister and brother are one year apart and have always been close. They also went to boarding school whereas Penny didn't. When her family moved to Australia, Penny lived as an only child for a number of years while her sister lived overseas and brother worked interstate. Due to these factors, Penny and her siblings perceived and experienced their mother's dementia differently:

> […] their life experience is totally different to mine. […] So, I guess I saw it from a very different perspective and ended up having a very different relationship. And I think that does make a difference. So, what I thought was acceptable in my care or acceptable in whether I visited or not visited was totally based on how I saw my relationship with my mum and our connection.

Penny explained that the way her and her siblings were raised by their mother helped them to manage the tension that arose, "She was a very strong Catholic. She had a very strong belief in doing service for others and to have a higher thinking when in difficult situations and I think that's how we tried as best as we could even though there was conflict." Penny revealed, however, that it has been difficult to restore family equilibrium, "I don't know whether we'll ever totally be healed from it but we have enough, I suppose, British upper lip to be able to have got through it in a fairly civilised way." Penny acknowledged, "I've never really discussed it with my sister but it would probably be something we'd need to go to counselling, I suspect, to have a facilitator."

Impact on adult children

Guilt is one of the most pervasive emotions experienced by adult children. Silvana and Pina occasionally cook something extra for Nonno to lighten his load. However, they both feel conflicted with their own responsibilities. Silvana commented, "You feel guilty.

You think you should be doing more." Pina echoed this sentiment, "Sometimes I think what could I have done for her?" Pina wondered whether it would have been useful to attend an Alzheimer's support group but needed some encouragement to participate, "I don't know how those groups would reach someone like me to initiate that and to sort of give me a push."

Penny has also considered whether she could have taken a more hands-on caregiving role, "I guess in now looking back I can reflect on that and think about why wasn't I available or why didn't I make the time. I think that's something I need to live with and work my way through."

Dementia can also cause emotional distress for adult children. Silvana felt the gravity of the situation when Nonna and Nonno's neighbour approached her crying and relayed concern about Nonna's safety, "It really moved me seeing the effects on their neighbour too."

Pina articulated that visiting Nonna and Nonno can be emotionally intense, "Some days when we'd visit Nonna and Nonno and it was a whole day experience it would be draining and sad, so some days I'd go home and cry but not often, and then other days I would reflect and try to be stronger and think well you've got to be rational."

Pina also finds parts of Nonno's attitude demoralising, "One of the hardest things was one of Nonno's reflections when he gets really down. It's hard to lift that up when he sort of says "I just don't want to be here anymore." During the week I found that really depressing."

Adult children from the same family will often experience different challenges and issues as their parent's dementia progresses. As described earlier, Penny's experience of dementia was vastly different to her siblings. Penny noted, "They obviously saw and went through things that were extremely difficult and heart rendering and emotional that I wouldn't have experienced being far away." For Penny, living far away made it challenging to observe her mother's deterioration every few months when she visited, "Often, if you are away for a long time, you have a perception of the person as you left them, not as they are right there in the moment and that can be very difficult.”

Adult children also face fears about their own likelihood of developing dementia. Silvana insisted, “I don’t want to be a burden.’ Penny also commented, ‘Definitely this whole experience has really scarred me for old age.” As a result of witnessing her mother’s deterioration, Penny believes that “as you become more demented it becomes like the peeling of an onion so the layers and layers come back and you start to see all the issues that were never resolved.” Penny stated, “[This] has really motivated me to do like sandplay therapy and to just resolve all that stuff.” Pina is also mindful of making healthy lifestyle choices as a preventative measure.

Impact on carers

The impact of dementia on the carers of those with the condition is profound and can be examined through the following three subthemes: *changes in daily life*, *self-sacrifice* and *the emotional impact of caring*.

Changes in daily life

Carers face many changes in their daily routines and are required to take on new roles and responsibilities as a result of dementia. The most significant change for Nonno has been having to assume domestic duties such as cooking, shopping, cleaning, washing and paying bills, “What she used to do, now I have to do it. These things I’ve never done.” In addition, Nonno is responsible for bathing and dressing Nonna, taking her to bed and replacing her ostomy bag. Silvana noted that this constitutes a major reversal in longstanding familial roles, “The caring and nurturing role was always left to Nonna because she was the homemaker and Nonno was the breadwinner.” This has made it extremely challenging for Nonno to adjust to caregiving, “It’s very hard if you do one role for so many years and after you got to change. That’s a big change. Big things in life.”

Since Nonno has taken over the household chores, the family home has deteriorated, with Nonno remarking that his house has turned into a “stable”. Ian reflected that

“When Nonna was well she would have the place spotless […] Nonno now has only time for the basics.” Consequently, Nonno has gained a new appreciation for all that Nonna once did, “You know what we say? The house has four corners. The man hold one, the woman hold three. You get me? For the job what she do. And don’t see what she do. But from the morning to the night, work all time. […] Only you put the price when you lose these things.”

Paola’s daily life also changed dramatically as her mother’s need for care increased. While professional carers bathed her and did “odds and bods”, Paola and her sister provided the majority of care collaboratively. They prepared meals for their mother, brought her to stay at their houses on weekends and, before she moved into San Giorgio, took turns sleeping at their mother’s house, “We worked, went home, did the home shift, went to Mum’s, stayed overnight, went back home, did the work shift. It was a big day.” Paola described this period as exhausting and reflected that “It was a tough, tough time on everybody but we’d all do it again.” Paola went on to explain, “Sleeping at Mum’s I always felt comfortable and reassured that she was okay and she felt at ease when we were there.” Paola and her sister even considered altering their houses to accommodate their mother to move in. However, both were juggling full-time work and did not want their mother to be left alone during the day and miss the little community within her street as well as the familiarity of her own home.

Self-sacrifice

There is a significant degree of self-sacrifice involved in caregiving. Nonno asserted, “Giverny, I am always prepared to offer my life to save someone else. You get me? Doesn’t matter how much I suffer as long as I see another one is better. […] I never look after myself. We used to say, “the shoemaker always wear the oldest shoes.””

Paola and her sister also prioritised their mother’s needs, “We would always put Mum first before anything else and then if we didn’t we would feel so guilty. If we happened not to visit her one day – this is particularly in that last 12 months – we would feel so bad about it.” Paola noted, “the other parts of our lives were on hold.”

Similarly, Penny's father was fully devoted to his wife and even moved into the aged care facility to be closer to her, which affected his mental health:

> […] he would spend maybe 7, 8 hours a day with her. Every time he would make sure – no matter how sick he felt – he would be down there to sit with her, hold her hand and just talk to her. […] So, basically he gave up living I suppose in a sense to be with her and I know that he found it very depressing because there was no one really for him to talk to. I mean he had my brother and sister but in a sense when you're locked in to that kind of building per se, you don't get outside and they were both people that loved to be out walking and enjoying the fresh air and swimming. When you lose all of that I think you deteriorate quite quickly mentally and I think there was stages when he was quite severely depressed.

The act of caregiving has also put Nonno's mental health and wellbeing at risk. Pina commented, "I'm just concerned that that constant mental chatter, that it always seems to be there in the back of your head, well that just gets you down."

The emotional impact of caring

The experience of caring for a loved one with dementia encompasses a broad range of difficult emotions including denial, anger, resentment, frustration and remorse.

Penny explained that her father went through a period of denial, "he wanted to feel that […] everything was going to be alright again and that she would get better and I don't think he ever quite reconciled himself that she wasn't going to get better and they couldn't just go home. That caused part of the depression for him." This denial turned into anger, "not being able to button up her buttons on her cardigan and my dad getting furious [saying], "Just get yourself together. If you just got yourself together, you'd be okay.""

Nonna's dementia has also exerted a heavy toll on Nonno and has robbed his cheery personality which Silvana fondly remembers, "Nonno was always happy-go-lucky, singing and whistling […]. Those days are long gone." Initially, out of feelings of anger and despair, Nonno would question his decision to have married Nonna and often proclaimed that the happiest time of his life was when he was single. Silvana recounted that “He was so angry he didn’t care what he said in front of her and that made her upset. She still has emotions.” Nonno also used to talk about Nonna’s inability to perform basic tasks in a demeaning way. This irritated Silvana, “He was always testing her, making her go get something and he knew very well she wouldn’t remember it. It’s terrible.”

Angered by his situation, Nonno would also call into question whether Nonna’s condition was brought on by her repetitive living:

> Generally, the migrant woman always suffer more than the local ones because local ones they go out or they enjoy, here, there and our woman say, “ah this woman why go play the ball? Cannot wash the dishes, can’t do this, can’t do that.” But that is problem because they have something what make easy for them. But our woman is always in house closed in. You know, that is boring. Always do the same things. Eyes look for the same things all time and that’s affect too these things.[38]

Nonno also feels resentment that he has had to become a full-time carer at a time when he should be slowing down and enjoying doing little jobs, “We work all our life […] In the end, you think now I’m relaxing, have everything done and you get this cold shower on you.” Nonno has remarked on occasions that he finds life tougher now than it was living between the German and American forces during the battle of Monte Cassino in World War II. As Silvana stated, “Nonno is now working as hard as when he started labouring in the steel industry.”

Due to his new responsibilities, Nonno has limited time for maintaining his quarter acre block vegetable garden which has been a major source of frustration. For Nonno, gardening is not simply a hobby but is an essential activity of daily living which stems from growing up on a farm in rural Italy. As Nonna’s dementia has progressed, Nonno has had to forfeit other activities that he once did with Nonna such as making wine, producing bottles of tomato sauce and preserving home-grown fruit and vegetables.

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[38] Yet this has not stopped Nonno from lecturing me to learn domestic duties, “You help Mummy and learn to cook and to do things […] besides your project. […] You know, tomorrow or you marry or something like that, you can manage.”

Nonno’s frustration has been compounded by the need to constantly correct everything that Nonna still attempts – with the best intentions – to achieve, “She just make more job for you because she used to do that and she wants to, but she can’t do it.” Pina explained how she tries to encourage Nonno to remain calm, “You just keep reminding him that it’s not her, it’s the condition.”

Nonno also expressed remorse for his lack of compassion at times, “Sometime you regret what you say. It’s not so easy. Sometime everyone gets cranky because things for me, was everything new.” Indeed, my family is reluctant to condemn Nonno as we recognise that caregiving is highly challenging, stressful and burdensome. Ian believes that “You would have to be a saint to cope without losing your composure.”

Coping strategies

Family members develop their own coping strategies to deal with the devastating and life-changing losses that occur with the progression of dementia.

Nonno engages in a process of sensemaking which helps him to adjust to the new situation and persist in administering care. Specifically, Nonno derives a sense of comfort from placing his experience within a wider social context, “We are not alone. Here yes, but you go in there [San Giorgio], you have some persuasion yourself. See another one there, another one there. Say we’re not alone. There’s too many in the world.”

Through sensemaking, Nonno has come to understand that adversity is inherent to life’s journey, “That’s part of the life, to suffer. We are born for suffer. […] life is a tunnel of problems and everyone got to go through. We say in Italy, “every house got one cross” and here say, “every roof have one leak”. So, everyone have something.” During the interview, Nonno conveyed, for the first time, a sense of resigned acceptance of his current circumstances, “Ah Giverny, this is the life. You cannot change life. […] You have to learn to live in this way. […] It’s hard but still you got to do it. You have no other choice.”

Nonno perceives the caregiving hardships as a continuation of his tough life, “I’ve been always a hard work person. I never had easy life. Never, never, never had. […] So, I not scare for hold her here, to do this, do that. I’m not lazy for that. I still manage to do it, till I can.” Nonno added, “anything that’s hard work you do for the family all comes easy.”

Moreover, Nonno believes that he has a personal obligation to honour his marriage vows, “Giverny, when we marry, we marry in altar for sickness, for happiness, for richness. We got to respect such promise. Now I don’t believe in what the priests say but if I make a promise, I must hold this promise.” Nonno also emphasised that he is reciprocating the care that Nonna provided him while he recovered from a brain tumour operation.

Penny approached her mother’s dementia with a high degree of acceptance and realism, informed by her interest in Eastern philosophies, “my mantra to my family was “she’s in a different plane of living or a different existing world”, who am I to judge it or to be angry. So, I didn’t do the whole logic thing of you must come back and “come on mum” or that sort of thing.”

In addition, the values that Penny’s parents instilled in her helped her to cope:

> […] my dad definitely taught me […] that love is action in the moment. It’s every moment. You’re making this choice again and again no matter how tough it is. I love this person and it’s something you need to keep reminding yourself and looking for the best and my mum was about looking for the best in each person. […] So, I think that’s how I was influenced to get through this.

The notion of unconditional love also helped Penny and her siblings reconnect, “We are actually probably closer now. […] I think we have because they have let go and forgiven or chosen to put it to one side and allow love of each other to come to the surface.”

After the passing of their parents, Penny and her siblings were able to “step out” of their everyday experience and see the bigger picture:

> When they actually pass away you can truly let go of all the caring and responsibility so you can truly grieve and remember them as the person they were in your life. And so, in that regard, you can forgive and move on with others and put it all back into perspective. When you are very emotionally drained and involved with what's happening, it's very difficult at that particular point.

Experience of residential placement

The transition from home to residential care is a stressful time for people with dementia and their families. The decision to place a loved one into residential care is marked by intense feelings of guilt. Silvana commented on the injustice that Nonna has cared for everyone else throughout her entire life and was then left in the care of strangers, "Nonna not only raised her own children but helped raise her four younger brothers as well as her grandchildren and it feels like we're abandoning her. That's the tragedy of it all." Paola and her sister also experienced strong feelings of guilt over placing their mother into San Giorgio, "We felt like we were the worst daughters in the world."

A sense of guilt is also felt in acting against the expressed wishes of a loved one. Silvana recounted that all Nonna wanted in old age was to look after a few chickens. Penny also recited her mother's dictate, "She had never wanted to go into a home. Ever since I was little that was her thing, "I don't want to go in a home.""

It reaches a point, however, where the caregivers are at the end of their tether. Penny commented, "when she went in there was no other way that we could have managed it." Similarly, Paola stated, "We couldn't give her that level of care.' Nonno also recognises that long-term care for Nonna is unavoidable, 'Eventually I can't do all this assistance what they do there. […] We carry on till we can."

While families are therefore forced to accept the inevitable, they must deal with the consequences of their decision. The emotional burden caused by carrying out the placement decision can be immense. Silvana cried on her first visit to San Giorgio after seeing Nonna wandering around the entrance foyer alone, "She looked displaced and lost. […] The whole ordeal hit me like a sledgehammer." Pina also found the experience distressing, “Initially it was awful. The first week was really emotional.” Pina particularly struggled with the thought of Nonna “just sitting there”.

Nonno reported feeling upset whenever Nonna asked to come home, “The very, very emotion when you go there and she come with you with hand, say “I want to come with you, I want to come with you” and another person have to take her. That does feel you very, very, very, very [un]happy about that. Sad. You feel very sad.”

Paola experienced the same predicament with her mother:

> […] she would literally sit at the chairs near the reception – the nurses’ station – all day waiting for us to turn up like, “They’re coming to get me. They’re coming”, and then we’d come and she would say, “Okay let’s go. Let’s go. Time to go. Alright let’s go. You know, let’s go now. I’m ready now. I’ve been here. I can go home now.” So that was always a challenge.

For families who have no previous experiences in relation to aged care, nursing homes can be confronting places. Penny summed up the thoughts of many when she remarked:

> It’s not just your own family but looking at all the others that are there, the atmosphere and the environment is quite bleak. They had a TV blaring all the time which just drove me insane, one carer to feed all of those people, difficulty getting around to each room on time. That bit makes me sad and I just think ugh. It’s just ugly. […] It’s not the people involved, it’s just the situation involved is ugly.

Under these agonising experiences, feelings of guilt, doubt and uncertainty about the placement recur. During this time, Nonno weighed the gains and losses from the placement and re-evaluated his decision to admit Nonna as a permanent resident. My family members and I considered the benefits of Nonna staying at San Giorgio including that she was receiving better hygienic care and having more human contact. Silvana indicated that despite her initial reluctance, she was very impressed by the level of care provided at San Giorgio, which exceeded her expectations. As such, she questioned whether it was the right decision to bring Nonna home, “Looking at how well she’s being cared for […] I think she’s in a better place.”

Furthermore, my family is worried about the impact on Nonno’s health. As already revealed, being a full-time carer is a demanding and stressful job. Pina stated, “I did confront him with that. You’ll both go down and he sort of said well that’s it. He sort of made a decision that if that’s the consequence, that’s the consequence and then what can you do after that? Just respect someone’s decision.”

My family is also concerned that Nonno will find himself in the same despairing position he was in earlier this year. Ian recalled that “Just a few months ago Nonno would do or pay almost anything to place Nonna in care.” When I discussed this with Nonno, he remarked, “Yes, yes you do it like that. But say is one thing, reality is another thing. […] Sometimes I say better you go out but next day you are not like that. You know what I mean? You not conserve any hide for the family. You get cranky but next day it wipe off.”

In further explaining his decision, Nonno indicated that he felt lonely without Nonna, “I still like to have her here. Even if I have to do the work for her, do everything. But still someone sitting here. I can see some person. Alone it’s very bad.” Nonno also described his emotional connection with Nonna, “Look Givy, you are now a grown person. Once you live with some person for 53 years, it’s something what you have in you self. You know what I mean? You feel something.”

Pina made a similar observation from Nonna’s perspective, “you can’t underestimate the power of what she’s always known, her connection with her husband, the love that’s there, even though it’s not perfect.” Thus, Pina agreed with Nonno’s decision to bring Nonna home, “It’s probably where she’d be best off.”

Ian believes that there is also a financial reason underlying Nonno’s decision, “Rather than spend money on themselves and find ways to make their life easier, Nonno is content on trying to cope the best he can as he wants to leave something for his grandchildren.”

Italian cultural influences

Italian culture has an important influence on the caregiving experience. Nonno indicated that placing Nonna into San Giorgio breaks from Italian cultural traditions regarding elder care, “See Giverny, Mummy she shouldn’t be there. She should be here. In Italy, we assist the old people, even 4, 5 years in bed and family assist them. […] Never, never, never go to the nursing place.” Nonno noted that nursing homes didn’t exist in his village and recalled that multiple family members were involved in caregiving, “I help my grandfather and nurse him to do all this. My brother was in there. My parents help them. […] You do what you can anyway.”

The cultural expectations associated with caregiving may also be a factor behind Nonno’s reluctance to seek external agency support. When I suggested to Nonno that he should at least access some form of formal care support services, he once again dismissed the idea, “Nah, nah I don’t believe in that because people come help you only for work, for money. […] nobody else can do what you do. You get me? The eyes of the owner fed up the horse.” Silvana considers this to be a migrant attitude, “They’ve been independent for over fifty years. They’re not going to ask for help now.”

Paola explained her role as caregiver with reference to Italian familial values and expectations of care, “The family is number one in our culture […] We don’t abandon our parents when they are elderly. […] Italian culture has a strong connection with belonging. […] There is an expectation that we will look after them.” Paola shed further light on these cultural influences, referring to her parents’ own experiences, “They felt heartbroken that they had left their parents. I’m sure had they been in the village they would have looked after their elders. Definitely it’s sort of downloaded in the values.”

Paola also commented on the gendered nature of caregiving in Italian culture, “The daughter takes on more of the care leading role. The sons seem to not have as a dominant position.”

Advice and wisdom

At the end of each interview, I asked the participants what advice they would offer others affected by a loved one's dementia. Penny stressed the need to "go with what it is in the moment." This was also expressed by Paola, "go with the flow and the ups and downs. […] Try not to judge it and don't challenge it either.' Paola added, 'just enjoy that journey. […] At the end of it you will say you've done all you could and that's always a good feeling."

Nonno emphasised the importance of having patience, "Generally for people in this sickness, you got to be very calm because the more you get upset, the more they get cranky." Pina reiterated this point, "you can be compassionate before but until you actually step through the tolerance and the patience you need, you'd never really understand it." Likewise, Penny suggested to "try to keep that lens of love on because it can get very angry and be immensely frustrating and difficult for people when they are dealing with others with dementia."

Paola proposed ways for maintaining connectedness, "Just show that affection. […] Just tell them about your world because even though they are a little bit in and out […] they still love to hear it." Penny also encouraged others to "say "I love you" before that persons disappears before your eyes."

Several participants suggested that families affected by dementia could be better educated. Paola revealed, "I never really learnt enough about it." This lack of knowledge can make it even more challenging for family members to manage changes in their relatives' condition, with Penny noting that "our life doesn't set us up to actually deal with people that act in a way that we don't see as standard or normal." Penny also stated that improving public understanding of dementia is vital, "I wish it was talked about more and people came to grips with it more, not to be emotionally involved but to understand perhaps some of the stages people go through."

Finally, Nonno believes that we must maintain hope for a cure, "It's different if a person pass away than still alive. You know, pass away you finish. But once you are alive, you still have hope that she will come good. […] We say, “hope is the first to be born and the last to die.””

Transition

The construction of family stories is a relational process. The control of story development shifts out of the hands of the individual and becomes a collective effort. In turn, the questions of who is speaking, whose views are incorporated and what presences and absences lie in the joint construction of a family narrative become consequential. Critical to telling family stories of illness is finding strategies and spaces through which vulnerable people who do not have narrative competency, such as the cognitively impaired, can be spoken of without being spoken for.

My focus on writing this thesis was overshadowed by Nonno's sudden passing on August 2, 2017. Three weeks earlier, Nonna returned home from respite care. She was with Nonno at the time of his passing. With the support of my family, Nonna has now been admitted as a permanent resident in a dementia-specific unit at San Giorgio.

As if the pain and grief that followed Nonno's death was not enough, I also had to contend with a number of new ethical issues in my project. Tolich (2004, p.105) observes that "People's lives may change in the course of the research, giving ethics a temporal dimension." Certainly, I had not expected to have to deal with the death of one of my participants, nor could I have necessarily predicted the complex feelings and ethical dilemmas that it would evoke and raise.

The first dilemma concerned the standing of Nonno's consent to use his interview data, and whether or not consent agency should be passed on to my mother and aunt. In light of the limited guidance in literature and in the absence of specific protocols enforced by my university's ethics committee, I followed the advice offered by Dr Siobhan O'Dwyer (2017 pers. comm, 22 August), "Personally I don't see that there is anything wrong with continuing to use his data, given that he gave consent while he was alive. […] I don't think it is necessary (or appropriate) for your mother or your aunt to make posthumous decisions on his behalf."

There are also significant relational ethical issues to be faced when writing about the deceased (Ellis 2007, p.14). Chief among these are representational concerns. As Couser (2004, p.16) states, "Death […] might seem to suggest utter invulnerability to harm; but I would argue that it entails maximum vulnerability to posthumous misrepresentation because it precludes self-defence." This was an important consideration in my research. While Nonno reviewed his interview transcript, he did not have an opportunity to verify my interpretations of his statements. As such, I can never know how Nonno feels about what is being written about him and how he has been represented in this thesis.

As I had textual control over Nonno's portrayal, I had unwittingly become the custodian of his trace in life. In deciding what to reveal or conceal, I moved back and forth between considering how Nonno would want to be remembered and the importance of constructing an account of his caregiving experience that was as complete and authentic as possible. Throughout this process, I worked hard to stay emotionally grounded and aware of my own subjectivities. Quite often, my decisions changed knowing that this thesis would create a lasting imprint of the person he was.

I also had to be mindful of how other family members, especially my mother and aunt, would respond to Nonno's story. It was my responsibility to protect them from additional emotional distress and the uncomfortable feelings that reading his quotes might instigate. The passing of time and the dulling of the pain associated with Nonno's death enabled my mother and aunt to respond to the findings and my interpretations of Nonno's interview data. They provided helpful guidance concerning his representation, and their suggestions have been incorporated within my writing to their satisfaction. Given Chapter 4 was written prior to Nonno's passing, we decided to maintain my family's narrative in its original present tense form in order to honour Nonno's story as it was lived and to enhance your – the reader's – impression of directly witnessing the situation. Thus, as I reviewed and edited this thesis, I made every effort to respect the rights, wishes and feelings of all those involved.

Chapter 5: An Unfinished Agenda

This thesis emerged from the observation that the voices of family members of people with dementia have been inappropriately neglected in previous research. Family caregivers in particular are focused on as the subjects of research, but as people, they are rendered invisible. Too often their stories are written by outsiders (e.g., academics, health professionals, care providers), whereas the insider's expertise is obscured. In line with the positivist tradition, their unique situations are reduced to a generalisable case file example. Drowned out in the process is what it actually *feels* like to have a loved one with dementia. Hearing the 'official' diagnosis for the first time, adjusting to new caregiving demands, learning to cope with the incremental relational losses and seeking residential care placement are some of the major hurdles facing families of people with dementia, and yet we do not hear enough about the ways in which they make meaning around these challenges.

In this thesis, I offered a glimpse into the subjective experiences of my family members and two non-family participants to examine how dementia has affected their lives. Although small in number, these personal accounts illustrate that narratives embody a rich source of data for conveying the extraordinarily difficult experience of having a loved one with dementia. The stories shared in this thesis, while demonstrating regularities in the experiences of dementia, indicate diversity in the ways that people deal with the condition. Each person's story brings us one step closer to understanding the impact that dementia has upon individual family members, the challenging and disruptive moments throughout the journey, and how these moments affect the family as an interconnected, dynamic system.

One of the most important implications gleaned from this thesis is the power of narratives as an opportunity for healing. We can view narratives as both a process and a product (Anderson & Geist-Martin 2003, p.140). The process of sharing their stories helped participants to make sense of their experiences. For example, Penny (2017 pers. comm., 26 June) felt that telling her story had been cathartic, "I found the interview to be part of my healing process. I wasn't fully aware that it would be part of grieving and letting go. I found a wealth of sadness still within that I have been processing over the last days since we met." As a product, these stories may help others experience their own journeys with dementia and determine the coping strategies central to their own healing processes. As such, this thesis may be utilised as a “narrative blueprint” (Fox 2007, p.8), providing a companion and framework for anyone who anticipates being or is currently the loved one of a person with dementia.

This thesis also provides a model for the study of family narratives of illness. The collaborative autoethnographic method demonstrated here offers a valuable way for us to listen directly to the voices of afflicted family members while documenting first-hand the ways they negotiate illnesses within particular cultural contexts. Collaborative autoethnography is able to elucidate and make explicit feelings of loss, denial, grief, anger and fear that may otherwise be silenced, hidden, unspoken or repressed. Collaborative autoethnography aims to be emancipatory, offering patients, carers and their families the opportunity to subvert dominant forms of representation and become agents of learning rather than objects of study. Despite its promising potential, however, collaborative autoethnography should be approached with due caution.

As I have discovered, the practice of collaborative autoethnography carries with it some pitfalls. In utilising collaborative autoethnography, I faced a conundrum: I both refused and disrupted the idea of the distanced and detached observer as scholarship, but also reverted to the very authorial omniscience academic format which I was seeking to challenge. Thus, it is not so easy to just say that as researchers we can present the ostensibly authentic, unmediated voices of our participants as if our own assumptions, knowledges and biases have no bearing on what we do or how we do it.

The main point of collaborative autoethnography is to systematically examine ourselves in relation to others and the multiple experiences, interpretations and voices emergent in our lives and in our stories. However, we cannot ignore how the privilege of the researcher functions in these relations. As researchers, we need to be clear about where we are coming from, how our perspective has shaped the conduct of research and to what authority we are laying claim. This is not new for social scientists and ethnographers, but it is particularly pertinent for collaborative autoethnographers to manage given their focus on developing intersubjective understandings.

This is also where my dual insider-outsider status turned out to provide a useful comparative lens from which to self-reflexively consider my own ways of being with others. The ‘field’ is a complicated place, made more unstable by the multiple fluid identities and shifting positionalities of the researcher. In my interactions with the study participants, the way in which I positioned myself was not necessarily consistent, but was rather under constant negotiation and reconstruction with each research encounter and according to the various intersections of family/non-family and Italian/non-Italian standpoints. When the ‘field’ constitutes various contexts, we need consider the possible impacts of these changes on our scholarship. This means taking account of who we are in relation to the people we study and remaining alert to which versions of ourselves play out in the research process.

The ethics of collaborative autoethnographic research are complex, multifaceted and contingent. There can be no ‘how to’ or standard ethical criteria that applies in all situations. Throughout this study, I encountered ethical situations that do not fit strictly under the procedures specified by ethics committees. This suggests that a rethinking of ethics review procedures may be necessary to allow for the unique conditions under which collaborative autoethnographic research occurs. Procedural ethics forms and processes are well intended and important to protect participants and prevent risk and harm. However, a prescription or typology for evaluating narrative research and its accompanying morals contradicts the dynamic qualities of ethics. Every situation is different and a preformed set of principles concerned exclusively (or primarily) with risk aversion restricts the agency of both researcher and participants. An evaluation of narrative research must, therefore, involve permanent vigilance and a sensitivity to the responsibilities owed to other people featured in or affected by the narrative, to the author herself, and to the reader.

Ultimately, there is much more to be uncovered about the processes, content and functions of family storytelling in the contexts of health, illness and providing care. For example, we would benefit from a deeper understanding not only of how illness narratives are told and heard among families, but how the everyday act of storytelling can be purposefully leveraged by patients, carers and their families to aid healing. Storytelling is an ordinary part of family life (Kiser, Baumgardner & Dorado 2010, p.2). As this thesis illustrates, we do not need to be taught how to talk about the illness of family members and ourselves. Moreover, research on family stress and narrative therapy has provided a strong argument for the importance and benefits of narrating difficult family experiences together (Koenig Kellas & Trees 2006, p.53). Based on these insights, communication scholars are well-poised to further investigate how we can scaffold and bolster families' natural storytelling abilities to support them to manage their own narrative learning. Equipping families with the resources to engage skilfully in the act of storying may enable them to better navigate experiences of disruption and make informed choices about how to move forwards.

As I put the finishing touches on this thesis, I have become lost in a web of difficult emotions. Instead of feeling excitement and relief at the accomplishment of this milestone, the waves of grief come crashing back over me. I realise that what I am mourning is not only the passing of a beloved soul, but also the loss of the intended reader of this thesis. I set out on this journey to find answers to Nonno's struggles and to show him that he is not alone. That he is no longer here to read what I have written fills me with despair. At times I worry that I have presented Nonno in ways not worthy of his stature. If Nonno could tell his story, I suspect he might rightfully portray himself as less angry, frustrated and resentful and more patient, understanding and accepting given the suffering he endured. However, I value being able to have captured the rawness of Nonno's emotions and share his story more deeply and richly. I view this as a form of legacy which Nonno has left and from which other caregivers like him – and families like ours – might benefit.

Reference List

Ablitt, A, Jones, G & Muers, J 2009, 'Living with dementia: a systematic review of the influence of relationship factors', *Aging and Mental Health*, vol.13, no.4, pp.497-511.

Access Economics 2009, *Keeping dementia front of mind: incidence and prevalence 2009-2050*, Alzheimer's Australia, Canberra, viewed 30 September 2017, <https://www.fightdementia.org.au/sites/default/files/20090800_Nat__AE_FullKeepDemFrontMind.pdf>.

Adams, TE 2008, 'A Review of Narrative Ethics', *Qualitative Inquiry*, vol.14, no.2, pp.175-194.

Adams, TE & Manning, J 2015, 'Autoethnography and Family Research', *Journal of Family Theory & Review*, vol.7, no.4, pp.350-366.

ADI – see Alzheimer's Disease International.

AIHW – see Australian Institute of Health and Welfare.

Alemán, MW & Helfrich, KW 2010, 'Inheriting the Narratives of Dementia: A Collaborative Tale of a Daughter and Mother', *Journal of Family Communication*, vol.10, no.1, pp.7-23.

Allen, J, Oyebode, JR & Allen, J 2009, 'Having a father with young onset dementia: The impact on well-being of young people', *Dementia*, vol.8, no.4, pp.455-480.

Allen, KR & Piercy FP 2005, 'Feminist autoethnography', in DH Sprenkle & FP Piercy (eds), *Research methods in family therapy*, Guildford Press, New York, pp.155-169.

Alm, AK, Hellzen, O & Norbergh, KG 2014, 'Experiences of Family Relationships When a Family Member Has Dementia', *Open Journal of Nursing*, vol.4, pp.520-527.

Alvesson, M 2003, ‘Methodology for Close up Studies: Struggling with Closeness and Closure’, *Higher Education*, vol.46, no.2, pp.167-193.

Alzheimer’s Australia n.d., *Dementia Language Guidelines*, Alzheimer’s Australia, viewed 30 September 2017, <https://www.fightdementia.org.au/files/NATIONAL/documents/language-guidelines-full.pdf>.

Alzheimer’s Disease International 2015, *World Alzheimer Report 2015: The Global Impact of Dementia*, ADI, London, viewed 29 September 2017, <https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf>.

Anderson, JO & Geist-Martin, P 2003, ‘Narratives and Healing: Exploring One Family's Stories of Cancer Survivorship’, *Health Communication*, vol.15, no.2, pp.133-143.

Anderson, L 2006, ‘Analytic Autoethnography’, *Journal of Contemporary Ethnography*, vol.35, no.4, pp.373-395.

Arrington, MI 2005, ‘“She's Right Behind Me All the Way”: An Analysis of Prostate Cancer Narratives and Changes in Family Relationships’, *Journal of Family Communication*, vol.5, no.2, pp.141-162.

Atkinson, P 1997, ‘Narrative turn or blind alley?’, *Qualitative Health Research*, vol.7, no.3, pp.325-344.

Australian Institute of Health and Welfare 2012, *Dementia in Australia*, AIHW, Canberra, viewed 29 September 2017, <https://www.aihw.gov.au/getmedia/199796bc-34bf-4c49-a046-7e83c24968f1/13995.pdf.aspx?inline=true>.

Bakan, DL 2016, ‘“The Fountain Pen”: Song and Storying through A/r/tographical Conversation with Senile Dementia’, *Creative Approaches to Research*, vol.9, no.1, pp.4-18.

Barnett, K & Cricelli, M 1990, ‘Caring for Caregivers: the Multicultural Respite Care Project’, *Australian Journal of Social Work*, vol.43, no.3, pp.39-43.

Becker, G 1997, *Disrupted Lives: How People Create Meaning in a Chaotic World*, University of California Press, California.

Becvar, DS & Becvar R 1988, *Family Therapy: A Systemic Integration*, Allyn and Bacon, Boston.

Benjamin, W 1973, *Illuminations*, Fontana/Collins, London.

Benedetti, R, Cohen, L & Taylor, M 2013, ‘“There’s really no other option”: Italian Australians’ Experiences of Caring for a Family Member With Dementia’, *Journal of Women & Aging*, vol.25, no.2, pp.138-164.

Berisic, M 2008, *Perceptions of dementia in ethnic communities: Project report*, Alzheimer’s Australia, Victoria, viewed 30 September 2017, <https://www.fightdementia.org.au/files/201012-01-Nat-CALD-Perceptions-of-dementia-in-ethnic-communitites-Project-Report-Oct08.pdf>.

Black, BS, Rabins, PV, Sugarman, J & Karlawish, JH 2010, ‘Seeking Assent and Respecting Dissent in Dementia Research’, *The American Journal of Geriatric Psychiatry*, vol.18, no.1, pp.77-85.

Blandin, K & Pepin, R 2015, ‘Dementia grief: a theoretical model of a unique grief experience’, *Dementia*, vol.16, no.1, pp.67-78.

Bochner, A & Ellis, C 2006, ‘Communication as autoethnography’, in GJ Shepherd, J St. John & T Striphas (eds), *Communication as…: Perspectives on Theory*, Sage Publications, Thousand Oaks, California, pp.110-122.

Botsford, J, Clarke, CL & Gibb, CE 2011, ‘Research and dementia, caring and ethnicity: a review of the literature’, *Journal of Research in Nursing*, vol.16, no.5, pp.437-449.

Boughtwood, D, & Gava, S 2010, *Italian-speaking family caregivers of people with dementia: Report on focus groups with the Italian community*, Aged Care Research Unit, Liverpool Hospital, viewed 2 October 2017, <http://coasitagedcare.org.au/wp-content/uploads/2012/01/CALD-Dementia-Research-Project-Italian-Caregivers.pdf>.

Boughtwood, D, Adams, J, Shanley, C, Santalucia, Y & Kyriazopoulos, H 2011a, 'Experiences and Perceptions of Culturally and Linguistically Diverse Family Carers of People With Dementia', *American Journal of Alzheimer's Disease & Other Dementias*, vol.26, no.4, pp.290-297.

Boughtwood, D, Shanley, C, Adams, J, Santalucia, Y, Kyriazopoulos, H, Pond, D & Rowland, J 2011b, 'Culturally and Linguistically Diverse (CALD) Families Dealing with Dementia: An Examination of the Experiences and Perceptions of Multicultural Community Link Workers', *Journal of Cross-Cultural Gerontology*, vol.26, no.4, pp.365-377.

Boughtwood D, Shanley, C, Adams, J, Santalucia, Y, Kyriazopoulos, H, Pond, D & Rowland, J 2011c, 'The role of the bilingual/ bicultural worker in dementia education, support and care', *Dementia*, vol.12, no.1, pp.7-21.

Boughtwood, D, Shanley C, Adams, J, Santalucia, Y, Kyriazopoulos, H, Pond, D & Rowland, J 2012, 'Dementia information for culturally and linguistically diverse (CALD) communities: sources, access and considerations for effective practice', *Australian Journal of Primary Health*, vol.18, no.3, pp.190-196.

Brodaty, H & Donkin, M 2009, 'Family caregivers of people with dementia', *Dialogues in Clinical Neuroscience*, vol.11, no.2, pp.217-228.

Bruce DG & Patterson A 2000, 'Barriers to community support for the dementia carer: a qualitative study', *International Journal of Geriatric Psychiatry*, vol.15, no.5, pp.451-457.

Burke, K 1974, *The Philosophy of Literary Form*, University of California Press, California.

Cacchione, PZ 2011, ‘People With Dementia: Capacity to Consent to Research Participation’, *Clinical Nursing Research*, vol.20, no.3, pp.223-227.

Carrafa, GP, Schultz, CL & Smyrnios, KX 1997, ‘Differences between Anglo-Celtic and Italian Caregivers of Dependent Elderly Persons: a Pilot Study’, *Ageing & Society*, vol.17, no.6, pp.699-712.

Celdrán, M, Triadó, C & Villar, F 2009, ‘Learning from the disease: lessons drawn from adolescents having a grandparent suffering dementia’, *International Journal of Aging and Human Development*, vol.68, no.3, pp.243-259.

Celdrán, M, Triadó, C & Villar, F 2011, ‘“My grandparent has dementia”: How adolescents perceive their relationship with grandparents with a cognitive impairment’, *Journal of Applied Gerontology*, vol.30, no.3, pp.332-352.

Celdrán, M, Triadó, C & Villar, F 2012, ‘When grandparents have dementia: Effects on their grandchildren’s family relationships’, *Journal of Family Issues*, vol.33, no.9, pp.218-1239.

Chang, H 2016, ‘Autoethnography in Health Research: Growing Pains?’, *Qualitative Health Research*, vol.26, no.4, pp.443-451.

Chang, H, Ngunjiri, F & Hernandez, KC 2016, *Collaborative Autoethnography*, Routledge, New York.

Chavez, C 2008, ‘Conceptualizing from the Inside: Advantages, Complications, and Demands on Insider Positionality’, *The Qualitative Report*, vol.13, no.3, pp.474-494.

Cheng, A, Cruysmans, B, Draper, B, Hayward-Wright, N, Jeon, Y, LoGiudice, D, Low L, Wu, H & Zogalis, G 2009, *Strategic Directions in CALD Dementia Research in Australia*, The Dementia Collaborative Research Centre, University of New South Wales, Sydney, viewed 30 September 2017, <http://library.bsl.org.au/jspui/bitstream/1/1222/1/Strategic_Directions_in_CALD_dementia_research_in_Australia.pdf>.

Coffey, A 1999, *The ethnographic self*, Sage Publications, London.

Cole, R & Gucciardo-Masci, T 2003, *For love, for faith, for duty, for deed: Beliefs and values about caring in Anglo-Celtic, Greek, Italian, Polish, Turkish and Vietnamese communities in Victoria*, Carers Victoria, Victoria, viewed 30 September 2017, <https://www.carersvictoria.org.au/Assets/Files/for-love-faith-duty-deed-2003.pdf>.

Collins, K & Nicholson, P 2002, 'The meaning of 'satisfaction' for people with dermatological problems: Re-assessing approaches to qualitative health psychology research', *Journal of Health Psychology*, vol.7, no.5, pp.615-629.

Couser, GT 2004, *Vulnerable Subjects: Ethics and Life Writing*, Cornell University Press, Cornell.

Cox, MJ & Paley, B 1997, 'Families as systems', *Annual Review of Psychology*, vol.48, pp.243-267.

Delamont, S 2007, 'Arguments against auto-ethnography', *Qualitative Researcher*, no.4, pp.2-4.

DeLyser, D 2001, '"Do you really live here?" Thoughts on insider research' *Geographical Review*, vol.91, no.1/2, pp.441-453.

Denzin, NK 1989, *Interpretive Interactionism*, Sage Publications, London.

Denzin, NK 2003, *Performance ethnography: Critical pedagogy and the politics of culture*, Sage Publications, Thousand Oaks, California.

Dickson-Swift, V, James, EL, Kippen, S & Liamputtong, P 2008, 'Risk to researchers in qualitative research on sensitive topics: issues and strategies', *Qualitative Health Research*, vol.18, no.1, pp.pp.133-144.

Dilworth-Anderson, P & Gibson, BE 2002, ‘The cultural influence of values, norms, meanings and perceptions in understanding dementia in ethnic minorities’, *Alzheimer’s Disease and Associated Disorders*, vol.16, no.2, pp.56-63.

Ellis, C 2007, ‘Telling Secrets, Revealing Lives: Relational Ethics in Research with Intimate Others’, *Qualitative Inquiry*, vol.13, no.1, pp.3-29.

Ellis, C 2008, *Revision: Autoethnographic Reflections on Life and Work*, Left Coast Press, Walnut Creek, California.

Ellis, C 2017, ‘Compassionate Research: Interviewing and Storytelling from a Relational Ethics of Care’, in I Goodson, M Andrews & A Antikainen (eds), *The Routledge International Handbook on Narrative and Life History*, Routledge, New York, pp.431-445.

Ellis, C, Adams, TE & Bochner AP 2011, ‘Autoethnography: An Overview’, *Historical Social Research*, vol.36, no.4, pp.273-290.

Ellis, C & Bochner, AP 2000, ‘Autoethnography, personal narrative, reflexivity: Researcher as subject’, in NK Denzin & YS Lincoln (eds), *Handbook of qualitative research*, 2nd edn, Sage Publications, Thousand Oaks, California, pp.733-768.

Ellis, C & Bochner, AP 2006, ‘Analysing analytical autoethnography: An autopsy’, *Journal of Contemporary Ethnography*, vol.35, no.4, pp.429-49.

Ellis, C & Patti, C 2014, ‘With Heart: Compassionate Interviewing and Storytelling with Holocaust Survivors’, *Storytelling, Self, Society*, vol.10, no.1, pp.93-118.

Elwood, SA & Martin, DG 2000, ‘“Placing” Interviews: Location and Scales of Power in Qualitative Research’, *The Professional Geographer*, vol.52, no.4, pp.649-657.

Eriksson, T 2010, ‘Being native – distance, closeness and doing auto/self-ethnography’, *ArtMonitor*, vol.8, pp.91-100.

Fadden, G & Smith, J 2009, ‘Family work in early psychosis’, in F Lobban & C Barrowclough (eds), *A Casebook of Family Interventions for Psychosis*, John Wiley and Sons, Oxford, pp.23-46.

FECCA – see Federation of Ethnic Communities’ Councils of Australia.

Federation of Ethnic Communities’ Councils of Australia 2015, *Review of Australian Research on Older People from Culturally and Linguistically Diverse Backgrounds*, FECCA, Canberra, viewed 30 September 2017, <http://fecca.org.au/wp-content/uploads/2015/06/Review-of-Australian-Research-on-Older-People-from-Culturally-and-Linguistically-Diverse-Backgrounds-March-20151.pdf>.

Fine, M 1994, ‘Working the hyphens: reinventing self and other in qualitative research’, in NK Denzin & YS Lincoln (eds), *Handbook of Qualitative Research*, Sage Publications, Thousand Oaks, California, pp.70-82.

Fisher, L 2006, ‘Research on the family and chronic disease among adults: major trends and directions’, *Families, Systems and Health*, vol.24, no.4, pp.373-80.

Fox, R 2010, ‘Re-membering Daddy: Autoethnographic Reflections of My Father and Alzheimer’s Disease’, *Text and Performance Quarterly*, vol.30, no.1, pp.3-20.

Freeman M 2000, ‘When the story’s over: narrative foreclosure and the possibility of self-renewal’, in M Andrews, S Sclater, C Squire & A Treacher (eds), *Lines of Narrative: Psychosocial Perspectives*, Routledge, London, pp.81-91.

Garwick, AW, Detzner, D & Boss, P 1994, ‘Family Perceptions of Living with Alzheimer's Disease’, *Family Process*, vol.33, no.3, pp.327-340.

Genoe, R, Dupuis, SL, Keller, HH, Martin, LS, Cassolato, C & Edwardf, HG 2010, ‘Honouring identity through mealtimes in families living with dementia’, *Journal of Aging Studies*, vol.24, no.3, pp.181-193.

Gilles, BA 2000, ‘A memory like clockwork: Accounts of living through dementia’, *Aging and Mental Health*, vol.4, no.4, pp.366-374.

Gilliard, J 2001, ‘The perspectives of people with dementia, their families and their carers’, in C Cantely (ed.), *A handbook of dementia care*, Open University Press, Buckingham, pp.77-90.

Globerman, J 1994, ‘Balancing tensions in families with Alzheimer’s Disease: The Self and the Family’, *Journal of Aging Studies*, vol.8, no.2, pp.211-232.

Globerman, J 1995, ‘The Unencumbered Child: Family Reputations and Responsibilities in the Care of Relatives with Alzheimer’s Disease’, *Family Process*, vol.34, no.1, pp.87-99.

Hall, SM 2014, ‘Ethics of ethnography with families: a geographical perspective’, *Environment and Planning A*, vol.46, no.9, pp.2175-2194.

Hämäläinen & Rautio 2013, ‘Participants home as an interview context when studying sensitive family issues’, *Journal of Comparative Social Work*, vol.1, pp.1-30.

Hamill, SB 2012, ‘Caring for Grandparents With Alzheimer’s Disease: Help From the “Forgotten” Generation’, *Journal of Family Issues*, vol.33, no.9, pp.1195-1217.

Hammer, C 1998, ‘Toward a “thick description” of families: Using ethnography to overcome the obstacles to providing family-centered early intervention services’, *American Journal of Speech-Language Pathology*, vol.7, no.1, pp.5-22.

Heggestad, AKT, Nortvedt, P & Slettebø, A 2012, ‘The importance of moral sensitivity when including persons with dementia in qualitative research’, *Nursing Ethics*, vol.20, no.1, pp.30-40.

Hellström, I, Nolan, M & Lundh, U 2005, ‘‘We do things together’: A case study of ‘couplehood’ in dementia’, *Dementia*, vol.4, no.1, pp.7-22.

Hellström, I, Nolan, M & Lundh, U 2007, ‘Sustaining ‘couplehood’: Spouses’ strategies for living positively with dementia’, *Dementia*, vol.6, no.3, pp.383-409.

Henderson, C & Andrews, N 1998, *Partial view: An Alzheimer’s journal*, Southern Methodist University Press, Dallas.

Henderson, R & Midgley, W 2010, ‘The question of ethics in collaborative research’, in CH Arden, PA Danaher, L De George-Walker, R Henderson, W Midgley, K Noble & MA Tyler (eds), *Sustaining synergies: collaborative research and researching collaboration*, Post Pressed, Brisbane, pp.104-113.

Heru, AM 2006, ‘Family psychiatry: from research to practice’, *American Journal of Psychiatry*, vol.163, no.6, pp.962-968.

Jones, D 2015, ‘A family living with Alzheimer’s disease: The communicative challenges’, *Dementia*, vol.14, no.5, pp.555-573.

Kaminsky, M Weiss, M & Metzger, D (eds) 2007, *Stories as Equipment for Living: Last Talks and Tales of Barbara Myerhoff*, The University of Michigan Press, Michigan.

Keady, J & Harris, PB 2009, ‘Editorial: Family matters’, *Dementia*, vol.8, no.1, pp.5-8.

Keady, J & Nolan, M 2003, ‘The dynamics of dementia: Working together, working separately, or working alone?’, in M Nolan, U Lundh, G Grant & J Keady (eds), *Partnerships in family care*, Open University Press, Maidenhead, pp.15-32.

Keyserlingk EW, Glass K, Kogan S & Gauthier, S 1996, ‘Proposed guidelines for the participation of persons with dementia as research subjects’, *Perspectives in Biology and Medicine*, vol.38, no.2, pp.319-362.

Kindell, J, Sage, K, Wilkinson, R & Keady, J 2014, ‘Living With Semantic Dementia: A Case Study of One Family’s Experience’, *Qualitative Health Research*, vol.24, no.3, pp.401-411.

Kiser, LJ, Baumgardner, B & Dorado, J 2010, ‘Who Are We, But for the Stories We Tell: Family Stories and Healing’, *Psychological Trauma: Theory, Research, Practice, and Policy*, vol.2, no.3, pp.243-249.

Kitwood, T 1997a, *Dementia Reconsidered: The Person Comes First*, Open University Press, Buckingham, United Kingdom.

Kitwood, T 1997b, ‘The concept of personhood and its relevance for a new culture of dementia care’, in BML Meisen & GMM Jones (eds), *Care-giving in dementia, research and applications*, vol.2, Routledge, London, pp.3-13.

Kjällman-Alm, A, Norbergh, KG & Hellzen, O 2013, ‘What it means to be an adult child of a person with dementia’, *International Journal of Qualitative Studies on Health and Well-Being*, vol.8, no.1, pp.1-9.

Koenig Kellas, J & Trees, AR 2006, ‘Finding Meaning in Difficult Family Experiences: Sense-Making and Interaction Processes During Joint Family Storytelling’, *Journal of Family Communication*, vol.6, no.1, pp.49-76.

La Fontaine, J & Oyebode, JR 2014, ‘Family relationships and dementia: a synthesis of qualitative research including the person with dementia’, *Ageing & Society*, vol.34, no.7, pp.1243-1272.

Lapadat, JC 2017, ‘Ethics in Autoethnography and Collaborative Autoethnography’, *Qualitative Inquiry*, vol.23, no.8, pp.1-17.

Large S & Slinger R 2015, ‘Grief in caregivers of persons with Alzheimer's disease and related dementia: A qualitative synthesis’, *Dementia*, vol.14, no.2, pp.164-183.

Lassiter, LE 2005, *The Chicago Guide to Collaborative Ethnography*, The University of Chicago Press, Chicago.

Lassiter, LE 2008, ‘Moving Past Public Anthropology and Doing Collaborative Research’, *NAPA Bulletin*, vol.29, no.1, pp.70-86.

Leslie, LA & Glossick, ML 1992, ‘Changing Set: Teaching Family Therapy from a Feminist Perspective’, *Family Relations*, vol.41, no.3, pp.256-263.

Low, L, Draper, B, Cheng, A, Cruysmans, B, Hayward-Wright, N, Jeon, Y, LoGiudice, D, Zong Ying Wu, H, Zogalis, G & Brodaty, H 2009, ‘Future research on dementia relating to culturally and linguistically diverse communities’, *Australian Journal on Ageing*, vol.28, pp.144-148.

Low, L, Harrison, F, Kochan, A, Draper, B, Slavin, MJ, Reppermund, S, Sachdev, PS & Brodaty, H 2012, ‘Can Mild Cognitive Impairment Be Accurately Diagnosed in English Speakers From Linguistic Minorities? Results From the Sydney Memory and Ageing Study’, *The American Journal of Geriatric Psychiatry*, vol.20, no.10, pp.866-877.

Malthouse, M 2011, ‘An autoethnography on shifting relationships between a daughter, her mother and Alzheimer’s dementia (in any order)’, *Dementia,* vol.10, no.2, pp.249-256.

Mason, J 2002, *Qualitative Researching*, 2nd edn, Sage Publications, Thousand Oaks, California.

McCallum, J & Gelfand, D 1990, *Ethnic Women in the Middle: A Focus Group Study of Daughters Caring for Older Migrants in Australia*, National Centre for Epidemiology and Population Health, Canberra.

McIlveen, P 2008, ‘Autoethnography as a method for reflexive research and practice in vocational psychology’, *Australian Journal of Career Development*, vol.17, no.2, pp.13-20.

McLean, A & Leibing, A (eds) 2003, *The Shadow Side of Field Work: Exploring the Blurred Borders between Ethnography and Life*, Blackwell Publishing, Oxford.

MacRae, H 2002, ‘The identity maintenance work of family members of persons with Alzheimer’s disease’, *Canadian Journal on Aging*, vol.32, no.3, pp.405-415.

Medford, K 2006, ‘Caught with a Fake ID’, *Qualitative Inquiry*, vol.12, no.5, pp.853-864.

Méndez, M 2013, ‘Autoethnography as a research method: Advantages, limitations and criticisms’, *Colombian Applied Linguistics Journal*, vol.15, no.2, pp.279-287

Merrick, K, Camic, PM & O’Shaughnessy, M 2016, ‘Couples constructing their experiences of dementia: A relational perspective’, *Dementia*, vol.15, no.1, pp.34-50.

Metta, M 2010, *Writing Against*, *Alongside and Beyond Memory: Lifewriting as Reflexive*, *Poststructuralist Feminist Research Practice*, Peter Lang, Bern, Switzerland.

Miller, K. 1997, ‘All in the family: Family folklore, objectivity, and self-censorship’, *Western Folklore*, vol.56, no.3/4, pp.331-346.

Morse, JM 2002, ‘Writing My Own Experience…’, *Qualitative Health Research*, vol.12, no.9, pp.1159-1160.

National Health and Medical Research Council, Australian Research Council, & Australian Vice-Chancellors’ Committee 2007, *National Statement on Ethical Conduct in Human Research*, Australian Government, Canberra, viewed 30 September 2017, <https://www.nhmrc.gov.au/guidelines-publications/e72>.

Nichols, P, Horner, B & Fyfe, K 2015, ‘Understanding and improving communication processes in an increasingly multicultural aged care workforce’, *Journal of Aging Studies*, vol.32, pp.23-31.

Ngunjiri, FW, Hernandez, KAC, Chang, H 2010, ‘Living Autoethnography: Connecting Life and Research’, *Journal of Research Practice*, vol.6, no.1, p.1-17.

Pace, GD 2015, ‘Doing close-relative research: sticking points, method and ethical considerations’, *International Journal of Research & Method in Education*, vol.38, no.4, pp.341-356.

Park-Fuller, L 2003, ‘A Clean Breast of It’, in LC Miller, J Taylor & H Carver (eds), *Voices Made Flesh: Performing Women’s Autobiography*, University of Wisconsin Press, Wisconsin, pp.215-236.

Pearlin, LI 1992, ‘The Careers of Caregivers’, *The Gerontologist*, vol.32, no.5, p.647.

Perry, J & Olshansky, EF 1996, ‘A family’s coming to terms with Alzheimer’s disease’, *Western Journal of Nursing Research*, vol.18, no.1, pp.12-28.

Phinney, A 2002, ‘Living with the symptoms of Alzheimer’s Disease’, in P Braudy Harris (ed.), *The Person with Alzheimer’s Disease*, Johns Hopkins University Press, Baltimore, pp.49-74.

Phinney, A, Dahlke, S & Purves, B 2013, ‘Shifting Patterns of Everyday Activity in Early Dementia: Experiences of Men and Their Families’, *Journal of Family Nursing*, vol.19, no.3, pp.348-374.

Poulos, C 2008, ‘Narrative conscience and the autoethnographic adventure: Probing memories, secrets, shadows, and possibilities’, *Qualitative Inquiry*, vol.14, no.1, pp.46-66.

Poulos, C 2009, *Accidental ethnography*, Left Coast Press, Walnut Creek, California.

Purves, BA 2010, ‘Exploring positioning in Alzheimer Disease through analyses of family talk’, *Dementia*, vol.10, no.1, pp.25-58.

Purves, BA & Phinney, A 2012, ‘Family Voices: A Family Systems Approach to Understanding Communication in Dementia’, *Canadian Journal of Speech-Language Pathology and Audiology*, vol.36, no.4, pp.284-300.

Rager, KB 2005, ‘Self-Care and the Qualitative Researcher: When Collecting Data Can Break Your Heart’, *Educational Researcher*, vol.34, no.4, pp.23-27.

Reed-Danahay, DE 1997, *Auto/ethnography: Rewriting the self and the social*, Berg Publishers, Oxford, United Kingdom.

Richards, R 2008, 'Writing the Othered Self: Autoethnography and the Problem of Objectification in Writing About Illness and Disability', *Qualitative Health Research*, vol.18, no.12, pp.1717-1728.

Reiss, D & Klein, D 1987, 'Paradigm and Pathogenesis: A Family-Centered Approach to Problems of Etiology and Treatment of Psychiatric Disorders', in T Jacobs (ed.), *Family Interaction and Psychopathology*, Plenum, New York, pp.203-255.

Riessman, CK 1993, *Narrative Analysis*, Sage Publications, California.

Roach, P & Keady, J 2008, 'Young People with Dementia: Time for Fair Play', Comment Piece, *British Journal of Nursing*, vol.17, no.11, p.690.

Rosenblatt, PC 1994, *Metaphors of Family Systems Theory: Toward New Constructions*, Guilford Press, New York.

Saldaña, J 2003, 'Dramatizing data: A primer', *Qualitative Inquiry*, vol.9, no.2, pp.218-236.

Salmon, N 2006, '*The Waiting Place*: A caregiver's narrative', *Australian Occupational Therapy Journal*, vol.53, no.3, pp.181-187.

Schaber, P, Blair, K, Jost, E, Schaffer, M & Thurner, E 2016, 'Understanding Family Interaction Patterns in Families with Alzheimer's Disease', *OTJR: Occupation, Participation and Health*, vol.36, no.1, pp.25-33.

Shanley, C, Boughtwood, D, Adams, J, Santalucia, Y, Kyriazopoulos, H, Pond, D & Rowland, J 2012, 'A qualitative study into the use of formal services for dementia by carers from culturally and linguistically diverse (CALD) communities', *BMC Health Services Research*, vol.12, no.1, pp.1-11.

Shanley, C, Leone, Santalucia, Y, Adams, J, Ferrerosa-Rojas, JE, Kourouche, F, Gava, S & Wu, Y 2013, ‘Qualitative Research on Dementia in Ethnically Diverse Communities: Fieldwork Challenges and Opportunities’, *American Journal of Alzheimer’s Disease & Other Dementias*, vol.28, no.3, pp.278-283.

Sikes, P & Hall, M 2016, ‘“It was then that I thought “whaat? This is not my Dad”: The implications of the ‘still the same person’ narrative for children and young people who have a parent with dementia”’, *Dementia*, pp.1-19.

Slaughter, S, Cole, D, Jennings, E & Reimer, MA 2007, ‘Consent and Assent to Participate in Research from People with Dementia’, *Nursing Ethics*, vol.14, no.1, pp.27-40.

Smebye, KL & Kirkevold, M 2013, ‘The influence of relationships on personhood in dementia care: a qualitative, hermeneutic study’, *BMC Nursing*, vol.12, no.1, pp.1-13.

Starkweather, S 2012, ‘Telling family stories: collaborative storytelling, taking precedence and giving precedence in family group interviews with Americans in Singapore’, *Royal Geographical Society (with IBG)*, vol.44, no.3, pp.289-295.

Taylor, J 2008, ‘On Recognition, Caring, and Dementia’, *Medical Anthropology Quarterly*, vol.22, no.4, pp.313-335.

Tolich, M 2004, ‘Internal Confidentiality: When Confidentiality Assurances Fail Relational Informants’, *Qualitative Sociology*, vol.27, no.1, pp.101-106.

Tolich, M 2010, ‘A Critique of Current Practice: Ten Foundational Guidelines for Autoethnographers’, *Qualitative Health Research*, vol.20, no.12, pp.1599-1610.

Tolich, M & Fitzgerald, M 2006, ‘If ethics committees were designed for ethnography’, *Journal of Empirical Research on Human Research Ethics*, vol.1, no.2, pp.71-78.

Tullis, JA 2013, ‘Self and others: Ethics in autoethnographic research’, in S Holman Jones, TE Adams & C Ellis (eds), *Handbook of autoethnography*, Left Coast Press, Walnut Creek, California, pp.244-261.

Turner, L 2013, ‘The evocative autoethnographic ‘I’: The relational ethics of writing about one-self’, in NP Short, L Turner & A Grant (eds), *Contemporary British Autoethnography*, Sense Publishers, Rotterdam, pp.213-229.

Vasta, E 1995, ‘The Italian-Australian Family: Transformations and Continuities’, in R Hartley (ed.), *Families and Cultural Diversity in Australia*, Allen and Unwin, Sydney, pp.144-66.

Vizzachi, BA, Daspett, C, Cruz, MGS & Horta, ALM 2015, ‘Family dynamics in face of Alzheimer’s in one of its members’, *Revista da Escola de Enfermagem*, vol.49, no.6, pp.933-938.

von Eye, A & Kreppner, K 1989, ‘Family systems and family development: The selection of analytic units’, in K Kreppner & RM Lerner (eds), *Family systems and life-span development*, Taylor & Francis, London, pp.247-269.

Walsh, F 1996, ‘The concept of family resilience: crisis and challenge’, *Family Process*, vol.35, no.3, pp.261-81.

Whitchurch, GG & Constantine, LL 1993, ‘Systems theory’, in PG Boss, WJ Doherty, R La Rossa, WR Schumm & SK Steinmetz (eds), *Source-book of family theories and methods*, Plenum, New York, pp.325-352.

WHO – see World Health Organization.

World Health Organization 2017, *Dementia*, WHO, viewed 29 September 2017, <http://www.who.int/mediacentre/factsheets/fs362/en/>.

Yerby, J 1995, ‘Family Systems Theory Reconsidered: Integrating Social Construction Theory and Dialectical Process’, *Communication Theory*, vol.5, no.4, pp.339-365.

Zylinska, J 2005, *The ethics of cultural studies*, Continuum, New York.

Appendix

Appendix A: Oral assent script and form

The following script was used to obtain my Nonna's assent. As noted in Chapter 3, I developed it in consultation with Dr Siobhan O'Dwyer and Dr Laura Béres.

"Hi Nonna,

Is it alright if I talk to you about a research project I'm doing at uni? You can stop me and ask me any questions at any time.

The project is about dementia in our family. Dementia is something that makes it hard to remember things. Dementia has become a big problem, not only in Australia but all around the world.

I'm doing a research project at uni to find out more about how memory problems affect family members. If it is okay with you, I'm going to talk to [insert names of the family participants] about how they have been over the past few years. I would like to ask for your permission to do this research because, when I talk to [insert names of the family participants], we will be discussing things about our family, including you.

This project could help people understand that they are not alone in their experiences and that it's okay to feel the way they do.

Do you have any questions about this study I'm doing?

Do you feel this is something that you would be okay with?"

End of verbal script.

To be completed by the person obtaining verbal assent:

Subject’s response:

☐ Yes
☐ No

____
Name of subject (printed)

____
Name (printed) of person obtaining assent

____________________________________ _________
Signature of person obtaining assent Date

To be completed by a witness:

- The information conveyed by the person obtaining assent was presented to the subject in a language understandable to the subject; and
- The subject’s questions were answered by the person obtaining assent in a language understandable to the subject.

____
Name (printed) of witness

____________________________________ _________
Signature of witness Date