THE LIVED EXPERIENCE
OF RISK FOR A PERSON WITH A RECENT
DIAGNOSIS OF DEMENTIA (Alzheimer's type):
A LONGITUDINAL PHENOMENOLOGICAL
STUDY

Submitted by

Sally Osborne

BA (Social Science), Grad.Dip. Nursing (Gerontics)
Grad.Dip. (Aged Services Management)
MHlthSc. (Aged Services)

Submitted in fulfilment
of the requirements of the degree of
Doctor of Philosophy

College of Arts
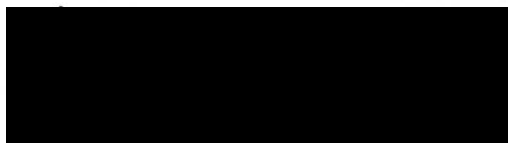Victoria University, Melbourne, Australia

November 2016

ABSTRACT

This longitudinal qualitative study explored the lived experience of risk for people with a recent diagnosis of dementia (Alzheimer's type). Risk is a concept used in dementia research when examining *choice* and *decision-making,* and is primarily a negative phenomenon associated with danger and hazard. In this study, risk is used as an exemplar of autonomy and rights—rights to independent action taken with free will and choice. These rights are entwined with key principles we live by: personal autonomy—the right to act independently—to take a risk.

A hermeneutic phenomenological framework informed by the concepts and understandings of its key thinkers Husserl, Heidegger, Gadamer and van Manen was utilised in this study to uncover the *meanings* associated with risk for the participants following a recent diagnosis of dementia. A purposive sample of ten (10) participants engaged in four (4) conversations conducted every six (6) months over a period of two years offered scope to monitor change within those meanings.

The findings indicate that risk was a normal part of life—indeed it was *life*. A diagnosis of dementia however, was a portent for change whereby the upheaval and uncertainty of everyday life precluded the desire to embrace risk. Paradoxically, risk was also withheld from the participants by significant others, resulting in feelings of impotency and distress. The lived experience of risk was explored at a time when participants were harnessing their personal resources in order to tackle the transient effects of living with dementia.

STUDENT DECLARATION

"I, Sally Osborne declare that the PhD thesis entitled: The lived experience of risk for a person with a recent diagnosis of dementia (Alzheimer's type): a longitudinal hermeneutic study is no more than 100,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work".

████████████████████ ....

Sally Osborne

Date: 23 November 2016

ACKNOWLEDGEMENTS

This journey has been undertaken in the pursuit of a fulfilled life for people living with dementia. This vision was shared by my supervisor Associate Professor Jocelyn Angus who was a tower of strength and inspiration throughout the five years of this thesis. Thanks for your wisdom and your motivation to do justice to the stories told by the participants.

My study acknowledges the wonderful support from the staff at Victoria University, including the City Flinders Campus library staff especially Meg Weller.

Thanks to Max van Manen for occasional help via email.

To the participants and their families and friends who provided the data for this study. They were generous and supportive and I will never forget them.

My husband John has been a source of strength and immeasurable support and understanding throughout. I simply cannot thank him enough, and I am certain that I could not have done this without him. His meals were prepared with love and our daily gin and tonics together were a salvation! To my family who have all lived alongside this thesis and provided support and encouragement. My message to my beloved grandchildren is that age is no barrier to achieving your goals.

I dedicate this thesis to the memory of my dear mother Madge who taught her four girls the importance of education. Her unstinting loyalty and belief knew no bounds. My thesis richly acknowledges her and it is to her that I owe my greatest thanks.

ABBREVIATIONS

AA	Alzheimer's Australia
CDAMS	Cognitive Dementia and Memory Service
CDC	Consumer Directed Care
DSM	Diagnostic and Statistical Manual of Mental Disorders
GP	General Practitioner
ICT	Information and Communication Technology
NEAF	National Ethics Application Form
NOK	Next of Kin
WHO	World Health Organisation

CONVENTIONS

The data from the study's conversations have been transcribed literally. This allowed for the natural flow of a narrative between two people, and highlighted colloquialisms, slang and jargon which were foot noted for explanation. Brackets were inserted to indicate accents, body language and props which were used in the telling of a story. Language inconsistencies or difficulties associated with having a diagnosis of dementia were also highlighted.

The following conventions within the transcripts facilitated understanding and meaning.

Italics	the words used by the study participants themselves
...	material edited out within a conversation or a pause, contained in original material
[ ]	comments added by the researcher to provide explanation or clarity
CAPITAL LETTERS	words or phrases emphasised by the study participants
Sic	linguistic inconsistencies

The conversations were denoted as follows (1: 19-20, p. 3) where:
the interview number (1:)
the line numbers   (1: 19-12,)
the page number   (1: 19-20, p. 3)
Where more than one interview was included it was denoted by the use of a colon (1:19-20, p. 3; 2: 34, p.11)

The use of the word wholistic is attributed to van Manen who incorporates the term into the wholistic reading approach which refers to the text as a whole (see section 4.1.7). The word 'holistic' is used in reference to care and also to view a person 'holistically'. The meaning is that the whole person is considered—their body, their mind, their spirit including emotions.

Within the conduct of this study, the term 'conversation' referred to the intimate discussions which were held between the participants and myself. They were referred to as interviews within the analysis which facilitated the discussion in which there were often multiple references.

LIST OF PUBLICATIONS AND AWARDS

'A self-narrative of life-long disability: A reflection on resilience and living with dementia'. J. Angus & S. Bowen-Osborne. *Dementia, 13(2),* 147-159.

Quiet, please, there's a lady on stage. Centering the person with dementia in a life story narrative. Angus, J. & Bowen, S. *Journal of Aging Studies, 25(2)110-117. .*

Dementia Nursing. A Guide to Practice. R. Hudson (Ed.). Ausmed Publications (2003)

Chapter 21- Leisure-S. Bowen (author)

Chapter 22- Creative Care-S. Bowen (author and editor).

Speaker: Hammond Care Dementia Conference, Sydney (June, 2012). 'There's a life for us—if we risk it!' Is a diagnosis of dementia a risky business? -

Speaker: Alzheimer's Australia National Conference, Hobart (May, 2013). 'Engaging in research: a risky business?'

Speaker: Alzheimer Europe Conference, Malta (November/2013). 'There's a life for us, if we risk it!' Is a diagnosis of dementia a risky business?

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

CHAPTER 1

INTRODUCTION

When I was a child, the lessons my father taught me had been about perseverance: never to accept limitations that stood in my way. As an adult watching him in his final years, I also saw how to come to terms with limits that simply could not be wished away. When to shift from pushing against limits to making the best of them is not often readily apparent. But it is clear that there are times when the cost of pushing exceeds its value. Helping my father through the struggle to define that moment was simultaneously among the most painful and most privileged experiences of my life.

(Atul Gawande: *Being mortal)*

Dementia—the word weighs heavily on the minds of people, irrespective of time, place or culture. It is spoken with dread and foreboding as scholars, clinicians and practitioners pursue a cure. Those with a diagnosis struggle for recognition and citizenship in what Post refers to as a 'hyper-cognitive' society (1995). Amid this maelstrom of upheaval and fear that privileges human capacities of rational thinking, people living with dementia are seeking a life with rights and respect—to make decisions—to take a risk, without stigma and undue restraint.

This chapter begins a journey of discovery of the *meaning* of risk for people following a recent diagnosis of dementia. It opens with the basic premise of phenomenology, that we are enmeshed in the immediacy of our experience because our world—with its other people, its histories and cultures, its practices and its events—precedes any attempt on our part to understand it or explain it (Gadamer, 2004; Giorgi, 1970; Husserl, 1907/1990; Merleau-Ponty, 1964; van Manen, 2014).Thus this chapter commences with an exploration of our cultural perceptions of ageing, its myths and realities, underscored by society's innate fear of growing old—and the inevitability of death. It is within this immediacy of cultural experience that various social constructionist frameworks and understandings of dementia and concepts of risk are introduced. The blurring of theoretical boundaries enmeshed within these world

views reflects the historical and sociocultural dimensions that inform contemporary understandings of dementia and concepts of risk. This is followed by an introduction to the research design, background and philosophical underpinnings of the study. Key definitions and core concepts are presented and provide guidance for the study's development in the chapters that follow.

1.1.   The paradox of ageing

In Western culture, the dominant view of ageing is as a natural biological process, beginning at conception or birth and unfolding throughout from growth and maturation and finally into old age or senescence and death (Vincent, 2008). This natural process of old age is eloquently narrated by Atul Gawande in his description of his father's last years and his coming to terms with *'limits that simply could not be wished away'.* Nevertheless, this lifelong process of 'ageing' is typically consigned to 'old age' and traditionally seen as a time of deterioration and decrepitude (Angus & Reeve, 2006; D. Davis, 2004; Estés & Binney, 1991; Minkler & Holstein, 2008; Powell & Hendricks, 2009; Vincent, 2008).

Within this framework, the construction of ageing inscribes interplay between social context and the people within it; central to which is the taken-for-granted societal assumptions that shape personal attitudes towards ageing (Powell & Hendricks, 2009). More specifically, it highlights the relationship between societal institutions and older people where ageist attitudes pose an enduring threat—the changing of which is a complex and difficult task (Angus & Reeve, 2006; Thornton, 2002). Ageism is a powerful vehicle for what Estés called the 'aging enterprise' (1979) whereby old age became subject to, and increasingly constituted within, a bio-medical discourse. The idea of a healthy old age was erased from this mode of discourse which viewed senescence from a pathological perspective, whereby this entire stage of life became one long progressive disease (Powell & Hendricks, 2009). It was not long before ageing became synonymous with disease, pathology and mortality rates.

The influence of the social sciences moderated this discourse of *hopeless* pathology with a critique of the "rigour with which medicine circumscribes its own discourse" (D. Davis, 2004, p. 369). Social science re-examined the separation of disease and the

process of ageing (Green, 1993). The clarification of the margins that defined Alzheimer's disease in the USA for example set the stage, in defining the boundaries between normal and pathological ageing (Gubrium, 1992). Although dementia is often associated with old age (Hughes 2011), it is *not* a normal part of ageing (Alzheimer's Australia, n.d.; World Health Organisation, 2016a). This widely held myth muddies the rhetoric surrounding 'new' grand narratives whereby ageing discourses under the various monikers including *productive, successful, and positive* ageing are the new 'norm'. Critical theorists contest their veracity and highlight the struggle to apply these normative concepts to a diverse ageing population (Deeg, 2013; Estés, 1979; Holstein, 1999; Holstein & Minkler, 2003). This position is endorsed by Martinson and Berridge (2015) who call for greater reflexivity in the use of these grand narratives which they argue contribute to, rather than dismantle ageism.

1.2. Dementia: a global health issue

The global ageing of the population is well documented and celebrated (Christensen, Doblhammer, Rau, & Vaupel, 2009; Fries, 2003; Gilliard & Higgs, 1998). There remains, however, a caveat that increases in life expectancy remain deeply embedded in negative pathological determinants of old age (Deeg, 2013; Overton, 1993). Dementia for example, presents a significant public health challenge (World Health Organisation & Alzheimer's Disease International, 2012) in both human and economic terms. It has been widely referred to as the public health challenge of the twenty-first century and the overwhelming priority of healthcare in the twenty-first century. The term dementia is most commonly associated with Alzheimer's disease which is a chronic, progressive and debilitating illness that gradually erodes identity, autonomy and independence (Pesonen, Remes, & Isola, 2011). Its global prevalence is one of the major causes of disability and dependency in society and the growing economic impact of dementia poses a challenge to health care services and care practices (Pesonen, et al., 2011; Zeigler-Graham, Brookmeyer, Johnson, & Arrighi, 2008), while the human cost to families, caregivers and communities is immeasurable. There is little doubt that life expectancy is related to health status, "[a]fter all the large majority of mortality is due to diseases" (Deeg, 2013, p. 143). The linking of age and ill-health however has become a part of a cultural narrative of decline: defined on the one hand by death and on the other by transitions defined by

the process of ageing. This in turn has been embedded in a wider *ageist* culture whereby, "ageing by definition was bad for you" (Vincent, 2008, p. 338). Increased life expectancy and older age generally results in increased ill health of 'epidemic' proportions (Australian Institute of Health and Welfare, 2016), central to which is the sensationalist rhetoric of 'epidemic' and 'tsunami' proportions of people living with dementia (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007; Hughes, 2014; Kukull, 2006). This has major impacts on health and welfare services (Australian Institute of Health and Welfare, 2012), and "threatens to overwhelm the health budget, the capacity of health services and the health workforce" (Calder, 2014, p. ii). The portent of a looming dementia 'epidemic' surrounds any discussion about dementia today (Courbage & Liedtke, 2012; Pérès, 2011) and is borne out in the alarmist narrative of Australian statistics related to dementia:

> *In Australia, there are more than 353,800 Australians living with*
> *dementia, and this number is expected to increase to 400,000 in*
> *less than ten years. Without a curative breakthrough, these*
> *numbers are expected to be almost 900,000 by 2050*
> (Alzheimer's Australia, 2016).

This positioning of dementia as a major health challenge is somewhat counteracted with emerging evidence that the prevalence of dementia is stabilising, rather than continuing to increase (Jones & Greene, 2016; Wu et al., 2016). While ageing demographics including "the bulge of baby boomers" will drive an increase in dementia numbers worldwide (Larson, Yaffe, & Langa, 2013, p. 2275), other research points to the declining prevalence or incidence rates of dementia among people born later in the first half of the twentieth century (Larson, et al., 2013; Schrijvers et al., 2012). At the same time, the stabilising prevalence of chronic illnesses such as dementia in this context must be treated with caution (Hughes, 2011; World Health Organisation & Alzheimer's Disease International, 2012). The long-term benefits of national policies related to education, general public health and better management of risk factors for dementia will continue to drive this important public health agenda. Public health campaigns about chronic illnesses such as hypertension, heart disease and diabetes, its modifiable factors and prevention strategies have played a part in extending life expectancy and

ameliorating the effect of chronic illnesses such as dementia (Owen, Healy, Mathews, & Dunstan, 2012; Ratzan, 1993). Regardless of the positive impact of public health strategies of living longer, healthier lives, longevity remains a *problem* of the ageing population where responsibility for limited welfare and healthcare resources is being redirected from the state to the individual (Deeg, 2013; Estés, 1979; Minkler & Holstein, 2008; Powell & Hendricks, 2009).

1.3.   Setting the context of this study

This brief depiction of the socio-cultural milieu exposes the immediacy of our experience in 'our world' and the associated stigma and social exclusion for those with a diagnosis of dementia. It is this lifeworld in which the core question of this thesis was set: *What is the lived experience of risk for a person with a recent diagnosis of dementia (Alzheimer's type)?* This study incorporates the phenomenological seeking of that meaning of *lived experience* for the person, not what others thought it may be. It differs from other forms of qualitative research which have not sought the immediate and lived experience "as he/she lives it" (van Manen, 1990, p. 31).

1.4.   Aims of the study

This hermeneutic phenomenological study uncovers meanings associated with the *lived experience* of risk, or the 'not taking' of risk following a recent diagnosis of dementia (Alzheimer's type). In particular, this study seeks to:

> ➢ understand what risk means for a person living with dementia;
> ➢ explore the context of adjusting to a diagnosis, and its effects, if any, on choice and decision-making following a diagnosis; and
> ➢ challenge the assumption that a diagnosis of dementia precludes risk-taking.

In this study, the meaning of risk for the person with a recent diagnosis of dementia was explored. It will contribute to a broader and more complete picture of the impact of living with dementia. In highlighting the importance of risk for people with a recent diagnosis, this study argues that there are constraints on risk-taking when a diagnosis of dementia has been made. These constraints will be identified from a

broad medico-socio-political and professional perspective, as well as a micro-social context which is the lifeworld (see section 3.5.1) of those living with this chronic and disabling illness.

1.5. Design of the study

A longitudinal study is an observational research method in which data is gathered for the same subjects repeatedly over a period of time. It involves repeated observations of the same variables (for example, people) over long periods of time and can extend over years or even decades, such as Snowden's Nun's Study (2001). While there is no definitive length of time for a study to be considered longitudinal, this study follows Saldaňa's (2003) advice that a longitudinal qualitative study and its appropriate length of fieldwork are what the researcher (and others) consider appropriate to fulfil the study's aims. The emphasis is on the continuous or repeated monitoring of people over time, rather than the length of time taken to complete the study.

Revisiting a phenomenon builds time into the research process which is well suited to answer questions about the intuitive change to the lived experience of risk in the lives of the participants over time. The longitudinal data typically provides information on the individual life courses encompassing various domains of interest namely, perceptions of risk and the effect that an early diagnosis of dementia has on that perception of risk. Specifically, it provides an understanding that people living with dementia are dynamic, not static entities (Murray, Kendall, & Carduff, 2009); and their evolving need to take, or not to take a risk. Within those data, transitions occurred-which may be transitory or permanent.

This study will conduct 'in-depth' conversations with ten people who have a recent diagnosis of dementia. They will take place at approximately six monthly intervals over a period of two years. This will result in approximately forty interviews which will allow ongoing opportunities for the participant to tell their own story of risk.

1.6. Implications of the study

This study is articulated at several levels. First and foremost, articulation begins at the individual level, where the voice of the person living with dementia is heard in all

its "livingness" (van Manen, 2016, p. 6). Secondly, this study is important at a policy level. Asking questions about risk governance will help to determine the policy needs of the participants—their needs and fears, in order to shape responses and contribute to new knowledge about the lived meanings of risk for people with a recent diagnosis of dementia. The 'management' of risk by others on behalf of people living with dementia is problematic, a position strongly articulated throughout the literature (Alaszewski, Alaszewski, Ayer, & Manthorpe, 2000; Bailey et al., 2013; Dartington, 2007; Dunham & Cannon, 2008; Harris & Keady, 2008; Hughes, Louw, & Sabat, 2006). Thirdly, the study has implications at a societal level. Citizenship is an issue of social justice (Brannelly, 2011) wherein people with dementia have rights to decisions about their own care (Boyle, 2008). The import of this research promotes their social citizenship (Bartlett & O'Connor, 2010), and demonstrates that life does not stop at a diagnosis of a condition such as dementia.

1.7.   Background to the study

My experiential journey began following a decade of aged care work—a passion directed towards the psychosocial needs of older people with dementia. It was a career that bore witness to care and support for people frequently defined by negative attitudes to risk. This experience shaped my beliefs and values about care and the importance of the dignity of risk[1] in the lives of the people I cared for.

My philosophy of care developed and was articulated through beliefs such as empowerment, relationship and meaningful communication. I was determined to learn and show *how* things could be done differently, and better. A systematic lack of understanding and compassion among staff members encountered within my facility raised urgencies such as training and support, and highlighted the importance of relationships and the reciprocal worth of older people. Upon reflection as a practitioner and a critical researcher, I recognise that risk is predominantly seen as a 'safety' issue as well as a philosophical and ethical challenge for practitioners and for people living with dementia. It is this challenge that must be managed—not the risk.

---

[1] The 'dignity of risk' is the principle of allowing a person the dignity of making choices regarding the taking of risk-—with subsequent enhancement of personal growth and quality of life.

People living with dementia 'know' what is needed to help them live productively and they understand how communities should be educated and adapted to let them remain included and engaged (Bruens, 2013). To this end, it is important that both the person and the disability remain a central part of social life (Bond, Corner, & Graham, 2004). Furthermore, people must be supported to shape the dignity of risk-taking in living with this chronic disability. In her first-hand personal memoir Morgan suggests "there is a life for us, if we risk it" (2009, p. 28).

1.8.   Philosophical approach to the study: situating phenomenology

Husserl (1859–1938) is considered the father of phenomenology and he broke with the positivist orientation of the science and philosophy of his day. The attraction of the phenomenological method was, for Husserl (1970) in its promise as a new science of being. Through this methodology, disclosure of a realm of being which presented itself with absolute certainty, arising from experience, seemed possible. Here experience is central to the endeavour and *how* experience appears to consciousness is the focus (van Manen, 2014). For a transcendental phenomenologist like Husserl, knowledge is therefore established in consciousness, and the priority is to describe that consciousness (Husserl, 1931a). Phenomenology, in this sense, was seen as a movement away from the Cartesian dualism of reality being something 'out there' or completely separate from the individual (Jones, 1975; Koch, 1995).

Husserl's original thinking provided the philosophical framework for the development of hermeneutic phenomenology. Phenomenology becomes hermeneutical when its method is taken to be interpretive (rather than purely descriptive as in Husserl's transcendental phenomenology). Heidegger (1889–1976) incorporated hermeneutics (as the art of understanding) into Husserl's school of thought and was fascinated by ontology, or *being.* He rejected the theory of knowledge known as epistemology, and adopted ontology—the science of being and this led to a conception of human existence as active participation in the world—of being there or *dasein.* Hermeneutics moved beyond the description of core concepts of the experience and sought meanings that are embedded in everyday occurrences (Lopez & Willis, 1994). Thus, the critical question for Heidegger was: *What is being?*

Heidegger believed that bracketing was not warranted because hermeneutics presumed prior understanding (Dahlberg, Drew, & Nystrom, 2008) and that it was impossible to negate our experiences related to the phenomenon under study. For Heidegger, personal awareness was intrinsic to phenomenological research. Heidegger rejected understanding *how* we know as humans, but accepted knowing as what it means to be. His philosophy makes it clear that the essence of human understanding is hermeneutic, that is, our understanding of the everyday world is derived from our interpretation of it.

The influence and reputation of Gadamer (1900–2002) in twentieth century hermeneutics was significant and for him hermeneutics was not a method for understanding but an attempt "to clarify the conditions in which understanding takes place" (1975, p. 263). Born in Germany, it was there that he was strongly influenced by the work of both Husserl and Heidegger and moved to extend Heidegger's work into practical application (Gadamer, 1976; Polkinghorne, 1983). Gadamer saw the work of hermeneutics not as developing a procedure of understanding, but to clarify further the conditions in which understanding itself takes place. This primary attention to context, underpinned the central theoretical role for dialogue and the role of the 'interview' (Hahn, 1997) are core elements that inform and provide structure for this study's method, data collection and analysis.

In agreement with Heidegger's view that language and understanding are inseparable structural aspects of human *being-in-the world,* Gadamer stated that "[l]anguage is the universal medium in which understanding occurs. Understanding occurs in interpreting" (1960/1998, p. 389). Gadamer viewed interpretation as a *fusion of horizons* where understanding happens when our present understanding or *horizon* is moved to a new understanding or *horizon* by an encounter. Thus the process of understanding is *a fusion of horizons.*

Speigelberg (1960) described the historical roots of phenomenology as a movement rather than a discrete period of time. This distinction is important as it reflects the view that phenomenology and hermeneutic phenomenology, and our understandings

of them, are not stationary, but rather dynamic and evolving, even today. The ideas and language presented herein, therefore, must to be viewed as changing and developing over time, not as static entities.

The scholarship and phenomenological research methods largely utilised in this thesis are that of van Manen (2014). Van Manen broke with the European thinkers as he was less interested in phenomenology as a philosophy, but rather as a unique way to understand human existence. Like those before him, he sought the *essence,* or the meaning of the lived experience (see section 3.5.2) (van Manen, 1990) and thus the aim of my study was to uncover[2] this *essence* of lived experience of risk for people with a recent diagnosis of dementia.

1.9. Understandings of dementia

The dominance of the biomedical paradigm has informed our cultural construction and understanding of the 'ageing' brain for the past several decades. Over a century ago, Alois Alzheimer first described the case of Auguste D., a patient who had profound memory loss, unfounded suspicions and other worsening psychological changes. In her brain at autopsy, he saw dramatic shrinkage and abnormal deposits in and around nerve cells. He was a pioneer in linking symptoms to microscopic brain changes and the neuropathology of this condition became known as Alzheimer's disease (Fox, 1986). Initially Alzheimer's disease was a term used largely to identify young onset dementia (George, Qualls, Camp, & Whitehouse, 2013), but by the latter half of the twentieth century it became a specific age-related, late-life disease affecting older people (Ballenger, 2006; George, Whitehouse, & Ballenger, 2011). This cognitive model conceived of dementia as a disorder of cognitive function, including memory, thinking and orientation, and persisted until the end of the twentieth century (Hughes, 2011). By the early twenty-first century further change to the construct of this disease demanded "an urgent and necessary renovation".

---

[2] For van Manen, a literal use of the word 'uncover' is the uncovering of something and is the process of how we come to understand phenomenological meaning. His method is not a step-wise set of procedures or techniques in arriving at phenomenological meaning. He adds that sometimes we stumble over meaning, other times (very often) it is a matter of being struck by a sudden insight. It reflects Speigelberg's (1960) idea that phenomenology is a movement whereby language such as the word 'uncover' is used within the relevant phenomenological literature as an accepted part of its lexicon and throughout the thesis (private email 24/6/2016).

People were living longer lives, a new cohort with 'early-onset' dementia had been identified (George, et al., 2013, p. 379) and dementia had emerged as a multifarious disease, socially constructed with social, economic, political and intellectual dimensions (George, et al., 2013, p. 379)**.**

1.9.1. *Defining dementia*

Alzheimer's disease is a form of dementia that specifically affects parts of the brain which control thought, memory and language. It is an acquired disorder of cognitive and behavioural impairment that markedly interferes with social and occupational functioning (Anderson, 2016). It is initially associated with memory impairment that progressively worsens and over time, ultimately impairs the ability to manage the basic activities of daily living. These changes in the brain can cause a range of behavioural issues, including wandering, challenging physical and verbal behaviour and hallucinations which can be distressing for the person living with this illness, their carers and families alike (Mace & Rubins, 2011; MacRae, 2008; Örulv, 2010; Pearce, Clare, & Pistrang, 2002).

Adding further to this multidimensional and complex syndrome, few generalisations can be made regarding the different types of dementia which are qualitatively distinct, but share some common features (J. Bradshaw, Saling, Hopwood, Anderson, & Brodtmann, 2004). For example, cognitive fluctuations are prevalent in both vascular dementia and Lewy body dementia and less so in Alzheimer's disease (Escandon, Al-Hammadi, & Galvin, 2010).

Providing care for people living with this condition demands an evaluation of needs— some of which will be social and not easily captured within the dominant medical model of care. This model views dementia as a disease and a pathological condition with rigid, fixed indicators of health and disease which are subject to diagnosis and therapeutic treatment (O'Shea, 2007). My study however views dementia as a socio-cultural illness where its symptoms and effects are shaped by social, political and economic beliefs together with values, assumptions and practices which surround illness. These elements determine how it is treated and understood and experienced by those diagnosed (Kleinman, 1988).

1.9.2. Dementia: the public discourse

The social construction of dementia has a high public awareness. The media talks of 'losing one's mind to dementia' and emotionally-charged metaphors such as a 'second childhood' (Prideaux, 2015) and 'never-ending funeral' (Beard, Knauss, & Moyer, 2009) shape and contribute to misunderstandings about dementia. This engenders fear and amplifies the negative impact of illness, further emphasising that dementia is still what many people fear the most as they age (George & Whitehouse, 2010; Sabat, 2010). This pervasive and negative construction points to the need for broader societal dialogue around the changing understanding of disease, and begs the question: *are our perceptions about dementia attributable to negative stereotypes, rather than the condition itself?* (Behuniak, 2011).

In her article entitled 'Essay on a Word' Sterin (2001) reveals the devastating impact that the word 'dementia' has had on her life since her diagnosis. It is negative "in the sense of implying something less than human; because demented really means mindless, or without a mind. And without a mind, one is not really fully human…in fact, not human at all" (2001, p. 7). Despite its controversial and transitional nature, dementia is used interchangeably with Alzheimer's disease in this study as it is the word the participants have themselves used to describe their experience of this illness.

1.9.3. Centring the person in research and practice

The overly negative medical construction of dementia (Bartlett, 2014; C. Clarke et al., 2010; MacRae, 2008) has been challenged on several fronts. Increasing public debate and advocacy has helped to refocus attention on the person and not the disability (Angus & Bowen, 2011; Brooker, 2007; Downs, 1997; Killick & Allan, 2001; Wilkinson, 2002). Furthermore, the experience of living *with* dementia has been increasingly recognised in research and practice (Bryden, 2005; MacRae, 2008; Mc Gowin, 1993; Mittler, 2011), whereby the importance of supporting people in living with, and managing the progression of, dementia is acknowledged (C. Clarke, 1999; Kitwood, 2013; Verbeek, van Rossum, Zwakhalen, Kempen, & Hamers, 2009). A psychosocial perspective in research and practice has harnessed this attention and repositioned people living with dementia as "surviving, continuing, viable selves that

can engage, and be engaged, even in the presences of considerable cognitive change and fragmentation" (Vittoria, 1998, p. 126).

The discrepancy between rhetoric and the reality for people living with dementia has important implications for the focus and goals of research. Of most benefit to those with a diagnosis is research which can be translated into clinical practice and whose focus reflects social needs and values (Kleinman, 1988). This study is ideally placed to fulfil both these important obligations.

Listening to the stories of people living with dementia privileges the lived experience; where frustrations and fears associated with a diagnosis, as well as preferences and needs, can be accurately articulated in the knowledge produced from one's own experience (Goldsmith, 1996; Steeman, Casterle, Godderis, & Grypdonck, 2006). These stories hold great value, as they may assist people in managing their disability and thus they become "active rational agents and not the passive victims of events" (Alaszewski, 2006, p. 44). Throughout this thesis, the situated knowledge from the socio-cultural lived world of the participants was at its core, providing insights and meaning into the lived experience of risk of people following a recent diagnosis of dementia.

1.10. Understandings of risk

Risk-taking is an important part of life because it is tied up with rights—the right to take a risk or the right to say no. The concept of risk in this study is used as an exemplar of autonomy and rights—to independent action. Risk serves as the lens through which issues of autonomy in a person recently diagnosed with dementia can be understood. We therefore express our autonomy through the principle or dignity of risk (Perske, 1972). For example, Dewing (2002) suggests that upon receipt of a diagnosis of dementia, independent decision-making is threatened and subject to measures of competency and capacity by others. This is often related to the concerns of professionals for safety, protection and issues of public liability (Morris, 2004).

1.10.1.   Risk: a social construct

A social constructionist view of risk was utilised in this study, as it assesses risk in a wider context where it is considered "a subjective, experiential, dynamic and changing aspect of everyday life" (Bailey, et al., 2013, p. 397). This concept of risk concerns not just the individual but also their wider contexts, where personal and societal perceptions of risk may vary—or even be in conflict due to different values and opinions. Upholding these extraneous values may be ultimately more important for the decision than any risk that may impact on that decision (Ale, 2009).

Beck's risk society (1992) is set amid values in an increasingly uncertain world where minimising risk is a pervasive and major concern. Giddens (1999) challenges the notion of a world which has become more hazardous, and views it as a society increasingly preoccupied with the future (and also with safety), which in turn generates the notion of risk. These are Beck's "man-made uncertainties" (2009, p. viii) especially created by science and technology, which in turn create as many uncertainties as they dispel (1999, p. 4). According to Giddens (1999) in a global world we often don't really know what the risks are—let alone how to calculate or manage them. What we do know however, is that they manufacture uncertainty which intrudes directly into personal and social life as well as collective settings.

This structural positioning of 'manufactured' risk directly impacts on people living with dementia. It assumes they are a homogenous group, rather than a diverse group of men and women living with various transitional stages of this longitudinal and chronic illness. The 'riskiness' of risk as Beck implies (1992), demeans and disables those coming to terms with a diagnosis of dementia. These structural influences can put a person's fundamental rights in question, particularly if their choice and decision making is withheld or withdrawn. There is a high cost associated in withholding choice, as personal dignity is partially manifested by the ability to remain autonomous—and being autonomous engenders risk-taking (Perske, 1972)—the right to act independently, to take a risk or not (Beauchamp & Childress, 1994). The inhibiting effect of withholding choice and decision-making erodes dignity. In a personal account, Morgan (2009, p. 27) describes the moment of diagnosis "where a person is at risk, from themselves, the system and society".

1.10.2. The embodiment of risk: a contemporary construct

From a more contemporary view, the concept of risk represents a new way of viewing the world— "its manifestations, its contingencies and uncertainties" (Lupton, 1999, p. 6). This concept also includes the idea of 'good' and 'bad' risk. Essentially, risk has a notoriously negative connotation, due to its conceptualisation as the chance of avoiding an unwanted outcome. But it can also be seen in a positive light which is more than the taking of bold initiatives. Titterton reminds us that "risk-taking is shared activity" (2005, p. 124); about making joint risk decisions and not leaving things to chance (S. Morgan & Williamson, 2014). This concept of 'good' risk was developed in adult mental health services in the late twentieth century to assess and manage risks with people who largely felt that health and social care services were irrelevant to their needs (S. Morgan, 1996). While this seemingly oppositional and dualistic nature of risk is acknowledged in the literature (Alaszewski & Coxon, 2009; Manthorpe, 2004), I agree with Wynne-Harley when he argues that "reasonable, informed and calculated risk taking…demonstrates an individual's right to self-determination and autonomy" (1991, p. 19). A key question for this study was: *Who owns the risk* [for a person with dementia] *and who is responsible for its management?* (C. Clarke, Wilkinson, Keady, & Gibb, 2011, p. 63).

1.10.3. Constructs of 'dementia' and 'risk': can they co-exist?

This brief overview demonstrates that the concepts of dementia and risk are multidimensional and ever-changing. Of specific interest to this study, was the relationship between a fluctuating yet progressive and varied set of indicators associated with dementia; a heterogeneous group of people living with a long and fluctuating chronic illness; and risk. The concept of risk is used extensively in dementia research and practice when examining *choice* and *decision-making*, and is primarily a negative phenomenon associated with hazard and danger (Alaszewski, et al., 1998; Bailey, et al., 2013; C. Clarke, 2009; Lupton, 1993; Manthorpe, 2007). Vulnerable groups in society have reported being *so protected* from risk that the protection itself paradoxically can become a source of harm (Manthorpe, 2004). Again Beck's notion of the 'riskiness of risk' (2009) fits well with Manthorpe's observations that support for people traditionally involves *aversion* to risk because of the concern for safety, protection and liability (Morris, 2004). This risk averse support

comes at a cost however, as it infringes upon the autonomy of people living with dementia (Nay, 2002).

1.10.4.   The reconciliation of social constructionism and hermeneutics

Social constructionism is a world view which can be traced back to existential-phenomenological psychology, social history, hermeneutics and social psychology (Holstein & Miller 1993, Watzlawick 1984). Social constructionism and hermeneutics co-exist within historical and sociocultural dimensions, as we do not construct our knowledge and interpretations in isolation. It demonstrates that knowledge is not passive, neutral or apolitical but rather contextual, embodied aspects of human experience (van Manen, 2007). Furthermore, social constructionism investigates the role that social influences play in knowledge and our understandings of reality. It shares the hermeneutical view that the experience of the lifeworld is the final measure and ground for understanding all aspects of being-in-the-world.

Based on the literature, a diagnosis of dementia exemplifies the context and the embodiment of human experience that embraces social constructionism and hermeneutic phenomenology. For the social construction of dementia shapes and contributes to negative conflation of risk (as discussed above- see section 2.1.3). From this contingent, multi-faceted place, Heidegger immerses and situates us in an ontological way in the *historicity* of the world, from where we construct our *own* understandings and uncover *our* meanings of being-in-the-world. These meanings are based on the lived experience for a person with dementia which may also be based on positive aspects of risk built up over a lifetime. While sharing an inter-subjective focus, hermeneutics can be seen as interpretive and based on *individual* meanings of the lived experience for a person, rather than societal perceptions or dominant world-views of the disease.

1.11. Positioning this thesis in context

This study's importance lies in the moral imperative to uphold the right to exercise choice and make one's own decisions whenever possible while living with dementia. Where appropriate the dignity of risk may entail interdependent decision-making between the person living with dementia and others involved in the care of that

person. This provides the person with dementia a sense of control in what may be an uncontrollable life situation.

Risk remains a value-laden concept; contentious and unattainable for most people with a diagnosis of dementia (Testad & Aarsland, 2010). This is evidenced in the World Health Organisation's report (World Health Organisation, 2016) which states that for people living with dementia and their family caregivers, their rights are often overlooked or even deliberately trampled. This results in feelings of defeat and devaluation and questions the value and saliency of policies and legislation based on the Universal Declaration of Human Rights and other international human rights instruments (World Health Organisation, 2016).

Contemporary positioning of risk in relation to dementia as a form of disability is taking place within the context of major cultural shifts in understanding the importance of enhancing the life choices of people living with dementia. For example, choice and control underpin the new paradigm of consumer directed care (CDC) which is a major cultural shift in how services are being delivered to people (H. Walker & Paliadelis, 2016). Greater consumer choice and decision- making, alongside flexible services are enlightened concepts within care provision. Kelly cautions however that CDC is "the brave new world of consumer empowerment" where care needs to be balanced with consumer choice and the management of risk. With many interests involved in the delivery of care, he reflects that this will be "an interesting journey ahead in terms of where the risk may lie (J. Kelly, 2016, p. 14).

Kodner suggests there are risks involved for those who don't have the capacity or the inclination to manage his or her own care (2003). Of further concern is that the philosophy of *care* and *caring* is considered incompatible with the "consumer centric objectives" of CDC (Gill & Cameron, 2015, p. 454).

In summary, risk is at once an everyday experience for everyone, a supposition in this study and in the coming chapters it emerges from the stories told by the participants. In a world already full of meaning, hermeneutic phenomenology shifts the focus from phenomenology's description of experience to that of meaning and

aims to bring to light and reflect upon the lived meaning of this basic experience. In its search for the lived experience of risk and its meanings for the participants, this study embraces the aims of hermeneutic phenomenology.

This introductory chapter began the journey of unravelling the complexity of living with dementia in a contested, contingent and constructed space where social and cultural ideas about risk offer challenges and opportunities to those with a diagnosis. It sets the stage to link hermeneutic phenomenology and other ways of thinking such as social constructionism to explore the ways in which that world impacts on the lifeworld of the participants in this study who are living with dementia. It is this lifeworld in which the core hermeneutic question of this thesis was set: *What is the lived experience of risk for a person with a recent diagnosis of dementia (Alzheimer's type)?*

1.12. Structure of the study

This study comprises eight chapters. In this introductory chapter, the core concepts of dementia and risk are introduced and explored as background and context for this study. These core concepts inform the essence of the research question. The study's aim, its design and underlying philosophy and key thinkers are introduced and the fit with the research question is demonstrated. My aim in the following chapters is to introduce and explicate the significant elements of this study as the research question is explored.

Chapter two reviews the literature surrounding the concepts of dementia and risk. It will highlight the fluid and manifold forms of understanding surrounding these two core concepts. Gaps in the existing knowledge of risk and dementia over time are identified and within that context, the research question is carefully positioned.

Chapter three locates hermeneutic phenomenology and its philosophical underpinnings. It introduces key thinkers who have contributed their ideas and concepts to the study and provided a platform from which the task of phenomenological method is constructed.

The phenomenological research method of van Manen is discussed in chapter four. This chapter also outlines the 'nuts and bolts' of the study's research design. Underpinned by the philosophical theory in chapter three, this chapter sets the stage for meeting the participants and engaging with them phenomenologically.

In chapter five, the personal stories of the participants are presented. The events, the people, culture and context of the stories will form their 'historicity' which provides a better understanding of their present and future transitional preferences and forward planning given their diagnosis of dementia.

Chapter six is presented in two parts. Part A is the methodological approach to the analysis of the study—the 'how' of the analysis. Part B demonstrates the 'what' of the analysis, introducing and analysing primary themes, associated minor themes and the units of meaning.

Chapter seven is a reflection on the analysis of the study. It introduces the study's findings within the context of the two primary themes and discusses their implications—for the participants, for those who care alongside them and for us as a society.

My closing chapter revisits the aims of the study within its summary. The implications for 'action' are set out and explicated, offering new and improved possibilities for people living with dementia and their carers.

CHAPTER 2

LITERATURE REVIEW

The time will come when diligent research over long periods will bring to light things which now lie hidden. A single lifetime, even though entirely devoted to the sky, would not be enough for the investigation of so vast a subject. And so this knowledge will be unfolded only through long successive ages. There will come a time when our descendants will be amazed that we did not know things that are so plain to them... Many discoveries are reserved for ages still to come, when memory of us will have been effaced.

(Seneca: *Natural questions*)

My background, deeply immersed in supporting the personhood of people living with dementia drives my questioning of the literature to begin to address my experiential concerns. The concept of risk both for the carer and the person living with a long, protracted and terminal illness raised some deeply concerning and ethical questions related to autonomy, choice and independence. There was a dearth of research to address this contentious issue which demanded a return to the question: *What is the lived experience of risk for a person with a recent diagnosis of dementia?* I agree with Ashworth (2006, p. 213) that "it seems a simple matter … to attend to the experience as it is given to consciousness" and yet, the positioning of a literature review within a phenomenological thesis is a debatable philosophical issue, further clouded by the institutional expectations and processes of a doctoral candidature. Heidegger provided guidance when he purported that conscious experience has an intentional character built on "a set of assumptions about our world ... on the basis of this intentionality the subject already stands in relation to things that it itself is not" (1982, p. 155).

This literature review brings to the fore and exposes this intentionality by considering the concepts that may underpin the research question. It will explore prior research and current thinking and demonstrate a 'gap 'in the knowledge in longitudinal research regarding people with dementia which provided the impetus and inspiration for this study.

2.1. Dementia: perspectives, constructs and manifestations

2.1.1. Dementia: a brief history

In approximately 400 BC Plato described an illness that gave rise to all manner of forgetfulness as well as stupidity in old age (Karenberg & Förstl, 2006). His work and that of Pythagoras, Hippocrates, and Aristotle described age-related cognitive decline. Moving forward in time, Cicero in De Senectute (44 BC) declared that ageing was *not* necessarily accompanied by significant mental changes. The nexus between ageing and dementia remains a common misconception across time whereby cognitive deterioration remains linked to the inevitable consequence of ageing (Hartshorne & Germine, 2015; Hughes, 2011). That is to say, age and cognitive decline as descriptors remain constant; yet the 'meaning' of each word has changed dramatically over time, as have the practices associated with each.

In the Middle Ages, there was a dearth of interest in dementia, as the Church became the centre of learning, and disease was a punishment for sin (Berchtold & Cotman, 1998). The founder of modern psychiatry, Pinel (1745–1826), was one of the first to provide clinical analyses of dementia and a systematic terminology followed which was the foundation of the modern classification of mental diseases (Boller & Forbes, 1998). This included specific refinements to the categories of dementia, one of which was making the fundamental distinction between *dementia:* 'the loss of mental faculties as a consequence of a disease', and *amentia:* 'a condition in which the intellectual faculties have never developed sufficiently in order to acquire knowledge' (R. Hunter & Macalpine, 1982, p. 732).

During the nineteenth century a more humanitarian approach to mental illness saw the closure of asylums, and clinical settings made possible widespread clinical and pathological observations of mental disorders (Berchtold & Cotman, 1998). In 1906, the German neuropathologist, Alois Alzheimer set new standards for understanding neurodegenerative diseases describing a characteristic set of clinical and neuropathological findings that represented the beginnings of the disease that would carry his name—Alzheimer's. His original report as discussed in Chapter one, was important because it contained both the psychological description of mental deterioration and the pathological description of the patient's brain. This was

embraced by Gruenthal (1927) and Rothschild (1937) who described the condition more than eighty years ago as a long process of pathological and psychological elements. This marked the beginning of a ground-breaking research effort into understanding dementia that continues today.

2.1.2. Dementia: a critique of its biomedical construction

How dementia has been defined historically over time—whether as an illness, a mental disorder or a disease associated with ageing—has implications for its management. Its dominant construction is as a biomedical disease—progressive, pathologically degenerative and terminal (D. Davis, 2004). More than a century has passed, and as Whitehouse (2007, p. 460) remarks, Alzheimer's disease remains "a bellwether condition juxtaposed between the hopes of science and the fears of social and environmental injustice". According to D. Davis, "the singularity of medicine's epistemological perspective" regarding a condition such as dementia is both pervasive and multifarious (2004, p. 369). For example, Harding and Palfrey (1997) highlight that a biomedical model denies the lack of consensus on the causes of dementia. From this perspective, dementia is seen to be objectively managed in a quest for certainty (Penrod et al., 2007). This belies the immense variability in both its presentation and its implications for people with a diagnosis (Cotrell & Schultz, 1993), and highlights a gap in the reality and the knowledge about people with dementia and their lived expereince of risk. Both Lyman (2000) and Robertson (1991) caution that harm may result from the bio-medicalisation of such diverse symptomatology, where biomedical notions of a single disease entity reduces the complexity of neurological diseases such as Alzheimer's (Gubrium, 1986).

To this end, Halfon, Larson, Lu, Tullis, and Russ (2014) assert that a biomedical paradigm is outmoded and overly simplified, and does not account for the wide range of factors which influence health. Deacon concurs, stating that this dominant model of disease "leaves no room within its framework for the social, psychological, and behavioural dimensions of illness" (2013, p. 847). For people living with dementia, a diagnosis carries with it psychosocial and physical costs which constitute a disjuncture—a "turning point[s], a "tipping point[s]" (Hendricks, 2008, p. 111) from the continuity of life's daily trajectory, towards an adjustment to the various discontinuities and unknowns of living with this chronic and disabling illness.

2.1.3. Dementia: a multi-dimensional and contingent view

In a significant shift from this prescriptive and singular epistemological perspective or what Powell and Hendricks refer to as a "bio-medical thrall" (2009, p. 84), an understanding of dementia has emerged which incorporates both its clinical implications and associated psycho-social changes and personal capacities. This social constructionist perspective of dementia provides a counterpoint to a biomedical thrall and manifests in a variety of ways which are multidimensional and ever-changing—not all of which are dependent on its pathophysiology (Albert & Mildorf, 1989; D. Davis, 2004; Manthorpe, 2003; McCormack, 2002).This position is endorsed by the European National Guidelines (National Institute for Health and Clinical Excellence & Social Care Institute for Excellence, 2007) which highlight the two perspectives of dementia—the medical and the social—"which are often not mutually exclusive. As a sociological phenomenon, the forces of medical, social and philosophical constructions also shape its perception (D. Davis, 2004). The ground breaking Nun Study based on the work of David Snowden supports this construction and has revealed that factors in the social environment may ameliorate the presentation of symptoms of dementia (Snowdon, 2001). These findings offer possibilities for understanding the lived experience of risk while having a diagnosis, and how this is manifest for the person diagnosed. This 'gap' in the existing literature surrounding dementia and risk and its understandings are the focus of this study.

The dynamic social constructionist perspective that privileges the multi-dimensional nature of dementia shapes the meaning and experience of this illness, which are deeply embedded in cultural and social contexts (Kleinman, 1988; Pierret, 2003). For example, age, mental and physical health and gender may all intersect with dementia and create additional discrimination within "socially constructed marginalized positions" (Innes, 2009, p. 38). There is a plethora of research which supports the view that an illness such as dementia is deeply embedded with negative cultural meanings reflected in the stereotypical bounds of an 'anti-ageing' society (Sanders, Donovan, & Pieppe, 2002; Langdon, Eagle, & Warner, 2007). While Rodeheaver and Datan (1988) suggest that older women face a 'double jeopardy' of being vulnerable to both sexist and ageist attitudes; those living with a diagnosis of dementia face

what could be referred to as a 'triple jeopardy' deeply embedded in these societal assumptions and attitudes.

How society responds to people with dementia is thus shaped, and in turn shapes, the subjective experience of those living with a diagnosis. In a society where stigma, social isolation and personal discrimination are outcomes of a diagnosis (Dartington, 2010; Kitwood, 1990; Sabat & Harre, 1994; Wilkinson, 2002) this scenario excludes people living with dementia of their "moral standing" (Post, 1998, p. 72) and robs them of their equal status as citizens in our communities. In her personal memoir, McGowin speaks of the contradiction between her own feelings of self-worth and the depletion of her cultural values as a person with Alzheimer's disease: "If I am no longer a woman, why do I still feel I'm one? My every molecule seems to scream out that I do, indeed exist, and that existence must be valued by someone!" (1993, p. 114). This illness is on a spectrum and each person is a singular, unique individual with their personal, unfolding story—no one prognosis, or story, fits all.

Harding and Palfrey contest the dominance of one model of dementia over another (1997). Whatever model is adopted affects both the experience of having dementia and how we support people living with a diagnosis and their families (Downs, Clare, & Mackenzie, 2006). The diverse and complex nature of the condition can be seen where no two people are likely to be affected in precisely the same way and a person may have multiple symptoms of the disease including other complex psychosocial pathology (O'Shea, 2007). Hughes (2011) reflects this position as he highlights that the standard 'medical' model nowadays is probably biopsychosocial, where elements of biomedicine and humanistic models of care combine to form a suitable framework for scientific study which begins with the primary source of information—the person living with this chronic and pervasive illness.

This study supports a biopsychosocial model of illness where holistic perspectives elucidate the variability of experience for people living with a progressive chronic illness such as dementia. Furthermore, this model provides the opportunity to study the construct of risk with all its impediments and its supports which have been under researched and over looked. This study aims was to explore the knowledge gap

between the *perceived* reality of living with dementia and risk and its *actual* lived experience.

2.1.4. Personhood: a legacy of Kitwood

Carl Rogers (1961) was the leading figure in the development of phenomenological, (or client-centred) therapy which focused primarily on a person's subjective experience (opinions, viewpoints, and understandings).Therapy was defined on the basis of the importance of good human-to-human relationship and phenomenological theory emphasized all aspects of human experience. Over time, Rogers' relational approach was replaced with a "well-intentioned but often paternalistic approach" (Dupuis, Gillies, Carson, & Whyte, 2012, p. 430) where input from the client was seldom sought. Person-centred theory continued to evolve and it was Tom Kitwood and the Bradford Dementia Group who propelled a paradigmatic shift in understanding dementia which followed (Kitwood, 1995, 1997b; Kitwood & Bredin, 1992a, 1992b). Kitwood (1997b) first introduced a new culture of dementia care that challenged the deterministic and causal relationship between neuropathology and aetiology, and this dislodged the powerful connection between the biomedical model and care practices (Behuniak, 2010). Kitwood (1993) heralded this paradigmatic shift for new understandings about dementia and its presentation when he announced that 'the problem' of dementia does not lie exclusively within the person diagnosed, but rather in the interpersonal, or social-psychological milieu in which it exists. This focus was on the *process* of dementia rather than the state of *having* dementia, and the person living *with* dementia was placed centrally within this oeuvre, providing a theoretical basis for delivering person-centred care (Dewing, 2008; Kitwood, 1990, 1997b, 2013). Dewing reminds us that Kitwood's ultimate purpose was of moral concern for "others" (2008, p. 11); and despite his untimely death in 1998, his concepts of personhood, malignant social psychology and person-centred care continue to evolve, forming the basis of excellence in the practice of care in relation to those living with dementia (Brooker, 2007; Dewing, 2008; McCormack, Karlsson, & Dewing, 2010).

2.1.5. Person-centred care: a relational approach

The term person-centredness is used freely within contemporary health and social care (McCormack, Dewing, & McCance, 2011) and concepts such as person-centred care signify a move to personalised care. Central to personalised care, the word 'person' resonates with those attributes that represent our humanness (McCormack, et al., 2011). This is supported by Little, who reminds us with profound simplicity that ultimately "personhood is linked to being human" (2014, p. 39).

Personhood then, is an innate attribute of *every* human being and is not reliant on cognition, memory and the ability to converse (Crandall, White, Schuldheis, & Talerico, 2007). Kitwood and Bredin define it as a socially based understanding of "the human being in relation to others" (1992b, p. 275) where it exists in the intersubjectivity of people together. McCormack and McCance make the point that intersubjectivity refers to "all those involved in a caring interaction and therefore encompasses patients, clients, families/carers, nursing colleagues, and other members of the multidisciplinary team" (2010, p. 4). This view is supported by C. Clarke and Keady (2002) who state that a person can only fully be understood by 'situating' him/her within a rich matrix of relationships and socio-cultural beliefs.

Maintaining personhood therefore is a collaborative and embodied relationship of care (Hydén, 2013b; Kontos, 2005; Mathews, 2006; Phinney & Chesla, 2003) where nurturing this new way of relatedness is critical at a time when capacities for communication are diminished, resulting in detachment and isolation. Importantly, within this relatedness to others, personhood flourishes when care is supportive and the basic human needs for attachment, comfort, occupation, inclusion and identity are met (Penrod, et al., 2007). Those living with a diagnosis remain active agents who maintain a sense of self by what they themselves say and do (Munhall, 1993).

Personhood is antithetical to what Kitwood and Benson referred to as 'malignant social pathology' (1997a), where nihilistic attitudes result in common care issues such as "infantilism, disempowerment and labelling" (Penrod, et al., 2007, p. 64) and where persons with dementia are constructed as 'a problem' that caregivers have to deal with. This was demonstrated in Ashworth's remarks on a previous study by A. Ashworth (1990) where individualised 'total' care was misconstrued by staff as

having to do 'three baths'. Today, debate about essentialist understandings and assumptions which surround the homogeneity of the delivery of deterministic task-oriented care practices (T. Adams, 1996, 2005; Baldwin & Capstick, 2007; Brooker, 2007; O'Connor & Purves, 2009) has ensued a move away from focussing on task-orientated care to that of interactions among those involved in care delivery (Nolan, Davies, Brown, Keady, & Nolan, 2004).

Attitudes determine the quality of our responses to others' personhood and how it is supported through our actions is the essence of person-centred care (Kitwood, 1997b). Kitwood's abiding message is that while personhood may be challenged in dementia, it is critical to maintain a "genuine living dialogue" (Malloy & Hadjistavropoulos, 2004, p. 155) with people living with a diagnosis even—in the most advanced stages of the disease. This connectivity "offsets degeneration and fragmentation" for those diagnosed (Kitwood & Bredin, 1992b), enhances the personhood of the caregiver (Penrod, et al., 2007) as well as eliciting important learning for health and social care professionals (Benbow & Kingston, 2016). My study embraces the centrality of personhood within a phenomenological philosophical framework which views the lifeworld from the world of those living with dementia.

2.1.6. Models of person-centred practice

This paradigmatic shift in person-centred care is recognised as a multidimensional concept, and its complexity is part of the challenge to articulate its meanings and describe its application to practice (McCormack, et al., 2011). Among the care models based on the positive social psychology of Kitwood (1997b), the Bradford Dementia Group has developed Dementia Care Mapping (DCM), centred on the social–psychological theory of dementia care (Kitwood & Bredin, 1992a). Here 'personhood' is central and people are given respect and status by others, regardless of any disability (Kitwood, 1997b, 1998). DCM is an observational tool that can support the introduction of person-centred care into a variety of settings and is designed to evaluate the quality of care and well-being of people with dementia within those care settings (Kitwood & Bredin, 1992a). It encourages care staff to think about how the person diagnosed is experiencing the care provided and its setting. DCM has also been shown to raise care staff awareness sufficiently to bring

about improvements in care (Page, Davies-Abbott, & Phillips, 2016). Introduced in 1992, this care model has grown in popularity throughout the U.K. and has gained recognition at an international level (Innes, Capstick, & Surr, 2000). More recently, the Person-Centred Nursing Framework is another model which has been established as a tool to overcome the gap between the theory and the reality of person-centred care (McCormack, et al., 2011). It has contributed to a deeper understanding about what person-centred care is, the organizational characteristics needed to support it, and ways to help organizations achieve and sustain it. The legacy of Kitwood continues with models of care that refine his theory and utilise it in everyday work practices.

Developing change in practices is not a one-time event, however, nor is it a one-person job. Instead it requires a sustained commitment from a whole team. The real challenge for organisations is the movement from individual, 'person-centred moments' to embedded 'person-centred cultures' (McCormack, et al., 2011). A valuable contribution to establishing such a culture is the telling of stories. Learning about a person's life is one of the significant ways in which those living with dementia map who they are. Stories constitute the core of this thesis and personhood plays a central role in all its aspects in privileging participants and the embodiment of voice in research and practice (Angus & Bowen-Osborne, 2014; Angus & Bowen, 2011; Beard, et al., 2009; Benbow & Kingston, 2016; Pipon-Young, Lee, Jones, & Guss, 2012). People living with dementia are increasingly acknowledged as tellers of their own story (R. Davis, 1989; Mittler, 2011; Sterin, 2001) which shapes and gives meaning to the clinical presentation of the disease. The authors can articulate their feelings, views and decision-making abilities for themselves (Bell & Troxel, 1994; Goldsmith, 1996; Keady, 1996), and their stories have assisted in the realignment and prioritisation of the needs of the individual person. Some of these needs will be social in character (O'Shea, 2007) and others such as independence and autonomy carry significant ethical implications for their maintenance. These non-disease-related needs are critical to a person's well-being (Hydén & Antelius, 2011; Milte et al., 2016) and central to person-centred care.

2.1.7. Personhood: A relational form of autonomy

While this care concept continues to evolve, my study relates closely to the definition of Nay, Bird, and Edvardsson which states "the need for a recognition of, and connection with, the person, a focus on the person's strengths and goals, and interdisciplinary approach, and recognition of the centrality of relationships" (2009, p. 109). These values of self-determination, respect and understanding are bound up in the philosophical principle of autonomy. The traditional liberal theory of autonomy is a Western cultural value which places emphasis on self-determination, liberty of choice, and freedom from interference by others (Perkins, Ball, & Whittington, 2012). Within my study autonomy is an important principle as its meaning is bound up with the ability to exercise choice and decision-making, and the taking (or not) of risk. Autonomy refers to personal autonomy, decisional autonomy and the agency that renders individual people capable of exercising choice and independent decision-making (Sneddon, 2013). Post (1995) cautions that autonomy is not a stand-alone principle, and we need to ask the question: *autonomy to do with what?* McCormack (2001) concurs, believing that there is a need to replace an individualistic view of autonomy with one based on 'interconnectedness and partnership' that recognizes the uniqueness of each individual, but also the interdependence that shapes our lives—for people diagnosed and those in his/her social world (O'Connor et al., 2007).

Within dementia practices, capacity and consent remain contested topics, and are evolving within changing expectations for people living with a diagnosis. The driving force that underpins the development of patient-centred care is the moral and ethical rights of individuals as people (McCormack, 2001). In line with this, McCormack, Dewing, and McCance (2011) have developed a theory of autonomy which is based on Heidegger's theory of 'authentic consciousness' (1962). This theory represents a value-based understanding whereby the person's values are held central to all decision making. This was upheld in this study as it aimed to interpret how risk appeared in the lived experience of the participants and to understand what risk meant for a person living with dementia according to those values.

The theory of autonomy that prevails in mainstream ethics today is based on the principle that people are mentally competent unless proven otherwise. When an older person has dementia, the notion of an autonomous decision-maker may not be a

realistic one as they may be reliant on others for care and support. When the person lives at home, families talk of an "autonomy management process" (Berry, Apesoa-Varano, & Gomez, 2015, p. 110) where they attempt to balance their concerns for reducing risk, while permitting forms of autonomy to promote wellbeing. Within institutional care, however an individual's concept of autonomy may not be realistic, or even acknowledged (H. Walker & Paliadelis, 2016).

As noted above, increasingly there has been a call for a relational conception of autonomy that acknowledges issues of dependency, interdependence and care relationships within factors that exist at multiple levels of social structure. Issues such as these determine people's ability to maintain a sense of autonomy in, an often socially challenging care environment. Social and institutional change is ongoing, as well as the multiple and ever-changing cultural contexts within which people are embedded, and these are important factors that shape experiences of being autonomous over time (Perkins, et al., 2012).

This conception of autonomy is supportive of the 'relatedness' of personhood (Kitwood, 2013), where autonomy may be seen as interdependent and relational; rather than a stand-alone concept which has little relevance to a person with a progressive illness. This move towards partnership and relational care re-positions person-centred care and autonomy within a humanist caring philosophy with principles of attachment and responsibility. This understanding is dynamic and realigns the positioning of that person, creating space for social citizenship to be seen and understood, and even actioned (Bartlett & O'Connor, 2010).

This thesis built on an understanding of relational autonomy that privileges interdependence and personhood and was demonstrated in the philosophy, research method and in the performance of all aspects of the research design and process.

2.1.8. Personhood and the role of citizenship

Citizenship is inherently a political term which draws attention to how the experiences of people with a diagnosis are shaped by socio-cultural practices and assumptions (O'Connor & Nedlund, 2016). Recently citizenship is conceptualised more as a social practice than a focus on legal rights and civic responsibilities (Prior, Stewart, &

Walsh, 1995).These civic practices are seen in action through organisations such as The Alzheimer Society of Ireland (O'Shea, 2007) which develops and maintains key government and political relationships involved in grassroots stakeholder engagement and campaigning. This 'citizenship in action' highlights the fight that people with dementia face to achieve rights and citizenship based on social justice principles (S. Wilson, Carryer, & Brannelly, 2016).

Citizenship is also central to community awareness programs that inform and involve others in dementia-friendly communities and villages, enhancing the citizenship of people living with a diagnosis (Alzheimers.net, 2013). At this civic level, person-centred care involves individual, organisational, communal and societal values and has a shared meaning-making system and identity (Hulko & Stern, 2009). This is consistent with how personhood is defined, the foundation of which is about the rights of citizenship (Bartlett & O'Connor, 2010). Whilst these voices of citizenship remain embryonic, the collective rallying cry is a worthy aspiration whereby the personal is (becoming) political.

This focus on citizenship broadens Kitwood's (1997) concept of personhood, which "recognizes the person with dementia as an active agent with rights, history, and competencies" (Bartlett & O'Connor, 2010, p. 39). Brannelly (2011) explains that for people with a diagnosis, coping with change and adaptation requires an emergent social identity—one which is reliant on the facilitation of, and the sustenance of citizenship through opportunity and relatedness. Looking at dementia through the lens of citizenship and human rights widens the scope of contemporary dementia care nursing (F. Kelly & Innes, 2013) by demanding that what is heard is acted upon (Bartlett & O'Connor, 2007).

Bartlett and O'Connor (2014) view personhood as essentially an apolitical concept concerned only with psychosocial issues which they consider may be too limiting. Their citizenship perspective (2007, 2010) was developed in response to the 'narrow' perspective of personhood which overlooked the inherent power within relationships and positioned the person diagnosed as dependent and non-agential (Österholm & Hydén, 2016). In their study Österholm and Hydén (2016) have also used the concept as 'citizenship as practice' to describe the agency of people diagnosed, how

they act throughout institutional talk, and voice their own concerns and wishes about supportive services.

This thesis builds on these principles to provide the foundation for understanding risk as a component of being-in-the-world for a person living with dementia and to bridge the existing knowledge gap which surrounds dementia and risk.

2.2.   Risk: perspectives, constructs and manifestations

The phenomenon of 'risk' has a long and complex history that can be traced back through time. The derivation of the word 'risk' comes from the Greek word *rhiza* for cliff and refers to hazard when sailing along a rocky coast (Norman, 1988). Today, definitions of risk reflect this dangerous exposure where risk is often associated with hazard and danger (Manthorpe, Walsh, Alaszewski, & Harrison, 1997), or in terms of an "unintended or unexpected outcome of a decision or course of action" (Wharton, 1992, p. 2). Risk remains a word "that simply means danger" (Douglas, 1992, p. 24). These definitions of risk however provide limited understanding of the contemporary debate in what Beck refers to as a "risk society" (1992) or what Burzyński & Burzyński, (2014, p. 34) refer to as the "grand transition" from the pre-modern towards industrial modernity, and more recently the highly complex social systems reflective of post-modernity.

The growing social awareness of risk during this grand transition has disturbed the traditional social systems which guaranteed ontological security and trust systems built on traditional values and beliefs, family structures and roles, and 'normal' developmental biographies (Burzyński & Burzyński, 2014). Durkheim's concept of 'anomie' or moral chaos, describes this social upheaval where societal values of stability, welfare and progress have been replaced by unpredictability and risk (1951). Human costs associated with this social upheaval can be seen in terms of threats to human agency and dignity (Burzyński & Burzyński, 2014). Scientific progress and rationalisation driven by the modern need for change have proved to be counter-productive, resulting in societal destabilisation and what became known as the "juggernaut of modernity" (Giddens, 1990, p. 139). This preoccupation with danger and risk is referred to by Giddens as a "phenomenology of modernity" (1990, p. 140) where uncertainty goes beyond the explanatory powers of science. Beck's

'risk society' (1992) emerged to describe the 'risk climate' as typical of developed societies where global and historical dynamisms shaped by socio-political forces impact the lifeworld of its members.

Alongside postmodernity, specialised fields such as science, medicine, law and the social sciences have intensified the nature of risk and its effects upon ordinary people's lives (Tulloch & Lupton, 2003). Burzyński and Burzyński contend that within scientific expertise the notion of risk has become an "indispensable element of insurance planning and other management strategies undertaken at individual and collective levels" (2014, p. 3). It is no longer a neutral term, with various interests 'high jacking' risk for their own particular discourse. In technical discussions, risk is considered a negative, and in calculations of costs and benefits, risk is usually considered in terms of cost (Teuber, 1990).

The nature of risk then becomes embedded in societal perceptions of risk and thus risk continues to be a dynamic construct of society. Society then regulates *what* risk means and *what* social and cultural determinants are taken into account in the decision-making process about the pros and cons of risk (Lupton, 1999). Within a wide range of political and economic determinants, decisions are made regarding what is acceptable public risk (Slovic, Fischhoff, & Lichtenstein, 2000).This form of risk decision-making is constantly contested and subject to disputes and debates over its nature, control and who is to blame for such creation (Tulloch & Lupton, 2003).This person-environment interplay reflects power differentials within society where "service provision is configured by the particular economic, social and political geographies of each location" (Blackstock, 2006, p. 163). For example, this person-centred environmental interplay between people living with dementia and the delivery of services requires a resource-intensive lens to meet the needs of both the person and the provider (Bailey, et al., 2013). Promoting services that maximise safety and security for carers and people diagnosed needs to be subject to rigorous questioning of options on behalf of the person with dementia with reference to levels of risk-versus-benefit strategies (Olsson, Engström, Skovdahl, & Lampic, 2012; Welsh, Hassiotis, O'Mahoney, & Deahl, 2003). In his study on the implications of surveillance measures for people living with dementia, Welsh (2003) cautions that there are ethical and moral implications associated with the use of systems designed to

promote the safety and security of people living with dementia. Such implications are tied up in human rights and civil liberties where the 'best interests' of the individual is paramount.

The issue of secure environments in dementia care is a contentious example of institutional risk knowledge being contested. A higher quality of life for people with dementia is inherent in buildings that facilitate independence, autonomy and decision-making (Fleming, Goodenough, Low, Chenoweth, & Brodaty, 2016; Namazi & Johnson, 1992). However, forms of institutional risk restraints have "insidiously seeped into the fabric of society with little public debate about its moral implications" (Welsh, et al., 2003, p. 372). In Namazi and Johnson's environmental study, *independent* access to outdoor areas had positive effects, as one resident proclaimed: "There's no need to lock us up; we should be free to come and go" (1992, p. 21)*.*

Titteron (2005) and Gilgun (1999) caution there is a need to think carefully about the concept of 'risk' and the language used—how we deal with a problem is influenced by how we define it, and this in turn influences how we respond to it. Responses may be mediated by many constructs—ethnicity, gender, age, nationality, sexual preference which is highly subjective and involves many value-laden choices that people make—both at an individual and institutional level (Ale, 2009). This social embeddedness of risk is not neutral and easily measurable, because it is laden with meaning, tension and complexity (Manthorpe, 2004). Of particular interest to my study is its relation with the principle of autonomy and the principles of person-centred care.

2.2.1. Risk: an ordinary part of life

Risk is a barometer of ordinary living (Manthorpe, 2007). Individuals participate in many risk-related decisions every day and where 'normal accidents' are a possibility for everyone (Perrow, 1984). This 'risk profile' of ordinary living is subject to change and is sensitive to the risks that affect our relations with self, with others and with society at large. Family dynamics, cultural beliefs, level of intelligence, education, prior experiences, and psychological distress are part of 'ordinary living' and may influence a person's understanding of their personal risk. These elements are closely linked to reflexivity, accountability and responsibility (Lupton & Tulloch, 2002).

According to Green, our risk profile is "experienced subjectively, culturally, morally, and politically, and our ways of defining risks and assessing their impact changes radically over time and context" (2008, p. 397). These shared and symbolic meanings of risk arise from membership of groups, access to material resources and relations of power and location within the life course. These normative constructs shape the person's capacity to be autonomous and inform their risk behaviour.

In a qualitative study on the use of information and communication technology (ICT) with people living with dementia, Olsson and colleagues interviewed spouses of people diagnosed and found that their overwhelming priority was to create a situation of safety and security for both themselves and their partners. However within the responses to preventing harm there were tensions from one partner: "Now, I've locked the seven-lever lock, and that's not good either" (2012, p. 108).

2.2.2. The framing of good and bad risk

Risk is a prevalent, necessary and unavoidable aspect of everyday lives, and its dual nature is now being acknowledged (C. Clarke, 2009; Mitchell & Glendinning, 2007; Sharara, 2007). It is frequently defined in pejorative and negative terms, namely harm and danger, rather than as a chance to gain benefits in a situation where harm is also possible (Alaszewski & Manthorpe, 1998; Olsson, et al., 2012; Welsh, et al., 2003). A positive concept of risk is affirmed by Millar (1998) who says that safety needs to be seen from the perspective of enhancing life's essential risk—that to shy away from life with its 'essential risk' is an 'unsafe' thing to do. This experiential dimension of risk is an essential part of the subjective experience of being human and provides a "lever for change" (Titterton, 2011, p. 39). Olsson et al., (2012) in their study suggest that despite a struggle to create safety and security for both carers and people diagnosed, a balance can be achieved by the use of resources such as ICT. This fits well within the concepts of relational autonomy and personhood within this study.

Fundamentally, both models of risk—the bad (as problematic) and the good (as contributing to quality of life)—fail to deal fully with the "contradictions and paradoxes inherent in living with a long term chronic illness in a disabling society" (Swain, French, & Cameron, 2003, p. 27); a society characterised by contingencies and uncertainties. Such a society has the potential to accelerate the restriction of choice

and decision-making for people with a diagnosis and restrict opportunities to exercise remaining abilities (Welsh, et al., 2003). Neither model takes into account the interplay between self and society, between the potential difficulties accompanying growing older and the context in which it takes place (C. Clarke, 2006; Olsson, et al., 2012). Nor does it account for individual differences—in people (with or without disabilities), communities, societies and/or cultures. This highlighted 'place' between the two models of care is where the aforementioned gap in knowledge that this study proposes to inform and begin the discussion on ways and means of bridging that gap.

Risk then is dynamic, with potential for future change depending on prevailing social and cultural differentials and changing political situations (Beck, 1992). Within this uncertainty, response to risk becomes a product of human action and decision-making. This concept of risk then, is a result of dramatic changes in the structuring of private lives as well as public life, which Beck refers to as a "social surge of individualisation" (1992, p. 97). An individual may have the freedom to choose, but also has the responsibility to make the right choices—which in turn may create new forms of risks. In the twenty-first century for example, traditional modernist forms of the nuclear family, marriage and lifelong employment are now uncertain and these forms are challenged and weakened by institutional interests such as the media, law, science, commerce and politics. This has made risk an effective strategy for changing the political horizon towards what Beck (1997) calls 'sub-politicization' where 'interests' that dominate the political horizon are subsumed by particular forms of expertise and knowledge. For instance, the dominant medical and knowledge and discourse surrounding risk has traditionally involved its minimisation and management—even elimination. There is a need therefore to seek ways in which risk and knowledge are experienced, perceived, defined, mediated, legitimated and/or ignored in everyday life (Able, 2009). This study is well positioned to inform the ways in which the lived experience is created for, and by people with dementia in everyday life.

A key development in the shifting perception of risk is its relation to rights—the right to take a risk is inherent within the principle of autonomy (Beauchamp & Childress, 1994). Welsh et al., remind us that a society free from risk is unattainable and "would

impose unacceptable restrictions on freedom" (2003, p. 374). Closely linked to autonomy is choice and control. Paradoxically this may mean the autonomous choice to give away control—the choice, however, remains with the individual. Norman (1980, p. 30) raised the issue of rights by asking the question: *How does one balance the risks of institutionalisation [of older persons] against the risks of remaining independent?*

2.2.3. Risk and professional practice

Risk is central to professional practice (Alaszewski, et al., 1998; Heyman & Henriksen, 1998; Keady & Nolan, 1994; Manthorpe, 2004). While managing the risk of harmful outcomes is central to health and social care practice, personalisation of services has allowed the person with dementia and their carer to have choice and control over the nature and receipt of support they are now entitled to (Australian Government, 2015; Olsson, et al., 2012; Welsh, et al., 2003).This is part of a shift of emphasis—from risk as something to be controlled and limited (residing with the person)—to risk which may be beneficial to the person (and residing in the context and circumstances surrounding the person) (T. Adams, 2010).

While professional and lay views have different knowledge bases on which to assess risk, possible outcomes of risk matter greatly if something goes wrong. The findings of Robinson et al., (2007) indicate that professional carers prioritise safety over autonomy, while people with a diagnosis may privilege other factors which recreate a sense of self and affirm their identities (Keady & Nolan, 1994; P. Robinson, Ekman, Meleis, Winbald, & Wahlund, 1997). A more nuanced understanding of risk may be achieved by the sharing of information and views (McCormack, 2001) and utilising relational autonomy and principles of personhood which is preferable to defensive practice and a culture of blame when things go wrong.

Risk then takes place in a fiercely contested public and private space. Tensions exist between bureaucratic, formalised risk management and the pragmatic approach which individuals take to risk in their everyday living (Bailey, et al., 2013). Lay risk knowledge is seen to be highly contextual, localised, individualised and "reflexively aware of diversity and change" (Tulloch & Lupton, 2003, p. 8). Allowing for this, Wynne (1992) positions the lay public as offering an equally valid approach to

understanding and dealing with risk as that put forward by the 'experts'. Horlick-Jones (2005) reports that a clash of perceptions between practitioners themselves (who often come from diverse disciplinary backgrounds) can occur within care, and this disparity of views ensures that this debate will rage on, reflecting the personal and professional divide by others who 'know better' (Dartington, 2006).

The core concepts of risk and dementia are contextually and contingently bound and the following section is an exploration of this interrelatedness and its application to my study.

2.3.   Core tensions between constructs of risk and dementia

The phenomenon of risk has become a significant issue for people with dementia (Marshall & Cox, 1998; Mitchell & Glendinning, 2008; L. Robinson, et al., 2007; Schoon & Brynner, 2003). The importance of individual subjectivity and lay expertise is acknowledged at a time when people living with a diagnosis have been widely excluded from a range of decision-making and research opportunities (Dewing, 2002; Harris & Keady, 2006; Wilkinson, 2002); where deficits are traditionally emphasised and where options for creative solutions for managing life with such an illness are reduced (C. Clarke, 2010). Within this scenario, risk is bound up with autonomy and rights, which may be contested or denied, in the name of beneficence and/or best practice (J. Adams, 1995; Hughes, 2010; Steeman, et al., 2006).

For the person living with a diagnosis each day brings its own catalogue of risks, some minor and some dangerous, central to which, is how risk is perceived by others (Benbow & Jolley, 2012; Olsson, et al., 2012). A 'bad' result of risk-taking may render their ability to manage risk 'impaired', and this can have a negative impact for them, and their rights; social inclusion and citizenship may become problematic. Here individual agency or personhood may be diminished or even withdrawn (Bailey, et al., 2013). Repositioning risk as a necessary part of wellbeing is essential to person-centred dementia care and to do this we must know the life story of the person diagnosed—including their ambitions, and how to support those ambitions (A. Clarke & Bailey, 2016). To this end, Sabat, Johnson, Swarbrick, and Keady (2011) challenge carers to think less about protecting someone diagnosed and avoiding risks, and more about determining and enabling reasonable risks in order to attain a

sense of achievement and purpose in their lives. Such collaborative decision-making has benefits for everyone.

It is argued that the increasing complexity of societal risk highlights a need to inform and develop negotiated partnerships in risk management within dementia care (T. Adams, 1999; Bailey, et al., 2013; C. Clarke, 2009; Manthorpe, 2003). It is also asserted that expanding social and cultural notions of risk will challenge the location and nature of this risk expertise, creating space for negotiated self-management. For the person living with dementia, this relational space may create ownership and a sense of control at a time when control may be slipping away in other important areas of their life, such as memory. (P. Clarke, 1996; Manthorpe, 2003). This is a complex space however, with moral and ethical concerns about choice and decision-making for people with a progressive illness (Olsson, et al., 2012; Welsh, et al., 2003).

2.3.1. Risk enablement

The understanding of negative risk is changing with the development of positive risk-taking which is at the heart of emerging agendas around self-management, personalisation and self-directed support (S. Hunter & Ritchie, 2007). This is illustrated in the report 'Nothing Ventured, Nothing Gained' (Department of Health, 2010) which highlights that minimizing risk often means foregoing benefits and restricting freedom, which in turn may be highly detrimental both to the person's sense of autonomy, and to their overall wellbeing. It can also be seen in the consumer-directed care (CDC) currently becoming best practice in Australian healthcare (Tilly & Rees, 2007).

The taking of risk while living with dementia can never be considered in isolation but instead in the context of a 'risk-benefit assessment'. This takes into account the wellbeing and autonomy of the person as well as their need for protection from physical harm. In a world dominated by risk assessments, the Nuffield Council's report (Nuffield Council on Bioethics, 2009) stated that, in real cases that involve people, it is difficult to work out exactly how to balance the risks and the benefits. This, of course is part of the point—that it should be difficult.

Positive risk management, or risk enablement in dementia involves making decisions based on different forms of knowledge. The first and foremost consideration is the experiential knowledge of people living with the condition whose ideas about risk are personal and built up over a lifetime (Titterton, 2011). Family carers also have knowledge to share about their relative living with dementia, and were seen in several studies to balance risk and become advocates with, and for, their relative diagnosed (Alaszewski, 2000; Barnes, 1997; Olsson, et al., 2012; Parker, 2001). Professional practice needs to overcome the protective and regulatory agendas associated with dementia care which impede positive risk-taking (Titterton, 2011) and where paternalistic interpretations of safety and human dignity dominate (Welsh, et al., 2003).

2.3.2. The risk conundrum following a diagnosis

In their critiques of ageism, Brearley (1979, 1982) and Giddens (1999) rejected the conflation of the term 'risk' with 'hazard' and provided a framework for understanding and assessing risk based on a particular situation—where the risks of action or inaction could be properly weighed up. Wynne-Harley agreed, stating that "an over-cautious lifestyle can bring its own hazards" (1991, p. 1) and demonstrated the right of a person with a diagnosis "to self-determination and autonomy" (1991, p. 29). With a rising number of people with dementia, and the majority living in their own home, Gladman's (2007) study on the sustainability of person-centred care highlighted the need for services to be sustainable, flexible and localised, with a focus on individual need and 'adaptive' rather than 'restorative' rehabilitation. This has the potential to embed dementia awareness into local communities, engage with people living with dementia, uphold their rights, promote positive risk taking and strengthen individual resilience—irrespective of age (Bailey, et al., 2013).

Within formal care practices there may be tension between respecting the rights of the individual and the rights of the collective (Ibrahim & Davis, 2014). For carers, a moral and ethical dilemma exists between taking risks and protection from harm when the effects of the illness are changing the way in which a person makes decisions. Uncertainty is fundamental to taking risks however, and good practice involves balancing the promotion of ordinary living against practical issues of safety (Manthorpe, 2007; Olsson, et al., 2012; Titterton, 2005; Welsh, et al., 2003).

Manthorpe et al. refer to this as a "risk conundrum" (1997, p. 71) which is bound up in moral, political, cultural and legal issues, and demonstrates the complex challenge which risk presents in care practices. Understanding the difference between "quality of health care and quality of life" is important however, if we are to uphold a person's rights while managing risk (Ibrahim & Davis, 2014, p. 151).

A 'person-centred' view of care with a focus on person 'directed' care provides an enabling environment which seeks to have the person in control of, and making decisions about their care (Maslow, 2013; Starfield, 2011). Risk is then repositioned as a necessary part of wellbeing (C. Clarke & Mantle, 2015). The dignity of risk places an emphasis on personal choice and self-determination, and carries with it the potential for failure (Nay, 2002; Parsons, 2009). The freedom to make, and continue to make choices is perhaps the greatest single index of wellbeing (Benjamin, Fheffetz, Kimball, & Szembrot, 2014).

2.4.   Situating the constructs of risk and dementia within this study

This study builds on the ideas of Burzyński and Burzyński (2014) and Giddens (1990) to develop a working definition that provides an understanding of the *meaning* of risk within the parameters of this longitudinal phenomenological study. The concept of risk enablement is operationalised as an exemplar of autonomy and choice, its meaning situated within the bounds of hermeneutic phenomenology. It is about the primacy of agency—the capacity to make choices and execute decisions without external influence. This description provides the means to explore the lifeworld of the participants; where the structurally-defined past, the present and the agential orientation to the future is weighed up in terms of 'risk' possibilities, as well as threats of living with a chronic and debilitating illness such as dementia. This definition acknowledges the influence of society's systemic and structural determinants of risk in a *hypercognitive* society (Post, 1995) and its close association with concepts of uncertainty and danger. The challenge is unravelling the nature of this risk knowledge and expertise and closely examining its impact on those living with a recent diagnosis of dementia.

This chapter situates dementia and risk as social constructs. Existing literature on 'risk' and 'dementia' focuses largely on physical safety including driving (Hunt, Brown

& Gilam, 2010; DeWitt, Ploeg & Black, 2009), living alone (Gilmour, 2003) and the environment (Lach et al, 1995). Risk's changing meaning and its relation to rights and risk enablement is explained and is seen within a context of strengths, values and relationship-based, person-centred care that privileges and enables personhood. This review however, has identified more fundamental considerations of the definition and management of risk, and has highlighted its *ordinariness* as an unavoidable aspect of everyday life. It has also noted its *experiential* dimension—which is an essential part of the subjective experience of being human.

This literature review highlights the need to support people to shape the dignity of risk-taking in living with this chronic disability. There is a need for a wider debate, and this study is well placed to contribute to a better understanding of risk and dementia which will make an original contribution in the field.

CHAPTER 3

PHILOSOPHICAL UNDERPINNINGS

*If I were to tell you where my greatest feeling, the bliss of my
earthly existence has been, I would have to confess: It has always,
here and there, been in this kind of in-seeing, in the indescribably
swift, deep, timeless moments of this divine seeing into the heart
of things.*

(Rainer Maria Rilke: Rilke and Benvenuta: An intimate correspondence)

This chapter examines the philosophical underpinnings used to inform the methodological framework of this research study. It will draw on the rich traditions of phenomenology and hermeneutics and the valuable insights which they offer. These traditions represent a paradigm that seeks *meaning* within human subjectivity and ultimately *understanding* and *interpretation* (Munhall, 1989, p. 16). Phenomenology and hermeneutics are both intrinsic to this study's design and conduct and will inform and exert influence at every stage of the study.

Selecting a methodology for this thesis began with my reflexive thinking about the research question. This involved examining and acknowledging my values, assumptions and preconceived ideas brought to the study and which necessarily shaped the question. The question arises from my *own* professional experience as a gerontologist, and it underpins my position as an observer of, and a participant in, the provision of aged care services. This position exposes my values and prejudices about care practices where tension surrounds the principles 'duty of care' and the "growing importance assigned to individual autonomy" and the enablement of risk (Mitchell & Glendinning, 2008, p. 299). This tension builds when human rights are bound in the concept of autonomy, which subsequently assumes ethical and legal implications deeply embedded in professionalism. Within this maelstrom of professional obligation and human rights sits the research question: *What is the lived experience of risk for a person with a recent diagnosis of dementia?*

3.1. Searching for a methodology

With the establishment of my research question on which to base a PhD thesis, I necessarily turned to the selection of a methodology which would acknowledge the *lived* experience of risk. The nature of risk is a sometimes sensitive matter, and requires an empathic manner to be worthy of the stories to be told in whatever way, place and time the participant chooses. In order to investigate the subjective nature of risk, I sought a methodology designed to bring the living of life to meaningful expression. That is the meaningfulness of risk in our lives—how it originates and how it occurs. Thus a symbiotic relationship between the research question, my worldview and the methodology and methods chosen was crucial (Clough & Barton, 1995). I first turned to the nature of qualitative research for an assurance that these three elements could be incorporated into its tradition.

Hermeneutic phenomenology is concerned with the life world or human experience as it is lived. The focus is toward illuminating details and seemingly trivial aspects within experience that may be taken for granted in our lives, with a goal of creating meaning and achieving a sense of understanding (Wilson & Hutchinson, 1991). Van Manen explains that "a good [phenomenological] description that constitutes the essence of something is construed so that the structure of a lived experience is revealed to us in such a way that we are now able to grasp the nature and significance of this experience in a hitherto unseen way" (1990, p. 39). Being sensitive to dementia and its variabilities in cognition, mood and communication requires such a focus in order to allow possible new meanings to emerge about a phenomenon drawing "something forgotten into visibility" (Harman, 2007, p. 92).

The methodology must also prioritise the ethics, or care of its participants. Having a diagnosis of dementia may result in fear of further loss and vulnerability and issues of privacy, confidentiality and consent remain critical in order to protect the participant from harm. Hermeneutic phenomenology is one such method in which ethical issues are important (Kahli, 2011).

3.2 Qualitative perspectives

There is not a context in which humans engage that does not require some process of 'taking in', or gathering information from the world around them. Long before the term 'phenomenology' was used, researchers were asking questions about people's lives, the social and cultural context in which they lived, and the ways they understood their world (Merriam, 2009). They embraced direct observation in the field, interviewing and collecting information, and their written reports were holistic in nature. This method of doing research challenged the orthodoxy of a scientific world view (Wolin, 2004), by seeing the world from the perspective of "those who were seldom listened to" (Bogdan & Biklen, 2007, p. 10). It became known as 'naturalistic' and 'interpretive', and these new methods of qualitative social inquiry were adopted by many disciplines.

In the early twentieth century, the term 'qualitative' was closely connected to natural science disciplines such as chemistry, physiology and later psychology and sociology (Brinkmann, Jacobsen, & Kristiansen, 2014). There are many, and at times, conflicting schools of qualitative thought which have been, and are driven by political and philosophical discussion from its early beginnings to its re-emergence in the 1960s and 1970s. In the 1970s there was exponential growth in the human and social sciences and this has continued today in what Brinkmann et al., (2014, p. 20) signal is "a new dynamic, multi-perspectival, and emergent social complexity". This complexity embraces a dynamic realism where people and their world are constantly changing and evolving, and cannot be easily captured with the more structured methods of quantitative research designed to measure data and formulate facts and patterns in research.

Definitions abound of what may constitute qualitative research. In its broadest sense, it is an exploratory methodological approach used to study complex phenomena (Merriam, 2009). In his writings on ethnography, Van Maanen stated that to operate in a qualitative mode is to trade in linguistic symbols, the purpose of which is to "attempt to reduce the distance between indicated and indicator, theory and data, between context and action" (1979, p. 520). The raw materials of qualitative study are therefore generated close to the point of origin, where the researcher attempts to come to terms with the meaning, not the frequency of the phenomena. In order to

learn more, the researcher develops a description of the context in which the behaviour is taking place, and attempts to see such behaviour from the other person's perspective. Such direct, first-hand and intimate knowledge of a setting leads to contextual understandings and empathic objectives, and these principles underlie and guide qualitative study today (Van Maanen, 1979).

Underlying this multifaceted concept of qualitative research are two key elements. Firstly, the position of the researcher as its "main tool" is central to this form of inquiry (Munhall, 1988, p. 150). Such essential involvement confers ethical and moral obligations upon the researcher in relation to his or her conduct and their behaviour within the research. Secondly, this research is highly subjective in its nature and its activity due to its naturalistic, direct involvement and participation with people. The participants in the research process are engaged and agential "interpreting their own experience and creating themselves by their inner existential choices" (Munhall, 1989, p. 22). In developing a interpersonal relationship critical to qualitative research, the researcher and participant engage in a dialogic process which yields rich data, and from this "conjoined position" (Greatrex-White, 2008, p. 1843), we can begin to understand and account for the nature of research findings. This research study wholeheartedly embraces these essential elements and builds on them throughout the research process.

3.3 Qualitative/quantitative perspectives and phenomenology

There is a growing call for researchers to think carefully about a chosen research paradigm, the type of knowledge that is produced (Carson & Fairbairn, 2002; Paley, 1998) and the need to adopt a more reflexive attitude toward empirical research (Alvesson & Skoldberg, 2000; L. Finlay & Gough, 2003). In line with this more open thinking, Greatrex-White (2008, p. 1843) calls for a move away from opposed dichotomies of thinking—the qualitative/quantitative, objectivity/subjectivity or researcher/researched, to a more "conjoined position" where issues of structure and agency need to be taken into account. These dichotomies have generated different kinds of knowledge, but also have much in common. To this end, Norgaard (2012) seeks an epistemology which can apply to all aspects of life; where inter-subjective knowledge incorporates the objective and subjective elements of reality and formulates a new theory and practice. He calls this 'modern' phenomenology. There

are times when these different approaches conflict however and so there can be differences and tensions in methodologies, as well as developments and turning points.

According to Langdridge (2007), our experiences can be best understood through stories that we tell of our experience and their meaning will be found in subjective realities and consciousness. This systematic, subjective approach of qualitative research describes life experiences and situations, and gives them meaning (Munhall, 2012). To understand the life world we need to explore these stories; this is the essence of this study's endeavour—to examine the *personal* experience of *risk* and to uncover its meaning.

While the realm of what is defined as 'qualitative research' is constantly expanding (Flick, 2002), so too is the tradition of phenomenology within its ambit. Phenomenology provides an excellent starting point for a comprehensive understanding of the natural sciences—their existence, practices, methods, products, and cultural niches (Crease, n.d.). Within this philosophical orientation, I was confronted by a diverse sweep of approaches and doctrines which was daunting. Through this labyrinth of phenomenological currents, I needed to orient myself to my research question in order to find my philosophical bearings. I sought the *nature* of this tradition and through my readings have discovered that it is pragmatic in its response to prior understandings of subjectivity; it is flexible to accommodate many directions; and it is natural as the subject matter is provided by everyday descriptions within the human life world (van Manen, 1997, 2014). These qualities are well suited to this study with its interpretive, holistic approach and sustained contact with people in their natural setting.

Phenomenology also seeks subjectivity through consciousness, which is the pre-reflective or "phenomenal world" and the knowledge being sought will come from "ordinary people in the everyday world"—rather than from the physical sciences (Giorgi, 2015, p. 148). Phenomenology is at once a method and an attitude, and a way of observing—which is new in science, but not in everyday life. This is the

interpretation of what we observe, hear, see, smell and feel, and it will be seen in personal experiential terms.

Importantly, the "openness" of phenomenology (van Manen, 2014, p. 15) seemed well suited to the nature of my research question, to the opening up of existential possibilities within the research area. I therefore sought a definition of the philosophical orientation in question, and among many definitions in the literature, Reeder's was chosen for its clarity: "[p]henomenology is a self-critical methodology for reflexively examining and describing the lived evidence [the phenomena] which provides a crucial link in our philosophical and scientific understanding of the world" (1986, p. 1). The lived experience of the participants in my study is set within a specific sociocultural milieu. Rigorous attention to *their* experience is maintained by a strong and oriented relation to the phenomenon (van Manen, 1990). This is facilitated by the reduction and epoché of hermeneutic phenomenology.

3.4 Phenomenology and its underpinnings

3.4.1. The seminal contribution of Husserl

Although there are certain precursors to philosophical phenomenology such as Kant, Nietzsche, and Hegel (van Manen, 2014); phenomenology as a twentieth century philosophical movement began as a reaction to the hegemony of a positivist perspective at the end of World War 1 (1914-1918). The ideologies of capitalism and its social order, and the cultural values by which it ruled were in turmoil. War and its aftermath were reflected in science with its emphasis on positivism, and philosophy appeared torn between positivism and subjectivism (Eagleton, 1983). Within this ideological crisis, the German mathematician later turned philosopher, Edmund Husserl (1859 –1938) "sought to develop a new philosophical method which would lend absolute certainty to a disintegrating civilization" (Eagleton, 1983, p. 54). His philosophical thinking would go on to influence those who followed in his wake— Heidegger, Gadamer, Ricoeur and van Manen amongst others. He became the reference point from which they took their philosophical bearings. Beginning with the *life-world* his conceptual vision inspired others to acknowledge and develop further key elements of their thinking.

Considered the founding father of phenomenology, Husserl described his life-world theory as an antithesis of all objectivism (1970), and sought knowledge and understanding (while retaining an objective outlook).This knowledge would be achieved by means of explicit description, where there is one correct interpretation of experiences—and a final, incontrovertible truth.

For Husserl phenomenology was scientific, describing it as the rigorous science of all conceivable transcendental phenomena (1907/1990). Its focus is on the way phenomena appear or give themselves—their *transcendence.* This was Husserl's scientific ethic which sought certainty through a self-critical examination and description of experience. If science can be described as an attempt to understand man and the world, and human experience provides evidence for our claims about the world, then phenomenology is scientific (A. Wilson, 1987).

Husserl referred to the presentation of phenomena as 'consciousness' which is a mental process including both its *mode* and its *object.* Consciousness is situated within personal experience, as we are 'conscious' of things around us. Events, people and objects all make up our mental life and form our prejudices, perceptions, thoughts, beliefs and hopes. Each mental state or experience has a characteristic feature of being *of* or *about* something, a representation, a sense of something. This representational character of mind or *consciousness* where the mind is directed toward 'something' relationally is *intentionality.* Quite simply, it is the description of the experience of the 'thing' we are interested in, in its appearance to us and this is the foundation for all knowledge. Husserl called this the fundamental property of *consciousness* and the principle theme of phenomenology (1970).

All experience is situated within an ever-present world, and for each of us it is 'my subjective world' (P. Ashworth, 2006). This is the human world as we find it, where people are "naturally engaged in their worlds" (van Manen, 1990, p. 18). It is where all thought and action takes place. This is where we seek wealth, fame, happiness and companionship, as children, adolescents, parents, teachers and so on. Our ways of being are a matrix of attachments that people have to that world—the lifeworld and it is only in our reflection on the lifeworld that we have a grasp of our

selves (P. Ashworth, 2006). This matrix is central to phenomenology—for Crease (2010) it is the soil out of which grow various ways of being, including science.

Phenomenology has been described as a method and an attitude. Within the lifeworld we are immersed in a natural attitude which represents the pre-given basis of all experiences—our biases, our values, our perceptions. Husserl wanted to find a position outside the lifeworld in his efforts to lay the foundation for a strict human science, his transcendental phenomenology (Nyström & Dahlberg, 2001). To achieve this, he bracketed *reality* or the everyday facts about the world and dealt entirely with experience as one is conscious of it as a central feature of everyday life. This bracketing is referred to as *epoché* dealing *only* with experience is what Husserl refers to as phenomenological *reduction*. The intention of reduction is to bracket our everyday suppositions and biases which may obfuscate the description of the phenomenon as it appears to us. For Husserl reduction means: "I stand above the world, which has now become for me, in a quite peculiar sense, a phenomenon" (1900/1970, p. 152).

3.4.2. *Heidegger and Gadamer: a hermeneutic turn*

Husserl was criticised for the idealism inherent in his scholarship (Stewart & Mickunas, 1990). While his foundational contribution to this study is acknowledged; it is with the thinking of Martin Heidegger (1889-1976) and Hans-Georg Gadamer (1900-2002) that has congruence between my study's tenets and phenomenology's applicability to it. Husserl's epistemology was to a large extent displaced by the ontology of Heidegger and it is within this hermeneutic scholarship that lived experiences are situated and temporalised.

From its beginnings in ancient Greece (Bleicher, 1980; Palmer, 1969), hermeneutics developed through the centuries and was employed from Homeric interpretations through to biblical exegesis and commentary (Prasad, 2002). In the early 1800s, the theologian Schleiermacher defined hermeneutics as the art of avoiding misunderstanding in order to gain access to the 'unadulterated' original meanings of texts. He sought an 'airtight, law-like explanation[s]' which became emblematic of the German Historical School (Wolin, 2004). This tradition was overturned by both Gadamer and Heidegger during the1920s as one's own particular historical

standpoint- their *historicity* was embraced as an integral part of our *being-in-the-world* (Wolin, 2004, p. 101).

The growth of philosophical hermeneutics began with the scholarship of Heidegger whereby humans are understood as hermeneutic [interpretive] beings who are capable of finding significance and meaning in their own lives (Draucker, 1999). Heidegger grew increasingly doubtful of the capacity of philosophy to articulate the 'truth' of Being and he became enamoured with the power of poetry, especially that of Rainer Maria Rilke to unveil the mysteries of Being. Phenomenology has a fascination with meaning—seeing it, or as Rilke puts it—the 'in-seeing' into 'the heart of things' (Rilke, 1987). Like poetry, phenomenology is a project which directs the gaze to where meaning originates. Its aim is to present detailed in-depth analysis of the experiences of particular people in particular settings.

3.4.3. Heidegger's conceptual vision

Heidegger uses the term *being-in-the-world*, of being co-constituted with the experiences of people being in the world where as *dasein* "directs our attention to what is relevant, it determines our perspectives whilst limiting our view of the world" (Greatrex-White, 2008, p. 1845). Dasein has a unique application for each of us, and only those who have undergone an experience can relate a similar *being-in-the-world*. Heidegger's *being-in-the-world* applies to the researcher and the participant in research. This calls for a reflexive stance on the part of the researcher where the phenomenon of risk will be interpreted and de/re constructed discursively and intuitively from within my *being-in-the-world.*

For Heidegger, realities are invariably influenced by the world in which we live—the *lifeworld* where interpretation is intrinsic to human existence. We are embedded in the world and our experiences are inextricably linked to context. While we are free to make choices, it is not absolute freedom for it is circumscribed by the specific conditions of our daily lives (Heidegger, 1962). For to be human is to be immersed and fixed in a literal, physical and tangible every-day world (Steiner, 1978). This is our 'thrown-ness' into an already existing world, our co-constitutionality with that world, and this renders our perceptions only partially subjective (Dowling, 2007). We

need to go beyond subjectivity in order to understand the nature of human phenomena. This emphasis on structure and agency of the everyday world is particularly relevant as this study assumes a socio-cultural perspective of the lived experience, whereby social, cultural and historical contexts influence and exert meaning upon that lived experience. *Being-in-the-world* may be coupled with the concept of *fore-structure of understanding* which refers to the interpretations that we make before something becomes knowledge. This may be seen in the way things are understood, and also in the ways things appear and are used. The *fore-having*, the *fore-sight* and something that we have in advance the *fore-conception* all make up this important concept of *fore-structure* which when brought to awareness, can be helpful in new situations and possibilities (Greatrex-White, 2008). This emphasis on structure and agency of the everyday world is particularly relevant as my study assumed a socio-cultural perspective of the lived experience, whereby social, cultural and historical contexts influence and exert meaning upon that lived experience.

In line with this thinking, Heidegger (1982) developed further Husserl's version of *intentionality* whereby the experience being sought exists within a context which contains a whole web of meanings that it has for us in lived experience (see section 3.5.2.). More than this, not only conscious experience has an intentional character; but so does every action built on "a set of assumptions about our world ... on the basis of this intentionality the subject already stands in relation to things that it itself is not" (Heidegger, 1982, p. 155).

3.4.4 Gadamer: a broadening of the vision

Hermeneutics developed in broader philosophical terms under the influence of Gadamer as he continued with the creation of a philosophical hermeneutics as a phenomenology of human understanding. Understanding became relational and productive—in other words there is no separation between the text and the reader (Prasad, 2002). Our horizons are made up of the past which speak to us in the present. The past that we choose to remember is a *present* past (van den Berg, 1972, p. 80). The present can also invoke the future as well in what is an interconnectivity of phases of time. Within phenomenology the horizons of a situation

and therefore the context is the source of meaning, and will be congruent to the *lifeworld* in which the lived experience exists (Giorgi, 2015).

A *fusion of horizons* took place in my study when a conjoined understanding emerged and articulated the conversations of the participants with their own background, or horizon. Drawing together the present, past and future phases of time, Gadamer's *fusion of horizons* enabled me to engage closely with the data (1989). It is a link between the data—changing with the ebb and flow of interpretation, and myself. The link between myself and the object of understanding [text] was utilised, where I changed my perspective to incorporate the other standpoint—while at the same time not leaving my perspective behind (Thompson, 1990, p. 246).

This fusion creates a 'dialogue' between many layers of data collection and analysis (McCormack, 2001). What results is a larger frame which can accommodate differences and multiple horizons which come into play in a reflexive interpretation. This co-determination of text and reader is Gadamer's version of the *hermeneutic circle* (1975) where understanding takes place through the interplay of the whole and the parts within the circle. This is a circular process, in which we move from an interpretation of the individual parts of the text, as determined by the whole, whilst the whole is determined by the individual elements of the work (Debesay, Nåden, & Slettebø 2008).

Gadamer's *hermeneutic circle* (1989) required me to review my personal perspective, and make a commitment to finding reciprocity and negotiation of meanings among the horizons of understanding. This is *not* a methodological circle according to Gadamer (1975) but rather refers to how the everyday person comes to understand in his/her world. Interpretation moves backwards and forwards, starting at the present, and moving "between a background of shared meaning and a more finite, focused experience within it" (Thompson, 1990, p. 243). It has no starting place or finishing line, but is the means by which we continue to search for new and better meanings. Through rigorous interaction and understanding, the phenomenon is uncovered. Gadamer cautioned that this does not mean the reader now fully understands some kind of objective meaning, but it is "an event in which a world

opens itself to him" (cited in Palmer, 1969, p. 209)—an event of which there is no final 'objective' solution (Tate, 1998).

Within this research, being a part of the circle incorporates the "values, histories and interests" of all its participants (Koch & Harrington, 1998, p. 887). Kvale (1996) sees the completion of the *hermeneutic circle* as occurring when a place of sensible meaning, free of contradictions has been reached—but only for the moment. An interpretation can never be said to be complete and therefore remains tentative and open to re-vision, and is precisely the point that some researchers celebrate (Parse, 1992) and others (Dreher, 1994) find incompatible with science.

The hermeneutic or interpretive turn in phenomenology acknowledges the place of 'historicity' or background within these concepts and then situates them within human reality. For both Heidegger (1962) and Gadamer (1989), all things have their place and time, and nothing past sits outside history. This is congruent with the socio-cultural 'lens' used to explore the concept of risk in chapter one (see section 1.10) and can be seen in chapter five (The *historicity* of the participants) where historicity provides the conditions for the structure and agency for human action.

Gadamer's emphasis lies beyond method on reflection and insight. His analysis was intended to demonstrate the many ways that human understanding can unfold in the context of, and embedded in, history and language. Truth, for Gadamer is found by entering into a genuine 'conversation' with the text (Sharkey, 2001). His emphasis on understanding and his conceptual insights will be a valuable addition to this methodology whereby the nature of meaning and understanding will be seen within the longitudinal data as the participants adjust to living with dementia.

3.4.4. The foundational contribution of van Manen
Following on from Husserlian phenomenology, the tenets of the hermeneutic scholars and their conceptual visions provided the framework on which this study is founded. This scholarship has been incorporated into the human science method of van Manen (1990) on which this study principally rests. This method incorporates both phenomenological and hermeneutic thinking—which van Manen describes as "the hermeneutic of descriptive—interpretive phenomenology" (2016, p. 48). While

this method has an emphasis on language, listening and the importance of silence when conducting hermeneutic phenomenological research (1990), it emphasises the source from which it has been developed.

Max van Manen (1942–) is a teacher from the Dutch or University of Utrecht tradition where the multidisciplinary nature and application of phenomenology can be seen. Here the applied domains of the human sciences such as psychology, education, medicine and nursing integrated existential-phenomenological philosophy into the languages and structures of their disciplines. This is reflected in the "multiple contemporary manifestations" (van Manen, 2014, p. 13) of its clinicians and practitioners, for example the psychiatrist van den Berg (Giorgi, 2015). Van den Berg took the simple events of everyday life and applied a new mode of understanding them—in essence he was founding a new way for psychology and psychiatry to be scientific.

Behind the complexity of phenomenological knowledge and guidelines, phenomenology is seen by van Manen as a practical and reflective method. It is about "wonder, words, and the world" for van Manen (2014, p. 13), and his particular scholarship has a multitude of movement and cultural influences including existential literature, avant garde arts such as Dadaism and the traditions of jazz music. From these different genres phenomenological meaning reflects a world view, a holistic attitude to life and meaning where there is no room for dichotomies or division. It is more than the name of a philosophical perspective—its philosophical attitude has empowered subjectivity to "radicalise itself and to struggle to dislodge and confront the unexamined assumptions" of our beliefs and views (van Manen, 2014, p. 13).

The writings of van Manen highlight the shift from objective, theoretical reflection to reflection that ponders, muses and contemplates on the meaning of things. His reflection is on the *how* of meaning (van Manen, 2016, p. 6) which becomes a methodological approach (Dowling, 2007) where human science research practice can be used interchangeably with phenomenology and hermeneutics. While he cautions there is no 'formal' method, there is however, a *tradition*, a body of knowledge and insights, a history of lives of thinkers and authors. This tradition allows the researcher moments of seeing-meaning or "in-seeing" into "the heart of

things" as Rilke (1987) so poetically puts it. This takes place in relation to what Heidegger (1985) calls *in-being* or our everyday being-involved-with the things of our world. It is here that every particular mode of being finds its "source and ground" (van Manen, 2007, p. 13) upon which this study was based. This method demands reflection that ponders and contemplates the meaning of things. The *how* of meaning is the hermeneutic of descriptive—interpretive phenomenology (van Manen, 2016). This sensitive and intuitive method begins with wonder at *what* gives itself and *how* something gives itself (van Manen & van Manen, 2014). This seemingly forthright search for meaning requires deep dedication, thoughtfulness, reflection and emanates from the 'primordial sphere of human existence'—from where meanings originate (Utrecht Summer School, 2013). The effect of the text or the return of the lived experience is "a reflexive re-living and a reflective appropriation of something meaningful" (van Manen, 1990, p. 36). It is something which can never be identical to the lived experience itself, but instead reveals something of its fundamental nature. It is this search for the *living* moment, the *now* as "a primal pre-reflective experience" (van Manen, 2014, p. 7) that holds such thrall for me as a researcher of the lived experience of people living with dementia.

Within the ambit of phenomenology, it was not possible to explain, nor was it a requirement to utilise all the concepts of its main thinkers in this study. Suffice to say, those which are foundational to its structure and central to understanding the lived experience of risk will be utilised and explained.

The following section provides an exposition of the key fundamental concepts of phenomenology for this study, which van Manen (1990, p. 47) refers to as methodological concepts. These concepts are *lifeworld, lived experience*, *essence* and *phenomenological attitude*. Their meanings continue to develop and evolve as many doctrines and approaches claim allegiance to phenomenology—developing its reach into new and diverse areas of scholarship.

3.5.   Metaphors of understanding

3.5.1. Lifeworld

Husserl named it first, the *lifeworld* (1913/1962). It is a province of Husserl's realm of investigation—the *things themselves* in their appearing (P. Ashworth, 2003). This is

the world as 'already there' or 'the original, natural life'. He used the term 'natural' for what is originary and naive, prior to reflection (van Manen, 1990). The natural attitude of the *lifeworld* is always directed at the world—to this, or that, and for Husserl, Dilthey (1833-1911) and Merleau-Ponty (1908-1961) the term arises from the *direct* exploration of the originary or pre-reflective (van Manen, 2014). It is always there, even within the process of reduction—it is life as we live it. All our thinking and actions take place here.

3.5.2. Lived experience

For van Manen, phenomenology's epistemological basis is the nature of human experience (van Manen, 2014) and it became the essential conception of phenomenology known as the *lived experience.* It is what we all have in common. For van Manen (1990) phenomenology always orients to meaning, lived meaning. Phenomenology therefore becomes a search for the meaning of lived experience. In order to 'get at' the meaning, a deep dedication, thoughtfulness and reflection is required and finally it is transformed into a textual expression of its *essence* (see section 3.5.3)—that which makes a thing what it is. The effect of the written word or the return of the lived experience is "a reflexive re-living and a reflective appropriation of something meaningful" (van Manen, 1990, p. 36), something which can never be identical to the lived experience itself, but instead reveals something of its fundamental nature.

In his book *Truth and Method* Gadamer (1975) posits two dimensions of meaning to lived experience—its immediacy and its content. It is the starting point for inquiry, reflection and interpretation and Merleau-Ponty supported this view: "The world is not what I think, but what I live through" (1964, pp. xvi-xvii). For Schütz (1899-1959) it had a temporal structure first of all—for it can never be grasped in the immediate, but only reflectively as the past. In the postmodern and deconstructive work of more language-oriented scholars such as Derrida (1930-2004), the idea of lived experience can be seen in terms of "the singularity of experience" or "absolute existence" (Derrida & Ferraris, 2001, p. 40). This focus on experience remains prominent in the human sciences and for van Manen (2014) this is due to two factors. Its ability to resist quantitative measurement is a feature of qualitative research from which it has been developed and its openness of method is another

feature which allows for the discovery of what can be thought and found to lie beyond lived experience.

3.5.3. Essence

Essence refers to the *whatness* or the *eidos* of things for Husserl (1913/82) and along with *intentionality* is key to our understanding of his phenomenology (Racher & Robinson, 2003). Merleau-Ponty saw phenomenology as being the study of essences which are the core meanings mutually understood through a phenomenon commonly experienced. Therefore, *essence* is taken to mean the most essential meaning for a particular context (Giorgi, 1997; Giorgi & Giorgi, 2003).

Phenomenological research is also the study of essences for van Manen who explains *essence* as "the inner essential nature of a thing" (1990, p. 177). It is that which makes a thing' what it is—and without which it could not be what it is. Van Manen also refers to it as a "universal" (1990, p. 10) and to uncover and describe it is the *raison d'être* of phenomenology. Within this study, van Manen's human science method will interrogate the data (1990) seeking the nature or essence of an experience. The conversations will be examined through the *being-in-the-world* of the participants, governed by their own *fore-structure of understanding* (Heidegger, 1962). The *essence* of the experience will then be understood.

3.5.4. Phenomenological attitude

Phenomenological attitude is a rigorous meditation and an active searching out of the processes and meanings of lived experience (Spiegelberg, 1960). At its core is a process of phenomenological *intuiting* in which the researcher attempts to be open and to meet the phenomenon with a fresh set of eyes. This highly demanding operation takes time and demands our full attention and patience. For the novice phenomenologist this attitude requires practice and a rigorous focus on the research question.

In descriptive phenomenology our habitual, taken-for-granted understandings are bracketed when we adopt phenomenological attitude (L Finlay, 2008b). For Husserl, this was his considered self-meditative process of *reduction* (Husserl, 1907/1990, 1931b). This disciplined approach was designed to let the phenomenon show itself.

This calls for engaging a phenomenological sense of wonder and openness to the world while, at the same time, reflexively restraining pre-understandings.

Hermeneutic thinkers view the phenomenological attitude in terms of openness and sensitivity. This is a less rigorous attitude than Husserl's reduction, where the researcher aims to stay open to all that is being given. This entails striving to be as present as possible to the phenomenon (via the participants, transcript or text) and to what is being described. This attitude involves being empathic, genuinely curious and open-minded while also being reflexively mindful of our context, our own position and perspective set within our particular personal, cultural and historical location (Finlay, 2008). This is an important skill to adopt as it allows access to a lived experience that may have eluded previous research, including traditional scientific research.

3.6. Phenomenology: divergences and tensions

The following highlights the differences or tensions between phenomenology and a hermeneutic tradition while providing a clearer picture of its underlying purpose and utility (Ehrich, 2005) and their application to this study.

3.6.1. Bracketing

The issue of bracketing is a fundamental strategy in phenomenology and the validity of a study can be demonstrated by its utilisation. Husserl was motivated to offer 'objective' data, and his 'transcendental' phenomenology proposes that researchers can, and must, transcend their natural attitude and suspend their beliefs about the existence of the objects of experience (Husserl, 1907/1990). He attempted to make phenomenology a rigorous science within the tradition of its time, and used the concept of bracketing to maintain objectivity. Bracketing involves putting aside what the researcher already knows about the experience being investigated and approaching the data with no preconceptions about the phenomenon (Dowling, 2004; Lopez and Willis, 2004).

A career in aged care informed this study with professional understandings and experience gained therein; and these experiences have both shaped the choice of research topic, the questions and their interpretations. Van Manen (2016) cautions

that "[I]f we simply try to forget or ignore what we already "know", we might find that the presupposition persistently creeps back into our reflections" (1990, p. 47). This is the position upheld in this study—that 'reduction' is previous knowledge used intentionally to create new understanding.

This positioning of reduction is supported by van Manen whereby the taking up of a certain attitude and practising a certain awareness to the things of the world as we live them (C. Adams & van Manen, 2008; van Manen & Adams, 2010) allows us to make explicit our pre-understanding, framework and biases (in order to engage in a conversation with the phenomena (Heinonen, 2015). For van Manen hermeneutic reduction ('openness') (van Manen and Adams 2010) is required, and this reduction gives us an overview allowing him to view the research process as a whole (Heinonen, 2015). For him to bracket means to suspend, to consider but *not* to deny, forget or ignore (Adams, 2008). At the same time, researchers need to reflect on their pre-understanding, framework and biases, searching for genuine openness in order to engage in a conversational relation with phenomena. Hermeneutic reduction also means to practise a critical self-awareness.

The two most critical components of bracketing are the epoché and reduction. Reduction is an attentive turning to the world with an open mind that is called by the epoché. It does not bracket the phenomenon away from the world; rather, it restores the contextual and existing meaningfulness of the world. It explores what is given in a moment of pre-reflective, pre-predicative (spontaneous) or lived experience.

3.6.2. Role of the researcher

Phenomenological research is a lived experience for researchers as they attune themselves towards the ontological nature of phenomenon while learning to *see* pre-reflective, taken-for granted, and essential understandings through the lens of their always already pre-understandings and prejudices (van Manen, 1990). A researcher inevitably influences the research process (Chan, Fung, & Chien, 2013) and being totally objective within that process is debatable. Exercising self-reflexivity however assists in the identification of any potential influences such as bias or assumed knowledge which may impinge upon the study (Primeau, 2003). These influences may be areas of bias or assumed knowledge and they may be minimised by their

bracketing (Ahern, 1999) or critically examined and incorporated into our thinking—depending on the phenomenological orientation of the researcher.

Self-reflexivity demands practical application to the research process. It involves being open to discovering new things, being attuned for the unexpected, being surprised at the unpredicted, and taking an active engagement with the text (Pezalla, Pettigrew, & Miller-Day, 2012). It means returning to the text over and over again in order to see, to listen and to understand as if for the first time (van Manen, 2014). It involves respect and sensitivity towards the phenomenon, an abandonment of oneself which may leave the researcher both vulnerable and humble (L. Finlay & Gough, 2003).

Keeping a reflexive diary and writing down my perceptions and feelings following each conversation is a way for me to bring reflexivity into consciousness, and it is an instrumental way of re-examining statements made by the participants which I might misconstrue on the first reading, a position endorsed by other phenomenological studies (Wall, Glenn, Mitchinson, & Poole, 2004). To generate the best interpretation of a phenomenon the researcher proposes to use the *hermeneutic circle* in which one's understanding of the text as a whole is established by reference to the individual parts and one's understanding of each individual part by reference to the whole.

3.6.3. *Nature of knowledge*

Cohen (2001) states that hermeneutic phenomenology is concerned with understanding texts. In this approach the researcher aims to create rich and deep accounts of a phenomenon through *intuition*, while focusing on uncovering and amplification, alongside of which is the avoidance of prior knowledge. In using this approach, we accept the difficulty of bracketing. To overcome this difficulty, we acknowledge our implicit assumptions and attempt to make them explicit (Kafle, 2011). Accepting the notion that there may be many possible perspectives on a phenomenon acknowledges and accommodates variability in subjective reality, memory and emotional well-being associated with dementia (Killick & Allan, 2001).

Husserl sought knowledge and understanding (while retaining an objective outlook) which would be achieved by means of careful description—his final truth. In a shift away from objectivity, Heidegger proposed that all knowledge originates from people who are already in the world. The position of the researcher is therefore 'relational' and supports the view of multiple realities are constructed and can be altered by the knower (participant). This is the lived experience in a moment of time—a particular time—the *now* which has the potential to change at any time. The findings related to the research question will be based on *that* time and *that* place and reflect the immediacy of the lived experience for the participants following a diagnosis of dementia. Meaning then, is a co-creation between the researcher and the researched, not just the interpretation of the researcher. As Giorgi stated "[n]othing can be accomplished without subjectivity, so its elimination is not the solution. Rather how the subject is present is what matters, and objectivity itself is an achievement of subjectivity" (1994, p. 205).

3.6.4. Nature of truth

From his background in mathematics and logic, Husserl (1900/1970) sees a single truth within phenomenology, and he attempts to reduce truth to evidence in his book *Logical Investigations.* For the hermeneutic scholars truth was not fixed, but contingent upon other considerations. There is ultimately no objective or absolute vision of truth for Heidegger and this is fundamental to the existential view of the finitude and perspectivity of human existence (1962).

Gadamer's goal was to explore the nature of human understanding where understanding is temporal, finite, and historical. He explicates truth as an event or experience in which we find ourselves engaged and changed. A fusion of horizons is involved in the search for meaning and truth, multi-perspectival and relative where people have a historically-effected consciousness embedded in the history and culture that shaped it (Gadamer, 1975).

3.6.5. Importance of language: the art of reading and writing

Hermeneutic phenomenology is attentive to the philosophies underpinning both hermeneutics and phenomenology (van Manen, 1990). It is a "research methodology aimed at producing rich textual descriptions of the experiencing of selected

phenomena in the life world of individuals that are able to connect with the experience of all of us collectively" (Smith, 1997, p. 80). From identification of the experience of phenomena, a deeper understanding of the meaning of that experience is sought (Smith, 1997). This occurs through increasingly deeper and layered reflection by the use of rich descriptive language (Kafle, 2011).

According to Sharkey (2001) hermeneutic phenomenology challenges the researcher to reflect deeply on what it is that the texts of the field have to say. The researcher is called to play with the texts – to get lost in deep conversation with them and the goal of this type of research is not to clone the texts of the field for the reader of the research, but to invite the reader to enter the world that the texts would disclose and open up in front of themselves.

Hermeneutical phenomenology pays attention to the rhetoric which is the writing or reporting style of the research referring generally to how language is employed. It demands for a typical rhetoric that best elicits the true intention of the research participants aiming to explicate the core essences as experienced by the participants. Here everyday language may not do justice to express what is intended by the participants, and the flexibility and openness of this philosophical method incorporates dementia's variable communication abilities (van Manen, 1990). A language mode with informal tone with idiographic expressions full of adages and maxims is considered suitable for reporting this type of research and fits well within discourse where memory and language skills may be impaired(Killick & Allan, 2001).

The data in this study were conversations which contain both verbal and non-verbal language where language is an expression of conscious *intentionality* in terms of meaning (Stewart & Mickunas, 1974, p. 105). *Intentionality* indicates the inseparable connectedness of the human being to the world, and this verbal and non-verbal language used in this study is an example of 'specific intentionality' where language exemplifies the directedness of thinking and acting in the 'here and now' in the world (van Manen, 1990). Language includes the manifold ways in which consciousness presents itself to the world. Phenomenology is sensitive to subtle linguistic undertones, to "language that normally would fall out of our accustomed range of

hearing" (van Manen, 1990, p. 111). This study involves people living with dementia where language disintegration is a hallmark feature of its presentation (Angus & Bowen, 2011; Bowen, 2006; Hydén, 2008; Hydén & Antelius, 2011). The conduct of the study will require a sensitivity to all language, including silence. For van Manen*, the* formative power of phenomenological texts lies precisely in the resonance that language can effect (1997) and he suggests that human science research *is* "a form of writing" (1990, p. 111).

3.7.   Situating this study within a hermeneutic framework

One of the core strengths of phenomenology is its application to practice. While I was guided by an understanding of its philosophical underpinnings, applied phenomenology is fundamentally a practice of writing that reflects *on* and *in* practice. This fosters and strengthens an embodied ontology and epistemology (van Manen, 2014). Van Manen describes the text as "an invitation to openness" (2016, p. 4), and from there the practice of phenomenology may begin. I maintained an open attitude to the data throughout the research process, and van Manen's reduction (van Manen & van Manen, 2014) was utilised in my study. Openness is *hermeneutic reduction* (C. Adams & van Manen, 2008; van Manen & Adams, 2010) where researchers need to reflect and incorporate their pre-understanding, framework and biases. This involves a different way of knowing the world (van Manen, 2014) as theory 'thinks' the world, and practice 'grasps' the world practically. In the human sciences, objectivity—one's orientation to the object, and subjectivity—the need to be strong in our orientation to the object of study in a unique and personal way, are not exclusive. Instead they find their meaning and significance in the oriented relation that the researcher establishes with the object and subject of this experience (van Manen, 1990). This object of study is effective with respect to the everyday practice of living where risk is situated. It offers insights and meanings for people in their world–in all its "livingness" (van Manen, 2016, p. 6).

Human experience is what we all have in common. The nature of risk while living with a recent diagnosis of dementia is a deeply personal and sometimes private matter and the method chosen needs to reflect this. Phenomenology is intuitive and reflective and uses practised modes of questioning to articulate the structures of meaning embedded in lived experience (van Manen, 1990). Its intersubjective focus

sets up a dialogic relation with the phenomenon, bringing the researcher into closer contact with lived experience. This is the place where the person and world [subject and object] are not separate but are one together—the "hermeneutic phenomenological consciousness" (Greatrex-White, 2008, p. 1845), resulting in a deep understanding and description of human meaning. This intensive focus was critical for my study as I have not experienced the phenomenon of risk while living with dementia and I was relying on this 'coming together' in order to understand "how the everyday, inter-subjective world is constituted" (Schwandt, 2000) from the participants' perspectives.

3.7.1. Application to the research process

The participants in this study had a diagnosis of dementia and the study's method needed to accommodate flexibility in the data collection and techniques of analysis. One of phenomenology's core strengths is flexibility (Pringle, Hendry, & McLafferty, 2011), and this was welcome as its method is not without its dilemmas and challenges (Koch, 1995). Van Manen (1990, p. 79) confirms this view:

> "Making something of a text or of a lived experience by interpreting
> its meaning is more accurately a process of insightful invention,
> discovery or disclosure—grasping and formulating a thematic
> understanding is not a rule-bound process but a 'free' act of
> seeing meaning".

Van Manen's method may be utilised rigorously or it may be adapted to particular needs (Heinonen, 2015). This was a sensitive research area for which my professional expertise was harnessed to appreciate the livingness of the participants as they negotiated a complex and transformative life situation. Hermeneutic phenomenology provided the conceptual 'tools' to ascertain the meaning of *risk at a particular time*. It made a significant contribution to the understanding and interpretation of the research question and the complexity of the phenomenon of risk and all its possibilities.

Phenomenology needs to be understood and practised as method and identified as a style of thinking—a manner of orienting to experience as we live through it—as it

embodies the research question. Van Manen (2008) further adds that a proper understanding of phenomenology can be gained only through doing it!   For van Manen (1984) a phenomenological question must not only be made clear, be understood, but also be 'lived'. To this end I began 'doing it' through the reflexive questioning of the research question that went beyond just writing it down at the beginning of the study. It did not appear in a 'light bulb' moment—but evolved over time, with much thought and reflection. Munhall (2013) also reminds us that once the researcher has decided on the research question, they have introduced their own learned knowledge and assumptions. My biases and assumptions were not bracketed or set aside, but were embedded in and essential to the development of the question. Hertz (1997) suggests that one might bring different selves or roles to represent them in the research endeavour, and they are all likely to influence the process. The reader must be drawn into the question in such a way that they become as interested in the nature of the phenomenon as I had over the past five years. This phenomenological questioning then demands that I "question deeply the very thing which is being questioned by the question" (van Manen, 1984, p. 46).

In summary, this chapter has demonstrated the importance of the philosophical contribution of hermeneutic phenomenology with its research priorities of meaning and interpretation. As a particular form of qualitative research methodology, phenomenology has a complex interrelatedness between philosophy and a method of human research. This relationship affirms the critical role played by philosophy in this study's development; its concepts with their philosophical underpinnings, and its terms of reference which gave the analysis a philosophical direction and credence. The phenomenological concepts such as fusion and temporality allowed for a flexibility and applicability of thought that transcends time and place, and permitted adjustment between the data and its interpretation. With the emphasis on joint understandings, hermeneutic concepts of *fusion of horizons* and *temporality* provide the space and justification for the historical and socio-cultural dimensions of the study which influence and exert meaning upon the lived experience. Meaning that never stands still however, as it is sought at a particular time and in a particular place. The importance of the nature of hermeneutic phenomenology's epistemology and ontology is therefore understood within those dimensions. Its thinking is the

corpus of scholars and its inclusive world view informed and enlivened the direction of this study.

CHAPTER 4

A PHENOMENOLOGICAL RESEARCH METHOD

When I heard the learn'd astronomer,
When the proofs, the figures, were ranged in columns before me,
When I was shown the charts and diagrams, to add, divide, and measure them,
When I sitting heard the astronomer where he lectured with much applause in the lecture-room,
How soon unaccountable I became tired and sick,
Till rising and gliding out I wander'd off by myself,
In the mystical moist night-air, and from time to time,
Look'd up in perfect silence at the stars.

(Walt Whitman: *When I heard the learn'd astronomer*)

This chapter presents elements of both philosophical and practical application to the research design of this study. These elements and their interrelatedness provide a coherent approach to the selection of the study's philosophical approach and method. This enables a logical progression in explicating its analysis, interpretation and trustworthiness of the study (Silverman & Marvasti, 2008).

4.1.　The human science method

This research study rests principally on the human science method of van Manen which is not a method in a "purely prescriptive or technocratic sense" (1990, p. 3). Like Whitman's astronomer (1867), this method does not rest on calculation and measurement, but rather it is an iterative process of questioning, sharing information, intuiting, analysing, describing and reflecting. These are phenomenological tools of discovery which seek to uncover the essence of meaning for the participants, allowing their voices to be heard. The subject matter of phenomenology (phenomena) embraces our experiential knowledge and understanding of the world. For van Manen, lived experience is simply experience as-we-live-through-it in our actions, relations and situations (2007).

Van Manen's 'Phenomenology of Practice' is a rigorous attempt to uncover and describe the structures or essences of lived experience (2007, 2014). When we

commit an essence to language (the human science text), the description shows us its "lived quality and significance" (van Manen, 1990, p. 10) in a fuller or deeper manner. This study sought to understand the participants' own interpretations of their experiences of past, present and future meanings of risk—the meaning for them embedded in the context of a recent diagnosis of dementia. This was their reality within the milieu of their own stories, and from here I wanted to understand the components of risk.

This research study was a form of writing and the creation of a written thesis was the core objective of the research process. While guided by the scholarship of van Manen (1990, 1997, 2007), I was mindful that there are elements of scholarship which fall outside our range of enquiry. These elements are important to understanding meaning, and they require sensitive and attentive listening to the nuances of language including voice tone, tempo, volume and pitch, emotions expressed through language, and the use of nonverbal body movements. Van Manen refers to these elements as "other voices" that we must be attentive to, and to "subtle significations in the way that things and others speak to us" (2014, p. 713).

Van Manen's research method (1990) provided structural guidance for this study and allowed me to proceed rigorously and systematically. His six methodological themes (1990) provided a broad structure for the conduct of this study. He cautions against the prescriptive application of these procedures; instead they are practical reference points which provide a flexible structure in relation to parts and to the integrated whole. These reference points provide the latitude to research in a way which is flexible and adaptive when a person is living with the demands of a chronic and disabling illness. Alongside of which, is the more traditional form of research design and scholarship.

These themes will now be explained in more detail.

4.1.1. Turning to the phenomenon of interest

The first step is to make sense of, and explore some aspect of human existence. Van Manen describes phenomenological research as being 'given over' to a quest, a true task, a deep questioning of something—and that something is the interpretation

of one researcher only (1990, p. 31). This step begins with the formulation of the research question, which was explored in the initial stage of setting up the study. This method places emphasis on the questions, and the way that they are understood The subject matter of the question—'risk within a recent diagnosis of dementia' required a method which methodically explores its complexity. It also required a reflexive approach which is sensitive to the strategic possibilities thrown up by varied contexts (Dowling, 2007). These contexts 'situate' the research question and embed it within the locus of the participant, facilitating an understanding of the lived experience for the person at that time.

The nature of dementia and its challenging life situation for the participants necessitates dementia-specific research methods which are ethically sound. The research question—its timing, positioning and how the question is asked—may be adjusted to suit the participant and their particular disposition on a certain day. This is based on "a profound reverence for human beings and their experiences" (Munhall, 1988, p. 150), and builds respect and trust while offering the possibility of rich data collection.

4.1.2. Investigating experience as we live it

The research question in this study was a dynamic, and challenging one. *What is the lived experience of risk for a person with a recent diagnosis of dementia?* The stories within the conversations attest to the lived experience of risk, but what was that lived experience of risk given a diagnosis of dementia has been confirmed?

Risk is multifarious, and within the uncertainty of a recent diagnosis of dementia, the research question posed challenges of its own. It required exploring the "integrated whole" of the lived experience of risk in order to ascertain its meaning at a particular time (1999, p. 56). A phenomenological framework was used to search out the meanings and relationships that knowledge and context have for each other, and in so doing built this integrated world of experience (Lincoln & Guba, 1985). This knowledge may be sensitive and may never have been shared before, and the researcher was privileged to be in that place on that day, at that time.

Uncovering meanings in phenomenological research called for a question which was very open in nature. This was followed by discussion led by the participant, not the researcher (Koch, 1996) but participated in by both parties. This allowed for the interview to stay as close as possible to the lived experience:

> *Can you tell me about a time when you took a risk*?
> *How did that make you feel?*
> In subsequent interviews:
> *Can you tell me a time when you wanted to take a risk, but didn't?*
> *Why was that?*

The "hermeneutic interview" or conversation (van Manen, 1990, p. 98) was utilised within this study, and this struck a balance between the need for structure and flexibility (2011). The process was both sensitive and deliberate, looking for not only what was said, but what was said between the lines (Kvale, 1996). This process also paid attention to silence, the absence of speaking, and "the silence of being or life itself" as emphasised by van Manen (1997, p. 356).

For Minichiello, Aroni, Timewell, and Alexander (1995, p. 79) a "productive interpersonal climate" builds rapport and trust between two people who are engaged in such a study. This resulted in rich disclosure. It revealed however the complex human side of the fieldwork process where there are no guidelines to follow. In-depth interviewing was utilised here, and a recursive form of questioning is a conversational method which treats the participant and their situation as unique. From one remark a question may be asked and the natural flow of conversation directs and engages in an interpretive search for what may be sensitive and personal meanings.

This study utilised a longitudinal framework designed to be sensitive to, reflect upon, and acknowledge change (Hycer, 1999). This is the natural evolvement of change (Murray, et al., 2009; Osborn & Rodham, 2010; Snelgrove & Liossi, 2013), which unfolds as part of the story of the lived experience of risk. Within the contours of longitudinal research, transitions will occur which may be transitory or permanent, but will represent change over time. With reflection and reflexivity, the determinants and direction of change may be discerned (Snelgrove & Liossi, 2013). This yields an

understanding of people as dynamic rather than static entities (Osborn & Rodham, 2010). This framework also privileges temporality that offers multiple vantage points and valuable insights into how changing contexts can influence experiences over time (Thomson & Holland, 2003). Heidegger uses the term *historicity* to explain this form of temporality whereby the reality (lived experience) and the world (context) are together as one (1962).The *historicity* of the research participants in the following chapter provided an opportunity to introduce the participants in their unique historical contexts which may have influenced their experience of risk over time.

4.1.3. *Reflecting on essential themes which characterise the phenomenon*

Van Manen suggests that phenomenology is the philosophical study of the *structures* of experience and consciousness. A true reflection on lived experience is a reflective and thoughtful grasping of *what* it is that renders an experience its special significance (van Manen, 1990). When we are unfamiliar with a certain lived experience for a person, we must attend to every nuance, and detail in order to get to the 'essence' of the phenomenon—its essential meaning. The central structure of an experience is its *intentionality*—being directed toward something—it is an experience of, or about, some object. This means stripping the text back; seeking and understanding the meaning in terms of units, structures and themes of meanings. This process began with transcription of the data—an iterative process of playing and replaying the audio-tapes for accuracy of content and presentation and delivery. Looking and listening for the beginnings of *meaning units* and *minor themes* that may give meaning to the phenomena was a rigorous task and one that was never exhausted (see chapter 6 parts A and B for a full explication of this process). Meanings may be found in repeated statements, changes in voice tone or pitch, syntax, body language, use of external objects with which to emphasise a point, or even in silence. From these beginnings, "we are able to bring into nearness something which tends to be obscure" (van Manen, 1990, p. 32).

4.1.4. *Describing the phenomenon—the art of writing and re-writing*

Reading and writing are core elements of hermeneutic scholarship. A meticulous application to these tasks forces us into a reflective attitude in which one writes in a deeply collective way, constructing a "full interpretive description" of the experience of the lifeworld (van Manen, 1990, p. 18). To do this, phenomenological *reduction*

allows us to see the universal, the essence or the *eidos* of lived experience. It involves steps, which reflect on, and bracket our biases and presuppositions, allowing us to see its essential structure. It is a gradual and careful process of uncovering meaning, which is tentative and always evolving (Caputo, 1987). This form of scholarship is the collective work of the researcher and the participant; reflecting multiple realities, where participants are "naturally engaged in their worlds" (van Manen, 1990, p. 18). The researcher should come away with the feeling "I understand better what it is like for someone to experience that!" (Polkinghorne, 1988, p. 46).

In order to do justice to the "fullness and the ambiguity" of the experience of the lifeworld, writing became a complex process of rewriting (re-thinking, re-flecting and re-cognising) (van Manen, 1990, p. 131). This writing and re-writing created depth, constructing multiple layers of meaning and laying bare "truths while maintaining an essential sense of ambiguity" (1990, p. 131). The written text made visible the thoughts, feelings and attitudes of the participants, and the following chapters will outline those thoughts and feelings relating to risk that people with a recent diagnosis of dementia may experience.

4.1.5. Maintaining a strong and oriented relation to the phenomenon

The most important source of data was the unstructured and uninterrupted stories (Kohli, 1981) where the research questions were open-ended, enabling the participants to set their own agenda and pace which gave them greater control within the conversational situation. At the outset, this study's intention was to gather data regarding risk and a recent diagnosis of dementia, and they remained the touchstone of this research. Van Manen (1990) cautions researchers to retain a strong and oriented relationship to the phenomenon under study and to remain devoted to the fundamental question.

I came to the study with an established background of understandings (Thompson, 1990), which was made explicit and acknowledged in field notes and a reflective research journal. These values, thoughts and beliefs constituted my 'horizon', and are included in the study through the *fusion of horizons* (Gadamer, 1975) (see section 3.4.2). They formed an important part of the orientation to the research

question and determined my situatedness as an interpreter of data. This acknowledgement both enhanced the study's credibility and assisted with its interpretation. These horizons provided the means by which the reader of the study was able "to audit the events, influences and actions of the researcher, a study may be considered to have rigour" (Koch, 1994, p. 976). These elements were incorporated into the study, and were present at every stage of the research process—from the initial framing of the research question to the chosen methodology through to the conduct of the study. This includes meeting the participants, conducting and transcribing the conversations and the subsequent uncovering of themes and their analysis. The field notes written at the beginning of each transcribed conversation were referred to, and 'set the stage' for the interview which followed.

4.1.6. Research: a partnership of shared meaning

A 'safe context' created in this study enabled the full and equal participation of the person with dementia (Dewing, 2002; Hellström, Nolan, Nordenfelt, & Lundh, 2007). This is a "moral space" where the integrity and rights of the participant are upheld, and where achieving genuine closeness to another is possible (Kitwood, 1997b, p. 97). This 'safe context' was the choice of the participant—the 'when and where' of meeting together. This consensual relationship-building was of great importance to this longitudinal framework and resulted in prolonged engagement in a relatedness of mutual trust and regard. This had manifold benefits for all concerned (Hellström, et al., 2007).

Van Manen reminds us that "it is not simply a matter of *what* is done, but also *how*" (1995, p. 656). The *how* of which van Manen speaks is characterised by the "intersubjective interconnectedness between researcher and researched" (L Finlay, 2009, p. 11). This human interconnectivity results in a partnership of shared meanings and a singular understanding, or *essence*. Such close co-operation builds mutual trust, which is necessary in order to ask the types of questions demanded of this method:

What is it like to experience...?
What is the nature of...?

These are deeply personal questions, and allow the participants to create and re-create themselves and their stories in manifold ways.

4.1.7. Balancing the research context by considering the parts and the whole
Phenomenology requires that the integrated whole of the phenomenon be explored, and this is achieved by a circular process of continual dialogue between words, phrases and concepts within parts and the interview data as a whole. The phenomenological attitude of van Manen (1990) (see section 3. 5. 4) seeks openness in our relationship with the phenomenon and this is achieved by constantly interrogating the text: *What is really being said here? What does it mean to take a risk?* Van Manen recommends stepping back and reflecting on the contextual 'givens' and how each of the parts contributes to the whole. He asks: *Is the study properly grounded in a laying open of the question? Are we open to all the possibilities for understanding the phenomenon?* (1990, p. 43).

The practical goal of data analysis is to uncover meanings and develop understandings related to the research question. While this analysis largely followed van Manen's method of hermeneutic phenomenological reflection (1990), it was assisted by NVivo to uncover primary themes and minor themes. This was done in order to facilitate analysis and move beyond description and also to demonstrate trustworthiness by accurately representing the experiences of the participants. Conducting research using different analysis methods—one manual and intuitive, and the other computer software resulted in triangulation which uses two or more methods to study the same phenomenon. Using both methods of managing data enhanced the audit trail (Lincoln & Guba, 1985) which in turn increased the validity of the study.

NVivo is a software tool which assists with the organisation and analysis of what can be large amounts of qualitative data. It is designed to facilitate text-searching and within this study was beneficial in the clustering of the structural meaning units of data into themes and minor themes. Its essential role was to supplement the manual interview data coding and triangulate the formation of themes, minor themes and meaning units. Streubert and Carpenter(1999) assert that when data collection

begins, so too does data analysis and here the organisation of NVivo facilitated these processes. The interviews were transcribed, encoded into NVivo and were then interrogated utilising van Manen's methods as follows.

Van Manen offers three methods for uncovering or isolating thematic statements of a phenomenon in a text and I utilised each method in the interrogation of the interview data (1990, p. 92). The holistic reading approach refers to the text as a whole and asks the question: *What sententious phrase may capture the fundamental meaning or the main significance of the text as a whole?* It is then incumbent upon the researcher to express that meaning by formulating such a phrase. Selective reading is the second approach, which begins with the transcription phase of the study, as is the detailed reading approach, which asks the question: *What does this sentence or sentence cluster reveal about the experience being revealed?* The detailed line-by-line is the third approach. Here I was be careful to apply a contextual lens to the single line. When a word was used, I sought a context: *What was its intent? Was it used in a literal sense? To what did it refer?*

This process resulted in word and statement identification with its intent and purpose clear, and this enhanced the trustworthiness of the study. The development of this method of analysis is taken up in chapter six (part A) which emulates the scholarship and tradition of analysis as described by van Manen (1990).

The interviews were also uploaded into NVivo where a similar process of aggregating and coding began. This process managed the large amount of data, one interview at a time until the first round of interviews were completed and the data was collapsed into one large cross-sectional source of data. This process continued for each interview, and then each round until an integrated whole eventuated at the end of the data collection. Reading, re-reading, listening and reflecting accompanied this process of seeking meaning.

4.2.   Practicalities: the nuts and bolts of research design

4.2.1. Ethics approval and processes for recruitment

 The application to the Victoria University Ethics Committee for approval was granted with the written provisional support of two CDAMS clinics within Melbourne. A letter

seeking their interest and conditional support (Appendix A) and two letters of provisional support subsequently became a part of my ethics application (Appendix B). I also sought the support of a third CDAMS clinic, in order to increase the possibilities for accessing potential study candidates and to expedite this stage of the study.

Following Victoria University Ethics Committee approval; the three CDAMS clinics each had their own individual Ethics Application Forms that required approval of their individual ethics committees prior to commencement of this research study. After the successful approval of three ethics' applications, there were further procedures and forms required of these practice clinics prior to recruitment of the participants (Appendices G, H, I, J and K).

After the process of ethics approval from each of the CDAMS clinics, I visited each clinic in order to meet supervisors and establish contacts within the organisation. This was also an opportunity to explain the study, and distribute 'Information to the Organisation Involved in Research' pamphlets for the staff to read (Appendix C). A follow-up meeting with the staff was organised shortly afterwards to promote the study, explain it more fully, and to invite any questions.

Upon the nomination of a suitable client by the CDAMS staff, and their initial verbal consent to participate, the client was sent two forms. The 'Information to Participants Involved in Research' (Appendix D) was a general outline of the research and its aims. The second form 'Contact Information for Potential Participation in Research' (Appendix E) set out requirements of potential involvement in the research, and sought a signature and date if the person wished to proceed. Initially the CDAMS staff were providing information to the client and answering any questions they may have, but time constraints required my attendance at the clinics to provide this support. This was an opportunity to establish early trust between the client and myself, and to clarify first-hand any issues they may have. The potential participant was requested to send both forms back to the CDAMS clinic if they wished to participate, and these were forwarded to me by mail.

Within a week of receiving the completed forms, I contacted the person and arranged a meeting, where further explanation of their rights and responsibilities within the research was given. Particular emphasis was given to the voluntary nature of their participation and the assurance that they could withdraw at any stage from the research process. I also responded to any further questions they had.

A signed 'Consent for Participant Involved in Research' form (Appendix F) was an ethical requirement for participation for the research to proceed. The potential participant was then asked for their permission for me to contact a 'person responsible' in the event of change or an emergency. This role is defined in Section 28(2) of the Guardianship and Administrative Act-1986 (Victorian Govt., 1986). A 'Participant Consent to Share Information' form (Appendix G) was then co-signed which contained the contact details of the 'Person Responsible or Next of Kin (NOK)'. The 'Initial Consent Supporting Participation in Research' (Appendix H) was then provided to the NOK for signature. My contact details were also included for the 'Person Responsible' or the NOK if there were any concerns. A follow-up form to be signed by the participant 'Ongoing Consent Supporting Participation in Research' (Appendix I) was a requirement for each subsequent interview. A form 'Verbal or Written Consent for Continued Participation in Research' (Appendix J) must be confirmed by the 'person responsible' or NOK for subsequent interviews, which may have verbal telephone approval and be signed by the researcher on their behalf. In the event of the participant not having the capacity to consent, a signature from the NOK was required. This was to be at the discretion of both parties, that is, the 'person responsible' or the 'NOK' and the researcher.

The rigorous lengths to which all CDAMS clinics went in order to involve NOK in the consent process, and subsequent participation of the participant was at odds with research demonstrating that the needs and preferences of people with dementia remain relatively stable, even as cognition declines (Feinberg & Whitlatch, 2001; Whitlatch, Pilparinen, & Feinberg, 2009). However, it is acknowledged that while self-identified needs and preferences may remain stable with advancing dementia, people with dementia may become less involved in decision-making and preferences over time (Menne, Tucke, Whitlatch, & Feinberg, 2008).

There were two significant issues that dominated the applications for ethics and they were informed consent and capacity.

Capacity of the person to participate in research was initially determined by the CDAMS clinics. The process of informed consent (Dewing, 2007) was then adopted at each interview to ensure the willingness of the participant to take part in the research and understand the research aims. Information regarding the capacity of the participant was also enhanced by telephone contact with the NOK before each conversation took place; upholding the trustworthiness of the study's data.

It was recognised that the participant may not be able, or may not wish to continue in the research, and that retention rates in this cohort may decline over time. The flexible nature of the study was also inclusive of those who may not be able to contribute to all of the interviews, or did not wish to continue. This is stated in the documentation (Appendices C, D, E, F, I) and was recorded as part of the research process, with any data obtained to be included as part of the final analysis. The role of the NOK was a requirement of the CDAMS clinics and there were two forms concerning their participation in this research. They were 'Initial Consent Supporting Participation in Research' (Appendix H) and 'Ongoing Consent Supporting Participation in Research' (Appendix I).

In this study, informed consent was interpreted in two ways. First, it was not seen as a discrete event, and to this end an informal consent process was ongoing throughout. This is a context-specific "here and now" consent (Dewing, 2007; Hellström, et al., 2007, p. 616) which is based on emotional rather than purely cognitive factors. This is particularly appropriate when a person's abilities are likely to fluctuate. The establishment and maintenance of a good relationship throughout was a fundamental goal in this study, and it enabled me to monitor the participant's willingness to proceed. Over time, knowing the person well allowed me to look for consent which was not only based on verbal language, but non-verbal and behavioural cues (Hubbard, Cook, Tester, & Downs, 2002). This is what Wilkinson referred to as "direct engagement" form of consent (2002, p. 11). This provided opportunities for the participant to have control over the research process. Re-establishing *who* you are, and *why* you are there was an important part of being sure

that I had informed consent for the interview. Second, that consent was given by the signing of an 'Initial Formal Consent Form (Appendix I). This was ongoing, requiring a renewed signature by the participant and the verbal consent or signature of their 'other' before each conversation was held (Appendices I and J).

4.2.2. Recruitment of participants

This study utilised a purposive sampling of participants with clients recruited from Cognitive Dementia and Memory Services (CDAMS) throughout Melbourne, Victoria, Australia. These clinics are specialist multidisciplinary diagnostic services for people experiencing memory loss and/or early cognitive changes. The primary target group for CDAMS is people who have a dementia-related illness with a particular focus on newly emerging cognitive issues. The clinics provide early diagnosis, advice, support and referral to other agencies. CDAMS also aims to support family and carers of those with newly emerging cognitive issues.

This purposive sample otherwise known as theoretical sampling (Glaser & Strauss, 1967), sought to observe and interview people who have had experience with a particular phenomenon of interest. In this instance, people who had recent diagnosis of dementia. For a researcher, the aim is to develop rich or dense description of that phenomena, rather than seeking a generalisability of findings. This study's purposive sample was used to meet the following inclusion criteria. They included:

➢ The person lived on their own at home and had a recent diagnosis of dementia—of which they had full disclosure and understood its implications. The diagnosis would be confirmed by a Mini Mental State Examination (MMSE) and required a score between 17 and 25.

➢ The person was a willing story-teller, and able to tell a personal story, or stories about risk taking in their lives. Questions surrounded risk, and the impact of dementia on the person's ability to take risk.

➢ The person was proficient in the English language. As dementia is a progressive and neurodegenerative illness, verbal abilities may diminish, and if English was not the person's first language, he/she may revert back to their mother tongue as the disease progresses. In order to achieve optimum

communication as the study progressed, a good understanding of all aspects of working English was essential, including non-verbal communication.

Appendices referred to in the following section 4.2.2 are listed at the back of the thesis and form part of the 'audit trail' (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

4.2.3. Interview process

Open-ended interviews were conducted in this study which provided the participant with the opportunity to fully explain their experience of the phenomenon. These interviews also allowed me to ask open-ended questions such as: *Can you tell me about a time when you took a risk?* which are broad in nature and allowed the participant to move freely in their description of their experiences, providing greater latitude in the answers provided. Over time they became one long story which continued with each visit. This is a benefit of a longitudinal research design which allows data collection to amass over weeks, months, or years.

The interviews took place at a time and place of the participant and their family, and were conducted in a personal and congenial manner. They were all held in private homes until several participants moved into care facilities where the subsequent interviews were conducted. In the case of married participants, their spouses were present, two participants had their children accompany them and three people who lived on their own conducted their conversations independently. Morning and early afternoon were the preferred times for meeting. Six people in total completed all four interviews, one daughter withdrew her mother after one session, another lady declined to continue after two interviews and two people died during the progression of the study.

Before interviews began I reflected on van Manen's (1990) advice to researchers which was:
- ➢ stay close to the experience as lived
- ➢ when asking what an experience is like, it may be helpful to be very concrete
- ➢ ask the person to think of a particular instance, situation, person or event

The questions are broad, open-ended and invite a response:

- *Can you tell me of a time when you took a risk?*
- *What was that like for you?*
- *How did it make you feel?*

This unstructured method opened up an intimate dialogue between two people, and its flexibility accommodates any new aspects that may emerge or be introduced by the participant. This was important because the communication abilities of people with dementia may be impaired, and I determined that to provide time and support for the person provided the best opportunity for stories of *risk* to emerge. In their published interviews with people living with dementia, Killick and Allan affirm this, stating that time is needed when engaging in discussion (2001). This time allows rapport to develop, and will enable the person diagnosed to feel comfortable to share some of their most personal moments, and some deeply held, rarely shared memories. People with dementia are traditionally positioned through their own and other's talk in ways that can disempower and this highlights the importance of relationship and trust within dementia care (Killick & Allan, 2001; Purves, 2010; Sabat & Harré, 1992).

Being prepared emotionally for the conversations was important for me, as dementia is associated with a variety of impairments of language and communication, some of which may be unexpected and possibly confronting. I approached each conversation with an open mind, vigilant not to miss anything, alongside a determination not to talk too much in order to fill in the gaps. Flick (2000) emphasised the importance of preparation for each meeting and in order to capture the best possible data, I have developed a pro-forma of the questions from the first conversation to the fourth. Building on what had been said before situated both the participant and me in the same place and ready to begin again. Kvale (1996, pp. 1-2) calls this "data capturing" and literally it is an interview or an exchange of mutual interest.

Table 4.1. Schedule of risk questions over four interviews

Interview	General Questions	Personal Questions
1. Setting up the story	Can you tell me a story about a risk that you have taken in your life? What was that like for you?	How did it make you feel?
2.Situate in the here and now Use other words such as manage/ challenge/cope Learn their language as people do not consider themselves to be risk-takers	How are you going? (indirect reference to dementia) Build on what has gone before, and engage with the present needs and wishes surrounding risk Pick out 'risk 'parts of interview one and revisit Look at present risk and look for a transition in comparing to the past Ask to retell a story and develop it- how does it impact on decisions today? What does it teach you today? Will you do anything today that you consider is risky?	Can you tell me the story about coming to Australia again? What was that like for you and your family? How did you manage that? And what happened next? I suppose you use those skills now?
3. Looking for transitions Close the door on general topics- be very specific	How has risk taking changed for you? What could occur today that would be risky? Why is that risky? What would you do? What leads you to that decision? (never ask why) Are there any other possibilities? Who would you consult, and why? Ask about the contrary case here: Tell me about a time when you wanted to take a risk, but didn't. Why didn't you?	Do you feel that you would do that again?
4 Review life story for critical events. Ask the part. To recall those events. Revisit the 'risk' questions	Can we talk about risk again today for the last time? Pick key events which were 'risky' Can we talk about the time that you took risk in your life? What was that like for you? Looking back, would you do that again?	Why would you take risk today? Why do you not take risk today? Is there anyone, or anything preventing you from doing so?

Interview	General Questions	Personal Questions
Focus on the future	Will you continue to do that, do you think? Do you take risk today? Explore- how, when? Would you like to take a risk today? What about the future? Do you see yourself taking a risk in the future now? Or ever?	How does that make you feel?

At the end of each conversation, I referred back to van Manen in order to ensure that the participants' purposes and mine were mutual. For van Manen the conversations serve two specific purposes: firstly, as a means of exploring experiential narrative material in order to develop a richer and deeper understanding of a human phenomenon. On a more personal level, the conversation becomes a vehicle to develop a relation with a partner about the meaning of an experience (1990, p. 66).

4.2.4. Data management and analysis

Data was in the form of fully annotated conversations, field notes and a reflective journal throughout the study. Interviews were recorded by two digital voice recorders, transcribed onto a hard drive secured by password and transcripts were stored in a locked filing cabinet on a USB drive. Initial interviews were between one and one and a half hours in duration, and subsequent visits were mostly shorter. Anonymity of the participant was assured by the use of a preferred pseudonym for the written record and password and secure file/ cabinet for data storage. All hard copies were transferred to the Victoria University after transcription, and will be securely stored there for five (5) years, after which time it will be destroyed.

Once the interview had been completed, it was transcribed verbatim onto a secure hard drive. Interviews were then uploaded to NVivo, and the preliminary identification of coding into meaning units began. NVivo software was used in conjunction with van Manen's methods of thematic analysis (1990). Additional material was gathered in a reflective journal, a diary and field notes to assist with analysis, and this became part of Koch's "decision trail" (1994).

Van Manen's methods of coding (see chapter 6.3) were used after each conversation and uploaded into NVivo. At the conclusion of each round of conversations all the data were pooled cross-sectionally in a search for common coding and themes across all the interviews. This was a continuous process— after each round and then at the conclusion of the data collection phase of the study. Data was not presented as a longitudinal narrative but as contributing to the properties of a category. The pooling of all the data after each interview round facilitated the analysis of the study, by providing successive opportunities to build on emerging themes and monitor transition within those themes (see Figure 6.2).

4.2.5. Interpretation

Analysis usually precedes interpretation, but in phenomenology the intuitive search for meaning begins with data collection. Here meaning and truth are not absolutes, and interpretation may have multiple meanings. The emphasis on openness in interpretation begins with what Gadamer (1975) refers to as his 'I -Thou relationship' which opens up a relationship with one's view, and that of others. This relationship demonstrates the open-ended and dynamic nature of human understanding. One's view cannot be about absolute truths, but rather insights into the *essence* of a phenomenon. This interpretation interrogates the findings that have been made in the analysis of meaning. To this end, both the analysis of meaning and the interpretation of findings are incorporated in Part A and Part B of chapter six.

 Part A sets out the procedural and iterative analysis of the data which were not purely hermeneutic but based on the method of van Manen (1990). Part B utilises and demonstrates the composing of primary themes, minor themes and the meaning units of which they were constituted.

4.2.6. Rigour in research

Rigour in qualitative research is "associated with openness, scrupulous adherence to a philosophical perspective, thoroughness in collecting data and consideration of all the data in the theory phase" (Burns & Grove, 1993, p. 64). This study aimed to fulfil these criterion and demonstrate "methodological congruency" (Roberts & Taylor, 2002, p. 375) between the kind of information that was being sought (the participants' interpretations of their experiences), and the method employed to

gather that information (conversations, observation, field notes). For a hermeneutic phenomenological study such as this, the multiple stages of interpretation that allowed patterns to emerge, the discussion of how interpretations arose from the data and the interpretive process itself were seen as critical to the rigour of the scholarship (Koch, 1995). This was demonstrated throughout this study.

In summary, method is a complex process and contingent both upon the nature of the research question and the philosophical position underpinning the study. When the participants have a diagnosis of dementia and are seen as vulnerable, particular attention is paid to *how* the study is conducted and is essential for a person-centred approach to research and trustworthiness of the data.

CHAPTER 5

THE *HISTORICITY* OF THE PARTICIPANTS

*I am told of a man who sets out to make a picture of the universe.
After many years, he has covered a blank wall with images... only to
find that at the moment of death that he has drawn a likeness of his
own face.*

(Jorge Luis Borges: *The Aleph and other stories*)

5.1.　Setting the scene

5.1.1.　The historicity of Heidegger

The participants' stories of risk were situated in what Heidegger (1962) refers to as historicity—the notion of background which is an inescapable part of the hermeneutic circle. A person's history or background is what culture gives a person from birth (Benner & Wrubel, 1989); it is handed down and presents a way of understanding the world. Heidegger notes that "the world is always the one that I share with Others" (1962, p. 155). Engagement takes place at a phenomenal level—person to person— where we encounter others in all our *historicity.*

The concept of *historicity* suggests that *dasein* is a part of a larger social and historical collectivity—as part of a people, as part of a world. Heidegger stresses that *dasein* is future-oriented: it responds to the past, in the context of the present, for the sake of the future. Dementia is a feature of the people in that world—a phenomenon in its own right—and this becomes a place Hughes refers to as "dementia-in-the world" (2011, p. 215).

5.1.2.　A storied world of dementia and risk

Dementia-in-the-world is seen in the stories told from a particular vantage point of the person as a being-in-the-world. This chapter reflects Hughes' "dementia-in-the-world" (2011) where possibilities exist for growth as well as managing losses. It situates the person in an ontological way and begins the participants' journey of the exploration of risk. Risk is seen in its livingness—in the *lived* experience of the past, in the *living* experience of the present and possible future potential for taking risk (Miles, Chapman, & Francis, 2015). This chapter moves seamlessly through the

conversations to where the past, the present and the future merge into one story—being in present time.

These vignettes encapsulate the past, present and future *dasein* of the participants. We met in a kitchen across a linoleum table, on a back porch where endless pot plants were lined up on a narrow ledge, and in a small sitting room amid the clutter and collections accrued over a lifetime. These were places chosen by the participants in which to meet me—personal private places where friends could meet and share tea and cake and tell each other about their lives and what mattered to them. The conversations became collaborations which are at the heart of this study. The participants told me *who* and *what* they stood for, and as a researcher, listening to, and sharing their stories was a privilege beyond measure. These are their stories.

5.1.3. Jessie's story

Jessie and her husband emigrated from Scotland to Australia in the 1960s when their family was quite young. Her mother had already settled here, but she was reluctant to make the decision, allowing her husband to decide to make the move. If it didn't work out, he would have blamed her, and: *that would have been awful, wouldn't it?* (4: 295, p. 13). But it did work out—Jessie made sure of that. She was determined to stay in Australia with her other family members but she did not tell her husband: *I didn't want him to think it was me saying let's go, let's go. So I let him make the decision* (2: 26-27, p. 2).

Finding permanent work was difficult for her husband Jimmy, but easy for the resourceful Jessie. She took any job that she could get to keep the family going, and relished the challenges that each job brought. She also enjoyed getting out and meeting people. She reflected of this time: *We done well* [*sic*], *never regretted it* (1: 21-22, p. 2).

After forty-nine years in the family home and now on her own, Jessie decided to go into an aged care facility. She was lonely and looking for company but acknowledged: *I think coming in here has been a big risk* (2: 25, p. 5). Making such decisions was the lived experience of risk for Jessie: *well I normally, I know myself what I want to do* (4: 187, p. 8), and while there have been: *maybe a couple of things*

like [*sic*] *I may have been disappointed in, but most things go well, I enjoy most things like* [*sic*] (3: 82-83, p. 3). She had always made the best of things, believing that it's up to yourself what you get out of life*: I'm a person who can adjust—who can accept things and say well this is it* (2: 129-130, p. 5). Now in her eighty-third year and widowed for fifteen years, Jessie acknowledged the impact of ageing and memory loss and the realisation that despite supportive children: *You're on your own, you're always on your own* (2: 59, p. 3). Despite this, Jessie's devoted children were a safety net for her, and they will protect her future choices and decision-making.

5.1.4. Jane's story

Jane's had a privileged upbringing, living in Europe, the United Kingdom and South Africa. Private schooling, travel and opportunity associated with her father's diplomatic postings did not prepare Jane for widowhood and being on her own. She decided to move to Australia to live with her only child. Shortly after her arrival she was diagnosed with dementia. When talking about risks that she had taken in her long life, she quickly dismissed them as being irrelevant in her present circumstances: *You got used to it, and it didn't worry you anymore. I don't know anything else* (1: 6-7, p. 2). Now in her eighties, the risks she had taken as a younger person were starting to catch up with her. A legacy of a bad fall from a horse as a teenager resulted in crippling back pain which dogged the two conversations we had together. Her life today was a far cry from what it had been, and she sat in a darkened room trying to escape the heat and the pain when I first visited her. With all her friends now dead, she saw little hope for the future.

Catching up with Jane again was a sad reflection of where her life had been. After a fall at her daughter's home and long-term rehabilitation, she was now in a nursing home—a place she described as: *hell* (2: 204, p. 9). All the nerve and daring she had shown in her life must be marshalled up again now: *I need to have courage for this place. It's not my idea of thoughts for old age* (2: 234, p. 9). After a life of bold risk-taking in Europe and in England during the war, Jane was ill-equipped to manage her life as a lonely woman living with dementia in an aged care facility. Admitting that she was not making decisions for herself anymore, Jane saw herself as: *a pretty ordinary, frightened woman* (2: 92, p. 9). She had no options left for taking risk or

managing her own life and she began to despair. She passed away a few days following this conversation.

5.1.5. Veronica's story

Born and raised in a large family in the bush, Veronica and her siblings: *were free to play out a lot of things* (2: 30, p. 2) in the helter skelter of country life. She recalled:

> *A little rural school about fifteen pupils and we had a pony*
> *paddock and the oval where they all played cricket and all that –*
> *yeah it was really well, what would you say it was a very natural*
> *life, if you know what I mean—close to the earth sort of thing*
> (1: 92-95, p. 5).

Joining a Catholic Order after finishing her teaching degree, she enjoyed roles as a school principal and later a chaplain. She subsequently left the Order with its: *hierarchical masculine orientation* (2: 70, p. 7) only to have a series of accidents: *Now I don't have a clear run—because of the hits on me* [*sic*] *head. I've had a few falls* (1: 336-337, p. 16). An unfortunate incident in a shopping centre saw her fall badly on a concrete floor, losing consciousness. This was followed by a fall in her garden which left her badly bruised and terribly shaken. Intelligent, perceptive and with a great sense of humour which sustained her, Veronica was alone and vulnerable now.

Her love of driving increased that vulnerability: *I did something stupid. I drove a car a long way and I got lost* (3: 80, p. 4). This incident occurred when she became disoriented while attempting to drive to a niece's home in the country. This fiasco had unnerved her: *you're not the same as you get old. You need to be a bit more circumspect* (3: 258-259, p. 9). She knocked on a stranger's front door at three am. and was fortunately able to tell the owners where her niece lived, and in the morning they were able to piece together the puzzle and make contact with her.

On my third visit, she identified moving into an aged care facility as future risk for her. When I saw her for the final conversation, it was at a large aged care facility outside

Geelong, and she was unaware of how she had got there. She remarked: *and here I am* [loud laughter] *it's not really a nursing home though* (4: 306, p.14).

Veronica said of her disabled brother: *I think having Michael—that's a huge gift* (1: 24-25, p. 20) and this acceptance exemplified how she managed the risk in her life. Veronica's awareness fluctuated, but her insight was peerless*: I've been banging me head so much lately I hit my head out there Oh geee* [*sic*] *that's where the Alzheimer's comes in. Oh dear* (1: 201-204, p. 10). When I asked her about risk today she was nursing a swollen knee from another fall and said that *she* was the current risk!

All our conversations together were highlighted by laughter—at her own expense, at the games she played with her brothers and sisters, and at the turn her life had taken. She summed up: *Mmmm boy I'm glad what I did when I did* (2: 232, p. 8). This was a marvellous story which *sorta just happened for a little girl from the bush* (1.321, p.15).

5.1.6. Pearl's story

Pearl was a lady who had: *done what I wanted to do, that's for sure* (1:100, p. 3). Moving to the Mornington Peninsula had been her husband's idea, but the rest of this story had been scripted by Pearl. Studying naturopathy at night school for four years, starting her own practice in her mid-fifties, and travelling the world for ten years on her own were elements of this risk story told by a lady who thought: *it's just quite normal for most people and their lives and things really* (1: 80-81, p. 4). A daughter present throughout steered the only interview in a direction where she saw risk. Of her mother's naturopathy degree the daughter said: *The bold risk was failing* (1:45, p. 2) to which her mother retorted: *oh well that's true, but I didn't fail, I didn't fail* (1: 46-49, p. 3). Looking through Pearl's 'lens', the biggest risk may have been for her not to have started the course in the first place. This story had been about a lady who had 'pushed boundaries', taken risks and created opportunities for herself. The conversation however had been overshadowed by her daughter's presence and frequent interruptions.

5.1.7. William's story

This story was set in a working class suburb where: *they used to fire guns up and down the street* (1:36-37 p. 2). At an early age William learned to stand up for himself and for others. He learnt boxing and judo: *to look after meself* [*sic*] (1:115, p. 5), and he left school at thirteen to help his widowed mother: *I just had to hope for the best (*1: 20, 8 p. 5). Colourful anecdotes of survival, hardship and loss were enhanced by use of the vernacular and first person dialogue: *and I said 'what'll I do then?' and he said 'run like buggery and go home* [laughter]. *See, so those sorts of things they stick in your mind* (I: 63-64, p. 5). Such typical, everyday activities that had been taken for granted before a diagnosis, now assumed greater significance as William sought to make sense of the current uncertainty related to living with dementia.

William's 'historicity' of 'being-in-the-world' as a survivor of his street fighting days— a man who could beat the odds—was now over. William knew it: *I'm not fit enough. I'm not tall enough. The kids today now are a lot taller* (1: 87, p. 5). Meaning and significance of these memories were enacted by clenched fists, body gesticulation and facial expressions. William likened life to a horse race: *What else can you do? Same as when you back a racehorse* [laughter]. *Put your money on and sometimes you get it back and sometimes you don't* [laughing] (1: 242-243, p.12).

But that was then. William's risk-taking had changed and his lived experience of risk had been eroded by the deterioration of his physical and cognitive abilities. His family had also intervened in concern for his safety. Ladders, chainsaws and even his bike were removed by his grandsons, and with them went his identity. This 'fixit man' had decided that when a job needed doing the time had come: *to get someone else to do it* (2: 157, p. 6). When I next met with Susie [wife] and William, he was in poor health and in considerable pain. Losses were mounting.

A lifetime of holidays in his beloved caravan at Barwon Heads was over, as Susie was not well enough to tow the van down to the coast, and William's licence had also been revoked: *Why have they stopped me from driving a car? The doctor done* [*sic*] *it* (3: 202, p. 7).These losses carried a heavy personal cost for William. They undermined his confidence and self-esteem, and robbed him of his dignity. They

constituted a loss of control, of choice and of autonomy and throughout our final conversation together, his speech rambled, and he was incoherent some of the time.

5.1.8. Chicks' story

On my first visit to Chicks' unit she was beautifully dressed. She enacted the events of her long life with the use of her small, expressive hands. She had deep red fingernails, bejewelled fingers and bangles jingling on her wrist, and they flashed through the air as she told of her: *magnificent childhood* (2: 6, p. 1). I could not help but comment on her wonderful appearance and she clearly enjoyed this validation. Killick & Allan remind us that "Individuality can be real only when it is acknowledged and upheld by others" (2001, p. 25). This diminutive lady was keeping up appearances and things were just the same as always.

Chicks adored her father, and this love of men had continued throughout her life. By her own admission she let the 'love of her life' slip through her fingers:

> *I started going out with Jimmy Williams [um] when I was 14—a*
> *lovely, lovely, lovely, lovely, lovely* [trailing off] *man and for some*
> *unknown reason I don't know what happened, but I was in Upwey*
> *and I met Len Hughes. I didn't like him but I met him and I started*
> *to go out with him* (1:93-97 p. 7).

This marriage to Len Hughes ended in divorce and Jimmy remains: *my first boyfriend...that's the man I should have married* (2: 46-47, p. 3). She admitted that she took no advice throughout her long life: *I was like if someone said 'do this' I'd think 'oh well that's what you think'* (1: 100-101, p. 5).

Chicks had assumed control of her life when her first husband Len Hughes ran off with a nurse. When I met her she was living in a large retirement village outside Melbourne. She and her second husband had moved in there, and when he passed away she began to withdraw. She had joined the social committee upon arrival at the village, organising many outings and functions. She had loved it. When I met her for the first time she had withdrawn from most of her social activities and preferred just a few people around her. Estranged from her children and

grandchildren she was still doing things her way and continued to take no advice because she 'still knows best'. Her *lived* experience of risk was about the survival of her family, and a daughter proved a handful for a working mother: *I think every policeman in Australia knew me. That* [*sic*]*, that's OK that worked out all right* (2: 198-199, p. 9).

She does know that: *things change in life, everything changes in life* (2: 331, p.14), and her days of taking risks—her *living* risk—are over. She drove with a limited licence after a CDAMS clinic assessment, and was content in the knowledge that: *if there was an accident it wouldn't be my fault because I know and I watch, and I don't take risks* (2: 260, p. 11). Other than a few memory lapses: *oh yeah I sort of forget* [laughing]... *forget a bit about what you're doing. It does get a bit 'why did I do that?' I should have done that instead* (2: 216-217, p. 10) she remained firmly in charge. Importantly for her there is no regret: *I wouldn't change my life the only no*[*sic*] [banging the table] *I wouldn't change my life one iota, because if I hadn't have gone through that bad stage, I wouldn't have come to that magnificent stage* (2: 345-348 p.16). There were two conversations held with Chicks. I sensed that she had become bored with the process, but she explained instead that she was not well enough to continue. At eighty, she remained a force to be reckoned with.

5.1.9. Dan's story

When he was six, Dan started school in London in the midst of the London Blitz. He could still recall the sounds from back then, and he simulated the Doodlebugs [V-1 flying bomb was an early German cruise missile] as they dropped bombs over London: *you'd hear it come over MMMMMMMMMMMMMMM and then it'd stop, and it falls and then BANG. And you'd get up and you'd turn round and the whole street's gone* (2: 41-43, p. 2). Another familiar sound was the wail of the sirens warning everyone to run for their lives.

A childhood spent in deprivation–little food and a disrupted education meant that Dan had to take risks to survive–and he did. Growing up, he identified closely with taking risks: *we actually fought with bricks, lumps of iron* [laughing] *oh yeah and that was life* (1: 244-245, p. 11). His historicity shaped him as a resilient person and this stood him in good stead for coming to Australia and taking risks. He and his

wife were ten pound Poms but the journey out was hazardous: *You get on the boat, this boat it was so old, it was in the paper, it was thirteen hundred people instead of six hundred and we were all under the water in the cabin* (1: 98-100, p. 5). Dan declared that this had been the biggest risk he had ever taken.

Initially life in Australia was difficult with jobs and housing in short supply. His wife Mary cried: *oh God what we done here? can we go back?* (1:110, p. 6). He took on anything that got in his way as he forged a new life for himself and his family: *in those days if you didn't try to get on you got nowhere 'cos nobody'd* [*sic*]*, not gonna help ya* [*sic*] (2: 185-186, p. 9). When a boss refused to pay him for a day's work, Dan recalled: *he wasn't gonna* [pay] *and he walked out and I got hold of 'im* [*sic*] *like,* [gesturing grabbing someone around the chest/ throat area] *like a leg of lamb, he gimme* [*sic*] *the fifty dollars and that's when I started to be smart in Australia* (1: 87-90, p. 5).

Hard, relentless toil was the touchstone of his life:

> *It's been a very hard working life. If you work hard in life you get*
> *your rewards. I mean nobody gives you anything. You have to put*
> *in the time to work and if you can work quite hard you can always*
> *make money* (1:163-169 p. 8).

Serious workplace injury to his coccyx was met 'head-on' by Dan as he took on authorities and won justice, but this came at a personal cost. Heavy drinking had been implicated in his diagnosis of dementia: *I made one mistake in life* [knocking his fist on the table] (2: 324, p.1), and this diagnosis presents risk now that he is not sure how he will manage. Throughout the conversations, he clutched the piece of paper on which Mary [his wife] had written the word Alzheimer's. This was a prompt for him.

This highly animated storytelling included body gestures, the use of objects to emphasise and illustrate, varying voice tone and volume accompanied by several

accents. In the third conversation Dan spoke in the Cockney back slang[3] from his butchering days in East London.

> Dan: *I'm quite well off really* 'cos [*sic*] *a lot of people you know*
> *have not got much yenom—sorry using backward slang again*
> *yenom money*
> Researcher: *How do you spell that?*
> Dan: *m-o-n-e-y you turn the letters backwards* (3: 279-282, p. 8).

This was the story of a working class masculinity which was played out in the workplace and the home. Dan was the provider for, and the protector of the family, and he felt a fierce pride in this provision. Hard work was what he was bringing to his battle with dementia−working in the house and garden and walking miles every day: *I've trained my legs into* [*being*] *a car* (3: 208, p. 6). While he told of his daily regimes with typical bluster, he conceded that: *as you go on it does get badder* [*sic*]*—there's no two words about it* (4: 246, p. 12). This lived experience of risk had been for a hard fought and often bitter survival, and having got there Dan has little appetite for risk today: *ah I just want the quiet life now* (2: 411- 412, p. 19). By the third conversation together he had declared war: *It's a war between Alzheimer's and the normal Dan, you know* (3: 18, p. 1). This battle with 'the big A' was still being waged when I said goodbye for the last time.

Throughout all the conversations I was empathic and curious. I was also mindful of my own position and perspective given my particular personal, cultural and historical location (L Finlay, 2008a). Dan's story of events or his standpoint, spoke to me so powerfully and I 'was open to', or allowed myself to be influenced by, what I had heard and learnt. I came to the meetings armed with my projections and pre-understandings, but after listening to Dan's riveting stories I re-examined them in the light of what I had learnt from Dan. This is the process of hermeneutics whereby a

---

[3] Back slang is thought to have originated in Victorian England, being used mainly by market sellers, such as butchers and greengrocers, to have private conversations behind their customers' backs and pass off lower quality goods to less observant customers.

fusion of horizons assisted interpretation and understanding from someone else's perspective. Understanding happens when our present understanding or 'horizon' is moved to a new understanding or horizon by a conversation with another person. This process of understanding a *fusion of horizons* is where the old and new horizons combine into something of living value.

5.1.10. Harriet's story

Harriet loved people. She was the only child of a widowed mother: *I've [been] moved around from pillar to post quite a bit with my mother* (1: 48-49, p. 4), but as always, she saw the positive side of things: *I was brought up to stand on my own two feet and as a matter of fact I'm very pleased that she brought me up that way, 'cos [sic] that's what I've had to do* (3: 61-63, p. 7). She attended to her mother until she passed away, and then moved to Australia with her husband and young son: *it was me who made the suggestion, not him, and then he said 'Well I'll go if you want to go'* (2: 40-41, p. 3).

Harriet and I met on four occasions. She reflected she had always been: *a bit adventurous in my life* (1:141 p. 6), and she and her husband: *stretched our wings* (2: 57-58 p. 4) and left England for Australia. She admitted that: *it was a bit of a shock but I've never regretted it—I like Australia* (2: 43-44, p. 3).

Over the two years that I knew her, this pragmatic woman confronted challenges in her life in a selfless and cheerful manner:

> *Well I've always tried to look on the bright side of life and if I've*
> *wanted to do something um I I I [sic] forget about myself and I do*
> *it, because I've always thought while you can do things, do them*
> (2: 277-279, p. 14).

However, a diagnosis of dementia had been a real shock for Harriet. This was the last thing she thought she would get and it changed everything*: I can tell that I am going down, I can tell I'm not stupid* (2: 269, p.14). She spoke frankly of independence, old age and death, and imposed limits on herself because now life is: *a bit dubious* (2: 63, p. 9). By the fourth meeting, her daily walking had ceased: *I find*

my legs go on me now (4: 248, p.10), and she felt that: *I can tell my body's probably, my body's more tired than my brain* (2: 311-312, p. 16). As her insight fluctuated she declared that: *I had a charmed life, even if it's something that's not quite right* (4: 141, p. 6).

Despite everything, her optimism and acceptance of things ensured she did not falter for long after her diagnosis*: But I'm not thinking as brightly as I used to do which is a bit of a problem to me. But I get along you know and I enjoy life* (3: 6-7, p.1). Of living to be now in her eighties she said:

> *It's a bonus yeah and [eh] I don't know how long—I know [um] that*
> *this will get me in the end I'm quite sure of that. But I don't know*
> *when it is and I'm not looking. In fact I don't care when it is [um]*
> *you know. If I've got two or three years, fair enough. If I don't fair*
> *enough because it doesn't worry me 'cos* [*sic*] *I'm not fear...*
> *fearing fear.*[*sic*] *I have no fear of death* (2: 85-89, p.10).

I oriented myself to Harriet's wonderful stories through the acknowledgement of my prejudices and fore-meanings. This allowed Harriet's story to present itself in all its otherness and assert its truth against my fore-meanings. I asked myself: What did Harriet mean when she said that she thought that dementia was the last thing that she would get? Did she think that you 'caught' dementia? In a subsequent meeting I tested my fore-knowledge and found that Harriet's truth was more to do with her love of reading and doing puzzles which she felt would keep her mind healthy and strong.

5.1.11. *Florence's story*

This was a story of 'no guts, no glory'. Over sixty years ago, a group of four young women set off for London when they were eighteen and one of those women was Florence: *you see the four of us were like sisters. Why would I stay home? It was the best thing we probably ever did (*2: 24-25 p. 3). These girls had remained friends ever since, and Florence and her old friend Gwen live within close proximity of each other: *She's tagged me as her memory you see* said Gwen [laughing] *but it's a bad habit to get into* (2: 63-64, p. 3). Throughout our time spent together Florence told of the upheaval and challenges in her life with her friend seated beside her, gently

prompting with facts or just nodding her head in agreement. After marriage, she moved to Nauru with her husband to: *get ahead* which was: *a big step when I think about it* (1: 36-37, p. 2). They subsequently had a disabled daughter who is now in her forties and in residential care. She remained the great uncertainty in her life from the beginning: *um that was a risk but I didn't think of it as a risk at the time* (1: 43-44, p. 2). For Florence, the weekly overnight stays at home together are over: *that's too hard now. It's too late in the game* (3: 162, p. 6).

Despite telling me over again that she was not the right person for this study, the four warm and funny conversations we had together gradually allowed risk to become apparent from her stories: *I didn't think of it as a risk at the time* (1: 52-53, p. 3) followed by: *It's probably the best thing that we did* (1: 53, p. 3). Florence lived alone in her own home and was independent, but on our first meeting she conceded that her memory was becoming a problem. She saw her driving as a risk: *I suppose, no I'm alright driving. I'm not scared driving. I wouldn't drive up the hills or anything* (3: 81-82, p. 3). She worked her way through the issues that arose with her dementia, for example she tied coloured ribbons on her car aerial to help overcome the problem of 'losing' her car in the supermarket car park.

Florence's need to manage and control her life in the face of memory loss was understandable, and at this time she had insight and independence to do so. But it was not without risk. She no longer wanted to try new things and was withdrawing from people. Her best friend Gwen commented: *I think it's out of character and it worries me that she's doing that* (4: 450, p. 20). Present and future risk was in the hands of Florence for now, as she withdrew from her social and physical activities. *I dunno* [*sic*] *you feel alone* (4: 96-97, p. 4) was a theme in the last conversation that we had together, and for a woman who had been: *the life of the party* (4: 189, p. 8) such disengagement may well have immediate health outcomes.

In our final meeting together, this fear of being on her own was strongly heard and it can be traced back to when she was eighteen and went to England: *but I wasn't going to be the one left behind* (1: 19-20, p. 1).The risk back then may have been not to go with her friends to Europe, but this fear of being alone was driving many decisions currently. She acknowledged that her world was shrinking: *You're not the*

same as you get older (4:170, p. 7). *The biggest problem* (3: 130, p. 5) of all however would be to move into a retirement village, and for her the risk was: *Not knowing anyone for a start* (2: 271, p.12). When we discussed risk for the final time, Florence assured me that: *I just go along with the flow and I don't do anything like that so you've probably come to the wrong person* (2: 77-78, p. 4).

5.1.12. Rosie's story

Reg and Rosie lived in the same house they built together over fifty years ago. They had prided themselves on its upkeep, and every five years they would paint it inside and out. Rosie identified the risk in her life as climbing up and onto the roof to paint, but conceded that these days: *I don't go right up on the top* [laughing] *you know I just put it where I can manage* (1:191-19, p. 9). Reg demurred at this point. Her older husband was physically disabled and did not get to the phone anymore, so Rosie was in charge of phone matters and arrangements. While she 'managed' things and presented a picture of control and organisation I had been 'stood up' three times by Rosie. I had rung and arranged a time to meet with her, but each time I drove the hour to her house she had gone out in her car. Her licence had been cancelled by her GP but this had either been ignored, or forgotten. Their daughter informed me by telephone that her mother's driving had caused great anguish in the family, and as a compromise the children had left the car in the garage but they had taken the battery out.

The last time we met, Rosie deferred to Reg frequently, and often repeated what he had said. She had reconsidered her situation, and felt that with advancing age: *These days I don't do silly things, maybe when I was younger I probably did more* (1: 34-35, p.15). Reflecting back on her life she said: *anyway we managed. We all managed* (1: 21, p. 2).

This chapter described the themes of adventure, survival and loss were seen and heard flowing from these sometimes intimate conversations. Anecdotes throughout gave texture to the daily shape of the lives of the participants. Whether they were faithfully mirrored events, or were seen through a distorted lens is—of little consequence. Importantly they situated the participants within what has been life's giddying ride. They were retold using Heidegger's conceptual vision of *historicity*,

and this heightened awareness of their significance and meaning. The stories were situated in the lifeworld of the participants who were seen as 'real' people who took 'real risks', and who sometimes failed. This added pathos and poignancy to their stories, and allowed me to engage on a more immediate and personal level. For the participants, this was their lived experience.

Importantly this chapter introduces the reader to the lives of the participants and paves the way to understanding the phenomenological analysis of its rich data.

CHAPTER 6 (PART A)

METHODOLOGICAL APPROACH TO ANALYSIS

In this chain and continuum, I am but one link. The story is me,
neither me nor mine. It does not really belong to me nor mine. I feel
greatly responsible for it, I also enjoy the irresponsibility of the
pleasure obtained through the process of transferring. Pleasure in the
copy, pleasure in the reproduction. No repetition can ever be
identical, but my story carries with it their stories, their history, and our
story repeats itself endlessly.

(Trinh Minh-ha: *Woman, Native, Other*)

This chapter explicates the analytic method that informs the interpretive analysis of the *essence* of risk in Part B of this chapter. The methodological excursion began with a hermeneutic phenomenological approach to language-oriented thinking, as seen in van Manen's human science method (1997). Throughout Part A of this chapter, conversational illustrations are used to demonstrate this analytic method that emulates and builds on the methodology of van Manen (1990).

6.1. Language as communication

Hermeneutic phenomenology privileges language as a means of interpretation. People living with dementia use the elements of language as social tools, the use of which is determined by the user to ensure purposeful communication (Sabat, 1991). Hydén refers to language as a "physical artefact" (2013a, p. 131) which can vary in pitch, rhythm, tempo and prosody and used to stress or clarify an aspect of the verbal sound. This gives the spoken word a new or an enhanced meaning. Dan for example, remembered war-torn London and the rhythm of his voice gathered pace:

You'd be walking along and you'd hear the [makes a sound like a
motor] *and you'd be pushed into the pavement and the arched*
curve and you wouldn't move, and if you did someone would go
[makes a sound like a whooshing bang] *and you'd get up and the*
street wouldn't be there there'd just be bodies everywhere
(1: 224-228, p.10).

Phenomenology comprises both verbal and non-verbal elements of language "to express and clarify meaning" (Hydén, 2013a, p. 131). How stories are told and occasioned are important sources of meaning within a story and offer rich insights into the *who* and *why* of a telling at a particular time. Within this study, many non-verbal possibilities were used within the conversations as sources of meaning. This included the use of silence, props such as a pocket knife and a coaster which was constantly pushed backwards and forwards along the table-top throughout the conversation to demonstrate a point. Chicks maintained her prior sense of self by bedazzling me with her stylish presentation—beautiful jewellery and matching clothing and footwear. She exuded confidence and style yet she shuffled her feet constantly under her chair. These non-verbal elements are frequently required in telling a story when verbal abilities are impaired. The person living with dementia becomes a "creative problem solver" (Hydén, 2013b, p. 365) in order to relate their version of events.

The use of the body as a form of communication included shrugging of shoulders, shaking of the head and the wringing of hands all of which enhanced the intensity of meaning throughout a dramatic telling. This effort demands of the listener to be equally creative and generous in their relations with the storyteller (Frank, 2004). The collaborative and embodied aspects of the conversations were annotated within the transcripts of the conversations, and contributed to the fusion of ideas in the search for shared meanings.

6.2.   Positioning the researcher: the fusion of ideas

In guiding this analysis van Manen's method (1990, p. 79) seeks a process of insightful invention, discovery or disclosure ... a free act of 'seeing' meaning. While no systematic rules apply, this analysis depends on "the interpretive sensitivity, inventive thoughtfulness, scholarly tact, and writing talent of the human science researcher" (van Manen, 1990, p. 34). Gadamer's hermeneutics (1989) assisted with moving beyond merely descriptive accounts, actively involving the researcher's world in the search for meaning. This was done by creating an inter-relational dialogue "where insiders' and observers' conceptions interact" (McCormack, 2001, p. 65); and where both parties bring their pre-understandings through their own historical context. Gadamer argued that the essence of historical context "lay in the never-

ending process of dialogic interchange between the interpreter and the text" (Wolin, 2004, p. 102). He resurrected the notion of *prejudices* as a central component of our 'intellectual situatedness' that constitutes our being within the text. Gadamer argued that *prejudice* is a positive concept rather than a distortion of the truth (Wolin, 2004) The 'interpreter' stands and establishes *prejudices* that affect how he/ she will make interpretations. For Gadamer, these *prejudices* are not something that hinders our ability to make interpretations, but are both integral to the reality of being, and are the basis of our being able to understand history (Gadamer, 1975, 1989). They form a part of the intersubjectivity between two people which is important and unavoidable. I was interrogated by the data throughout this study. The participant had an active role in this interpretive process, by rephrasing and clarifying the intended meaning:

> Researcher*: When we were talking about your childhood, your*
> *family, growing up, moving away and school and then an*
> *academic career with lots of fantastic travel you summed it all up:*
> *'Boy I'm glad I did what I did when I did it'*
> Veronica: *Mmm*
> Researcher: *What did you mean by that?*
> Veronica*: 'Cos* [*sic*] *I was er* [*sic*] *venturing out in a wider way*
> Researcher*: Yes and that's not something that you'd do today?*
> Veronica*: Probably not 'cos* [*sic*] *I'm in my seventies now* [laughing]
> (3: 141-148, p. 6).

This dialogue provides an example of Gadamer's *fusion of horizons* (1975) where the prejudices of the participant and those of the researcher meet in order to create a new understanding. My understanding here was that Veronica felt that dementia had 'curtailed' her life—that her memory loss and frequent falls were slowing her down however on further questioning she admitted that age was the obstacle for her.

Understanding then "becomes a living event" (McCormack, 2001, p. 67) in which the interpreter and the teller actively participate in the story that unfolds. This was a frequent occurrence within the interviews, as understanding is always in constant movement, from the whole to the parts and vice versa (Heidegger, 1962). This longitudinal design provided trustworthiness to the research process as it afforded an

opportunity to seek clarification in subsequent interviews. I sought clarification of meaning on many occasions by reflectively asking:

What did you mean when you said...?
Is this like...?
Would you do it again...?

This is a way of being in the world—a very specific kind of engagement with the world (Merleau-Ponty, 1962/2006; van Manen, 2014), which uncovers insights and meaning, and brings us in more direct contact with that world. The stories told are the data of this study, and the data are composed of elements—words, phrases and sentences from the being-in-the-world of these conversations and its interrelatedness with my field notes. These elements will illustrate aspects of the objects of analysis—meaning units, minor themes and primary themes, and will be examined many times over in multiple readings and listening as the essence of risk is sought.

6.3.   Drawing the elements together

The analysis began with the highlighting of elements within the story, as discussed in the detailed reading approach of van Manen (1990) (see 4.1.7). This was achieved by going from the parts [of the text] to the whole and back again (van Manen, 1990) and was an iterative and inductive process of deep engagement with the data. I continually searched for possible meanings which could be followed up in the next conversation as I read and re-read what had been said and in what particular context. This information was then entered into two tables 6.1 and 6.2 below. These tables were created for each conversation for all of the participants.

 In Table 1 the elements were grouped and referred to as 'Literal coding of content'. The first column is an extract from the conversation with the participant, referred to as the 'Script'. The second column highlighted key words, phrases or sentences from the script, the third column summarised the interpretation of my understanding of the key words, phrases or sentences within the context of the conversation and the participant's story.

The following table is an example of Jessie's first interview.

Table 6.1 Literal coding of content–words, statements, ideas

Transcript 1/1 Jessie		
Script	**Word/phrase/ sentence**	**Understanding of this within the context of the interview and the life story**
"I never, ever regretted it, never"	Never regretted It	Positive outlook—always no regret
"Well, in a way when I come here, and my mother was here and different ones I get a wee bit earnest and I thought I wonder if I'll like it and all that but we all come out my husband and I and the children Well I felt a bit excited coming to my mother ya know but deep down I thought "Am I doing the right thing?""	Am I doing the right thing?	This was a major risk for Jessie and her family
"I hope it's all right especially for the men's part you know because my mother was here"	For the men's part	Concern about how her husband would cope and therefore unwilling to make the decision to come to Australia
"I just got on with it, I just got on with it you've just gotta get up with life you know whatever happens not let it worry you"	Just got on with it	Coped with whatever came along
"You have something and then you lose it"	Something and lose it	Nothing is forever

In Table 2 incidental data highlights repeated words and phrases emphasised in their form of delivery and referred to as 'Incidental coding'. These forms of delivery are demonstrated in three columns, the first being the relevant phrase or emphasised words, the second column displays the reason that the data has been highlighted and the third column 'meaning' provides a possible interpretation of the content of the first column, and a potential meaning unit.

Table 6. 2 Incidental coding

Transcript 1/1 Jessie	Reason	Potential meaning unit
"I'm quite happy"	Repeated twenty times	Kind of person that they are
"Work-'cos I've always worked" "Try and keep it alright" (reference to when her husband had no job)	Referred to three times but with many associated themes. Work allowed her to get out of the house, make friends, meet people, pay the bills when her husband could not get work, *we did alright*	Independence
"I never, ever regretted it, NEVER"	Voice tone, increased volume, emphatic delivery	Regret or lack of it
"If it's something that I really want to do"	Repeated three times	Independence

These two tables demonstrate a process where similar meanings are grouped and labelled with a word or a phrase summing them up. This 'phenomenological reduction' (Moustakas, 1994) is an iterative process of "looking and describing and then looking again and describing again" (1994, p. 90). This process is not only a way of seeing, but a way of listening to the phenomena, and this opens up its textures and other ways of meaning.

Both tables provided careful management of the data as it generated and provided subsequent reference points for discussion in ensuring conversations. Eight of these tables were completed for each participant if they took part in all four interviews. The process of grouping and naming continued until the completion of the data collection stage. Meaning units began to appear as can be seen in the right hand column of table 6.2, and they are increasingly horizontalised where initially, all meaning units stood alone. Overtime they may overlap or become redundant and may be deleted.

This leaves only the horizons: "the textural meanings and invariant constituents of the phenomenon" (Moustakas, 1994, p. 97). This is the gradual paring back, contrasting, comparing and exposing of a thought or statement in an effort to eventually comprehend its *essence.*

The reading and re-reading of the transcripts and the listening to their telling continued as the second phase of the analysis began. As the titles of meaning units were created, they frequently underwent multiple changes as they shifted in emphasis, or were changed in order to make them transparent and relevant. Listening and re-listening to the taped conversations invoked feelings, hunches and views that I needed to capture and 'think through'. Aspects of speech such as a prolonged silence or a deep sigh added salience to an otherwise ordinary sentence or statement, and were noted within the transcript of the conversation. I also referred back to them by listening to the tapes again.

This process acknowledged the 'being-in-the-world' (Heidegger, 1962) of the participants and revealed their positioning within their stories. The lived experience made sense in these terms, and my understanding of the data was enhanced. This method also acted as a means of checking emerging issues from the data which I wanted to discuss with participants in follow-up conversations. The hunches and ideas maintained the hermeneutic focus of the research approach that is the making explicit of my 'prejudices' (Gadamer, 1975). For example, within the meaning unit of *ways and means,* deterministic words such as *personality* were replaced*,* and became *human nature,* and finally became *kind of person that they are.* This thinking allowed the process to be less prescriptive and more open—always searching for nuances and other ways of expression.The contents of each meaning unit were then re-examined, and an expression or quotation from one of the participants within the unit was sought in order to encapsulate its meaning. For example 'humour' was a meaning unit as many of the participants loved to laugh. After Harriet accepted her diagnosis she said: *I haven't lost my sense of...joking* [searching to find the word humour] (4: 200-201, p. 8). NVivo is designed to work with the rich text-based information of qualitative data and each conversation was imported, and meaning units and later minor themes were created from the tables. This system of gathering and collating the ideas is called aggregating, and it assisted with the refinement and

sorting of ideas within a very large amount of data. The interviews were pooled and contrasted after each one had been transcribed and uploaded into NVivo. For instance, following the second round of interviews, Table 6.3 connected the previous interviews with similar statements. This table highlighted similarity in content and meaning, and over the two conversations, it emerged as a possible meaning unit. These transcripts were then uploaded to NVivo and the search continued for similar words and statements which uncovered patterns and replication of meaning—as seen in the table of 6.3. Florence for example exemplified this 'building on' from what has gone before in previous conversations. In the initial conversation, Florence said of moving to Nauru with her husband and children:

> *Oh yes, I think when you're young is the time to do these things.*
> *You don't want to be trooping somewhere with your husband and*
> *kids, take them out of schools to move them somewhere else. But*
> *[um] as I say I didn't think of it as a risk I just went along. It's*
> *probably the best thing that we did* (1: 50-53, p. 3)*.*

When talking of going overseas with her girlfriends at eighteen in the second conversation Florence recalled:

> *But I was the one who was least keen to go. I was more of a*
> *homebody and it all turned out wonderfully well. We did office*
> *jobs, we took time off, we hitchhiked all over Europe staying in*
> *youth hostels and sleeping out at times. Yeah you see the four of*
> *us were like sisters—why would I stay home? It was the best thing*
> *we probably ever did* (2: 24-26, p. 2).

These interviews were imported in part into table 6.3 where many key statements were contained within a possible meaning unit.

Table 6.3 The linking of phrases and meaning over time

Conversation 1	Conversation 2	Possible meaning unit
"It's probably the best thing that we did"	It was the best thing that we probably did	Kind of person that they are
"I haven't got a boyfriend-wouldn't know what to do with it if I did"	F: And we're all still here. I often wonder which one of us will be the first to die I said to Gwen [laughing] Gwen: And I told her to shut up [laughing all round] F: How will I know? I'm the first one to lose me [*sic*] memory [more laughing]	Humour

Within van Manen's human science method (1990), interpretation begins with data collection, and as the data was transcribed, it was then coded and pooled in the search for meaning. Table 6.3 demonstrated *how* the meaning units of *kind of person that they are* and *humour* were created. The longitudinal nature of this thesis allowed for further conversations with many more statements and further 'building on' of these meaning units took place. By the completion of all four interviews, there were forty meaning units in total. While each meaning unit encapsulated an aspect or a thing, I was beginning to see statements that related and overlapped with each other within the data and eventually these combined to form the minor theme of *ways and means of doing things.* This minor theme is based on a quote from William who related the story of being in a shop when quite suddenly he heard the sound of shots being fired nearby. He tells it thus: *And I got down on the floor and crawled under the edge and got out and went home and never went back at all. So there's always ways and means of doing something* (1:180-182, p. 9). This minor theme was abbreviated to *ways and means.* There were eventually five minor themes in total—*ways and means, loss, thinking, age* and *risk* (see Graph 6.4).

Tables 6.1 and 6.2 demonstrated how I laid bare the data as I searched for words and phrases which signified a deeper meaning. For example, the word 'happy' (table

6.1) was used by Jessie twenty times in her first interview—and the word 'quite' preceded happy on fifteen of those instances. This is the most outstanding use of one word in all the interviews. It demanded a reflexive search for a deeper meaning by asking myself:

Why the use of this word and not something else?
Is quite happy the same as happy?
Or is it something similar? Did it really mean that she was happy?
Could you really be happy that much in one interview?
Did the word have multiple meanings for Jessie?
Or was it really saying that she was not unhappy?

In interview two, Jessie was 'quite happy' five times, but the word does not appear in the last two interviews except to comment on her move into a nursing home: *Who could be unhappy in here? I think it's good it's up to yourself* (2: 131, p. 2).

To establish its intended meaning I referred to the different contexts of being happy which were used by Jessie, and fitted into several minor themes. For example, *but I do alright which is good and I've got Meg and the kids, oh no I'm quite happy* (1: 60-81, p. 4) which referenced her day-to-day life, which fitted into the minor theme of ; 'kind of person that you are' and: *I enjoyed it, but I'm* [*sic*]*, I was happy to come back, yeah, quite happy here* (1: 3, p. 3), which was how she felt after her only trip back to her homeland Scotland. This fitted into the minor theme of *ways and means* as Jessie's ongoing positive attitude reflected her approach to life—she accepted her lot and made the very best of it. In the last interview two years later, Jessie nominated *dancing* and her inability to *work* as two of the losses in her life, for she loved to do both but no longer was able to do so. Her optimism nevertheless remained undaunted and the importance of work was reinforced in the context of the last interview when she asked me *if I had a job and if I was happy?*

Jessie: *Are you out each day- do you work each day? Are you happy?*
Researcher: *Yes I do, I do, and I'm happy*
Jessie: *From Monday to Friday? work each day... are you happy?*

(4: 31-33, pp. 15-16).

The meaning here is about being engaged and doing things that make you happy, and 'work' was coded in *loss* because it is something of value which Jessie can no longer do. It fitted into several minor themes. It was coded in *loss* and *kind of person that they are* as it also reflected Jessie's strong work ethic. This demonstrates a "collaborative hermeneutic conversation" (1990, p. 99) where the participant may reflect on experiences in subsequent interviews, and where the meaning "a deepened and more reflective understanding of the meaning" can be determined (1990, p. 86). Reading the interviews may obfuscate their intended meaning in what can only be seen as highly nuanced language, and therefore the knowledge of the personal story of each participant is important. My experiential knowledge of communication in dementia, and the work of van Manen (1990) came to the fore. Going back and reading the reflective journal and field notes 'grounded' initial thoughts about minor themes and allowed the study to move forward reflexively.

The *hermeneutic circle of understanding* (Heidegger, 1962) was at work here, with three phases of analysis—prior understanding, interrogation of the social phenomenon and reflection on presuppositions, all of which interrelate, and become the notion of 'reflexivity' (McCormack, 2001, p. 67). This enhances the rigour of the study (Guba & Lincoln, 1994).

6.4.   The progression of analysis

The thinking of hermeneutic phenomenology was utilised to identify minor themes from meaning units described above by a careful process of reflection and analysis. The quality of linkages is only as good as the data to support them and before writing each day, I read through each participant's individual interviews again. I then re-read key words and statements to ensure that one had not been overlooked—or more importantly misinterpreted. This is what Merriam refers to as "imaginative variation", which involves viewing the data from various perspectives (2014, p. 26). The words contained within the statement stood apart from their 'owner' and could be seen in a more analytical, de-contextualised light—not connected to a personality or a place but an outright, stand-alone thought, opinion or idea. This made the analysis clearer for me, as the phenomenon was isolated in order to comprehend its essence. A

statement being owned by more than one participant resulted in repetition, but it meant that a single statement could be viewed in a number of ways, and that it had been imported into at least one node, and not overlooked. The process of identifying words, statements and their classification was dynamic and fluid over time, and attention was paid to the preceding and proceeding statements as this often 'set up' the intended meaning of the statement.

I then needed to closely examine the content of each minor theme and interrogate its meaning. This was done while maintaining a "strong and oriented relation" (van Manen, 1997, p. 135) to the research question of risk:

What is the lived experience of risk for a person with a recent diagnosis of dementia? Does the minor theme reflect all the meaning units?
Is there a better term that encapsulates all those meanings?
Will it hold up to scrutiny as the analysis proceeds?

This was a process that ultimately enhanced the trustworthiness of the analysis and of the study. Being able to include a word or statement in more than one meaning unit permitted an exhaustive review of its meaning, and this is important when a person has dementia. A marked variability in the use of language can be observed in this study, and it was important that the intent of the language used was as close as possible to its interpreted meaning. The coding of interview tables (Tables 6.1 and 6.2) allowed me to manipulate the data and conduct various searches seeking description and intuiting for its meanings. This was done while adding to, and then reducing the content of the meaning units. This is the viewing of phenomena through the interpretive schema of Gadamer which allows the integration of the participant's concepts with those of the researcher (McCormack, 2001).

6.5.   Assigning themes to the data

The five minor themes (i.e. *ways and means, loss, age, thinking and risk*) were developed and then used to inform and create the primary themes of this study. I continued to work the data within the transcriptions while listening to the audiotapes of the interviews, with the research question firmly within the framework. Slowly the linking of minor themes became two themes within the data, and it was done by

looking for patterns of words, sentences and ideas and seeking their intended meaning within the many entries in the conversations. Moving them around, together and often inserting them in two places at once required intuition as in van Manen's wholistic/ semantic approach) (see section 4.1.7), and a concentrated 'look and see' approach to the data. On occasion it brought together what appeared to be disparate comments linked only by the same word, but when considered intuitively within the context of a life story they became similar in intent and meaning—or they became more disparate. Eventually there was reflexivity between the minor themes and the two 'potential' primary themes of *transition* and *resilience* emerged from the data.

This analysis is an iterative process of reading/re-reading and listening/re-listening and is Part A of this chapter. The resultant coding was demonstrated within the tables. From the coding, the uncovering of the two primary themes, their meaning units and minor themes were revealed for "the possibility of plausible insights" (van Manen, 1990, p. 9), and their orientation to the research question.

CHAPTER 6 (PART B)

AN INTERPRETIVE ANALYSIS

That is the way I think of the short story and what is part of it, the sketch, anecdote, jokes cunning, philosophical, and biting, legends and fragments. Where do they come from? Who invents them? Everyone perhaps. Who remembers them so that they pass endlessly across city life? I know some of those marvellous rememberers who pass on their daily earnings in story; and then they are forgotten to become, fragments, mysterious inclinations. Any treasury of story is a residue of the past and a record of the day.

(Christina Stead: *Ocean of Story*)

Christina Stead notes that we may find stories are "a residue of the past and a record of the day" (1986, p. 3) and it is here that "those marvellous rememberers who pass on their daily earnings in story" enabled this interpretive analysis to begin.

The analysis was centred on the participants' stories while demonstrating the dialogic nature of phenomenology—a situation which van Manen (1990, p. 100) refers to as "talking together like friends". This intersubjective research is between two people who will build a mutual relation with the phenomenon. The analysis began with the transcription of the conversations and reading and the listening to them over time as detailed in Part A of this chapter The following themes provided the "universes of meaning" that we can live through (van Manen, 1990, p. 90), in order to find out *how* the residues of the past can inform the present experience of living with dementia.

6.6.   The emergence of themes: a graphical depiction

The two primary themes embedded in the lived experience of risk were *transition* and *resilience*. They were tightly intertwined, sharing meaning units and minor themes which provided insights into the lived experience of risk. These primary themes allowed the navigation and exploration of these universes that permitted understanding of the *essence* of risk for the participants living with a recent diagnosis of dementia.

Central to the emergence of these two themes were core questions such as: *How do the themes transition and resilience articulate the lived experience of risk? What are the pathways that they take to this lived experience?* This is demonstrated below in a simple matrix of the analysis of this study.
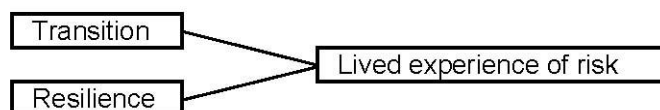
Figure 6.1 Analysis of this study

NVivo was utilised to chart transition and resilience within the meaning units of the lived experience of risk for the participant following a diagnosis of dementia. Using the conversation data and associated material this empirical analysis focused on the participants' life worlds. The graph below (Figure 6. 2) demonstrates the frequency of, and trends in coding by primary theme across four conversations with six participants over a period of two years. The data from participants who did not complete all interviews was withheld as it did not wholly represent the full progression of coding over what was approximately two years.
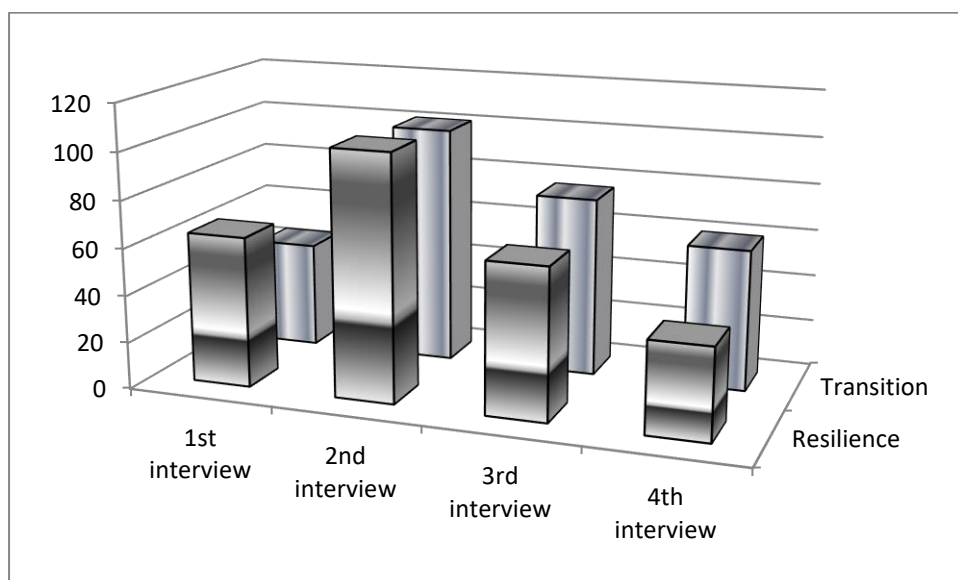
Figure 6.2 The frequency of coding of the two themes *resilience* and *transition* across conversations

This graph highlights the frequency of coding of the two themes across subsequent conversations. For example, in the first conversation there were fifty-eight references to aspects of the primary theme of resilience. In contrast there were forty references which were encapsulated in the other primary theme—transition.

Initially the frequency of the coding for both *transition* and *resilience* was generally low in relation to the later conversations, particularly in relation to the second conversation. This discrepancy may be related to the first interview being essentially a 'getting-to-know-you' conversation with an introductory focus on risk, as well as establishing an understanding for the participants of the aims and objectives of the research. There was also a discrepancy in the coding frequency between the primary themes which may have been due to the participants coming to terms with transition. This initial time together began the process of building familiarity and trust. Over time, this enabled a "true conversation" to commence (van Manen, 1990, p. 98), whereby a personal relation developed between two people and the phenomenon to which they were both oriented. The conversation is then structured as a triad, and "its hermeneutic thrust" (van Manen, 1990, p.98) is oriented to sense-making and the interpretation of the phenomenon, whose role is to keep the personal relation between the researcher and the participant centre stage (Wiles, Wild, Kerse, & Allen, 2012).

When I met the participants for the second time, the highest number of codings was recorded overall as the participants were keen to continue telling stories of risk. The telling and re-telling seemed like a new story being told for the first time—littered with new details, new people and new versions of already-told events. I was also able to build rapport to ask questions of the story thus far:

> *What did the participant mean by that?*
> *What happened next?*
> *How did that make him/her feel?*

Keeping the question open and oriented to the substance of the phenomenon being investigated are van Manen's (1990) strategies. The participant became the co-

investigator in the study and this allowed the experience to be explored more fully, demonstrating the importance of the relationship in establishing trust and mutual understanding between two people who had not known each other long (Sellevold, Egede-Nissen, Jakkobsen, & Sørlie, 2013).

The reduced incidence of coding as demonstrated in the later interviews illustrated the effects of a progressive illness on the communication abilities of the participants. These effects were witnessed first-hand in our face-to-face interviews. Instances of anomia and aphasia were progressively discerned as the participants were telling their stories, and the effect of a failing memory was a comment made reflectively and often. For example: *yes, my memory's the only thing. My memory's the worst part, 'cos [sic] I'm losing that a bit. See I can't remember what I did yesterday* (Florence 1: 270-271, p. 12). As the participants developed a sense of the meaning that risk held for them, they were able to explore *present* risk or what I will refer to as *living* risk that is, whether or not they were currently taking a risk.

The primary themes could not be limited to essential characteristics, rather they were amalgams of the thoughts, ideas and statements of the participants which made up the meaning units which were then grouped into minor themes and from which two primary themes were uncovered. Each stage of the analysis was closely interwoven. Through a careful and sensitive process of interrogation, the thematic strands of meaning coalesced together or were pulled apart as the meaning units and minor themes were uncovered and ultimately they combined to form the primary themes of resilience and transition. All these elements were embedded in the lived experience of risk; tightly intertwined. They are the 'how' of *how* the primary themes became the essence of risk.

The following sections explore the themes of *transition* and *resilience*, their associated minor themes and the meaning units of which they are composed. It begins with the primary theme of *transition.*

6.7.   The primary theme of transition: defining its meaning

Everyday reality is characterised by relatively stable patterns over time where transitional change may be slow and subtle. Typical structural life transitions such as

going to school, working life and retirement buffer the experiential variances upon which one's everyday life is built and maintain continuity and stability throughout a lifetime (Selder, 1989). *Transition* is a primary theme used in this study to identify the variances in the meaning of risk which the participants attach to the transition of living with dementia. These experiential variances represent major transitional change associated with dementia as a result of processes which occur during transition. They may be physical, social, environmental, cognitive, behavioural and/or interpersonal changes that happen over time. Changes such as these have variable impacts on people, and in the case of a stressful transition such as an illness "they move the individual in the direction of vulnerability and risk" (Schumacher, Jones, & Meleis, 1999, p. 7).

For the purposes of this study, a transition is defined as the movement from "one life phase, situation, or status to another" (Schumacher, et al., 1999, p. 2). The passage, however, is rarely linear and can be plagued by uncertainty, loss and doubt. Transitions can be precipitated by significant marker events or turning points which may be sudden or gradual, and require new strategies to cope with daily life experiences (Rose & Lopez, 2012). This 'transition point' has been described as some form of destabilisation in the life of a person, which may result for example in a change in the level of care and/or support they require. Following on from this, a 'care transition' for a person living with dementia is taken to mean any movement between or within support interventions, whether it is due to a change in the type or level of care required or due to other factors (Manthorpe, et al., 2011). This transition may mean a move from home to high care in an aged care facility; or for a person living at home it may involve changes in caring arrangements, including informal or formal community services.

The following section uncovers the meaning of the three minor themes of *thinking, age* and *risk.* Their meanings cohered around the primary theme of *transition* which resisted a singular definition, instead articulating a particular and personal response from each participant. Within the three minor themes there were many meaning units, and they will be uncovered and explored in this chapter**.**

Figure 6.3 demonstrates the three minor themes of *thinking, age* and *risk.*

THEME   MINOR THEME   MEANING UNIT

```
                                          ┌─ Acknowledged memory loss
                                          ├─ Refusal to accept loss and diagnosis
                          Thinking ───────┤
                                          ├─ Lack of insight due to dementia
                                          └─ Change to do with dementia

   Transition                                ┌─ Ageing
                             Age ────────────┤
                                             └─ Age and dementia

                                          ┌─ Risk and dementia
                                          ├─ Risk today
                             Risk ────────┤─ Future risk
                                          ├─ Denial of risk
                                          └─ Participant's perception of risk
```
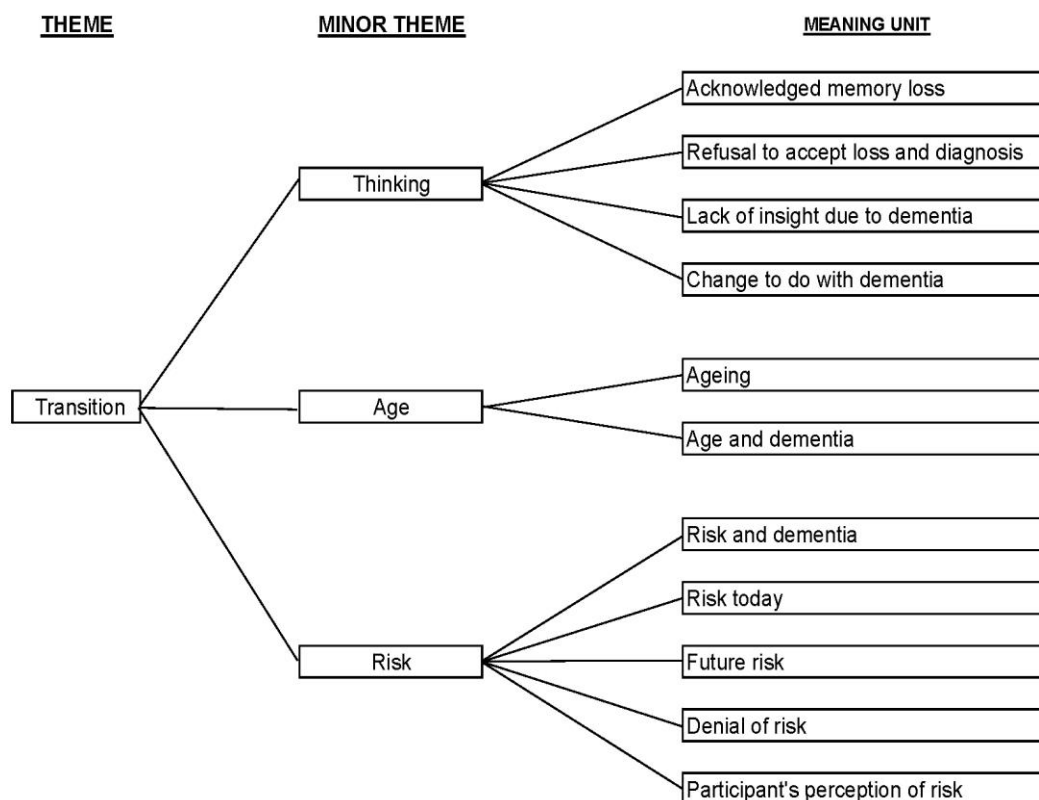
Figure 6. 3. The primary theme of *transition* and its attendant minor themes and meaning units

This matrix conceptualises the break-up of the theme of *transition* into minor themes and meaning units. Their interconnectivity is visible whether going from the parts to the whole, or vice versa.

6.7.1. Thinking: a minor theme within transition

> *Well when you get Alzheimer's—it's a disease that doesn't touch*
> *you for quite a long while and then all of a sudden you can't think*
> (Dan 3: 6-7, p. 1).

How the participants viewed their world, their reality was encapsulated in this minor theme of *thinking,* filtered through the lens of a diagnosis of dementia. This was

thinking that was bound up in memories, in idle thoughts and in talking about one's life *then*, *now* and *into* the future. Speaking *with* the participants and listening to the prosody within their stories shone a light on *how* and *what* they were thinking, and *why*. Four meaning units made up this minor theme, and they referred to changes in cognitive abilities, a shifting memory and variable insight. They were *acknowledged memory loss, refusal to accept loss and diagnosis, lack of insight due to dementia* and *change to do with dementia* (see Figure 6.3).

Fluctuations in and diminishing verbal abilities and cognisance were evidenced across the longitudinal contour of the conversations that we shared. For the participants, it imposed the reality of the effects of dementia related to *thinking.* Their experiences of transition of their communication abilities associated with thinking were managed in their own particular ways. Florence, for example, was enjoying telling her story about going by sea to Nauru with her new husband, and the conversation flowed until she faltered: *I don't even know how long it took. You're making this memory go right back and I can't remember* (1: 148-149, p. 4). This memory lapse signalled the end of the storytelling about Nauru on that day. With her best friend Gwen by her side in the subsequent conversation, Florence acknowledged her memory loss and deferred to Gwen when she had difficulty recalling events:

> Florence: 'Cos [*sic*] *I was a bit older, I can't remember how old I*
> *was. Gwen will know, ask Gwen the questions* [laughing]
> Gwen: *She's tagged me as her memory you see* [laughing], *but it's*
> *a bad habit to get into*
> Florence*: No it's good it keeps you on your brain* [*sic*]. *You see I*
> *am losing mine. So put that down in your paper* [both women
> laughing]. *I definitely am* [laughing]. *I write in that book-where is it?*
> *Oh I don't know somewhere around. I write in a diary nearly every*
> *day* (2: 61-67, p. 4).

Within the conversations, laughter kept these difficult moments light and bearable for Florence, and she used it to offset the reality of the transitional effects on her memory

and her life that she was experiencing. This allowed her to look to the future and move forward with her life.

Other participants expressed feelings of frustration and loss when commenting on their increasing difficulty with memory and reasoning. Harriet prided herself on her ability to think and rationalise: *you've got to be wise now you can't do things that you did earlier on* (3: 196-197, p. 9) but her memory was now 'letting her down', and her new reality was a serious matter: *but I'm not thinking as brightly as I used to do, which is a bit of a problem to me* (3: 6-7, p. 1). With great trepidation Dan recalled dementia's effects: *You don't know. You cry, you wake up and you think Christ where am I? And then you say,* [pause] *even now you say 'Where I been* [*sic*] *this morning?* (1: 360-361, p.15). This exemplifies the reality of Dan's experience of memory loss associated with living with dementia as he explained: *You gotta* [*sic*] *have two sides of a brain. But half of it goes and you don't know where it's gone to. And you can never find it* (1: 360-361, p.15). Along with his fear of further memory loss was quiet acceptance and resignation: *Your brain goes a bit, doesn't it?* (4: 283, p. 13).

Dan's memory loss was only part of the problem however: *I don't think I do things that wrong, but sometimes you know it just happens* (4: 236-237, p.11). General confusion and disorientation to time and place turned Dan's world upside down, causing anguish and despair, and he lashed out at those closest to him:

> *Sometimes when I'm sitting here and I've got this* [dementia]. *And I don't know me* [*sic*] *name or where I've been. I don't like that. I like to know everything so I can counteract it. Now the only thing I can look forward to is getting in the box* (3: 333-336, p. 30).

The insidious nature of transient memory loss was emphasised and articulated by Harriet when she mused that: *I'm forgetting a lot and I don't like this forgetting a lot, because it's part of my problem* (4: 45-46, p. 6). She accepted her cognitive changes, knowing that they were ongoing: *I've gone down even more so, and I can tell that I am going down, I can tell I'm not stupid* (2: 298-302, p. 15).

Unlike Dan and Harriet who acknowledged the association between memory loss and dementia, Chicks did not want to contemplate that she had a diagnosis at all, She avoided the association altogether by glossing over the lapses in her memory and importantly the uncertainty by actively maintaining an image, both personally and publicly. This was a presentation of self which was in danger of being eroded by dementia. It was not long before she 'dismissed' me, explaining that she was too busy to continue meeting. She was wary of the conversations being recorded on the two audio machines, and repeated several times that if I asked her anything that she considered private then she simply would not answer me. I assured her that I would not be asking sensitive questions of her, and I was on guard throughout the time together, allowing her to take the floor. At no time did I want her to feel diminished by her memory changes, and Chicks' dignity and rights were upheld at all times. This is a vigilant reminder of van Manen's 'phenomenology of practice' (2007) where phenomenological research is the attentive practice of thoughtfulness and tact (van Manen, 1984)—and not just about the phenomenon itself. More importantly it is about the experience of the phenomenon and its impact on the person.

While exhibiting and acknowledging memory loss in her verbal communication: *I've forgotten what I was going to say again* (2: 11, p. 1), the word memory was avoided altogether in the conversations that I had with Chicks. Fluctuations in memory were evidenced however in the short and final conversation: *I've forgotten what I was going to say* (2: 11, p. 1); and *it has something to do with—ah* [delay] (1: 47-48, p. 3) and: *Oh God, her name's gone from me* (2: 123, p. 6). Chicks was fearful of losing control of her life, and she was hanging 'on tight' to what she had. Her voice was at times shrill in its emphasis of what she was saying: *AT MY AGE TAKE A RISK?* (2: 70-71, p. 12). She did not bother with anything that stood in her way of having a good time, and having dementia posed an unthinkable risk for her.

Chicks' seemingly unshakable self-confidence was being tested now by the unwelcome uncertainty of a progressive illness, and there would be no more discussion: *No I wouldn't change my life, the only, no* [banging the table], *I wouldn't change my life one iota. Because if I hadn't have gone through that bad stage I wouldn't have come to that magnificent stage* (2: 345-348, p. 15). This was a bold

declaration which aimed to protect the normality and continuity of Chicks' identity before the onset of dementia. It marked a profound change in thinking for Chicks, a denial of all that she had been told by her doctor, and it would require an emotional effort for her to keep the facade of being 'normal' going.

The field notes from Chicks' first interview set the stage for her presentation; of her home, her aesthetic and herself. Chicks was full of life and fun, supporting her story with gesticulating hands with bright red fingernails and multiple bangles jangling along to the cadence within the telling of the story. I counted at least a dozen rings, with five or six just on her wedding finger. She wore a richly coloured beautiful butterfly scarf which she kept throwing back over her left shoulder. Later I was shown her oil paintings and the family photos throughout the house. Her beloved second husband's photo was on display in her lovely unit, and a third relationship with Frank was displayed in the spare bedroom. Frank had been a generous and kind man, but she said that he had his problems; he drank too much but not when he was with her, as she would not allow it. These notes from the first interview indicate that Chicks was a little muddled regarding dates and names but they were the only signs of memory loss.

Memory is something that you have worked for all of your life—we collect and build our memories to create a unique sense of self. Rosie was only too aware of memory's importance, but she was relying on other people's memories to fill in the gaps of her life story now. She had a protective husband who was always by her side during our conversations. Reg provided emotional support for Rosie's participation in the study, but he was inclined to answer the questions on her behalf, and when I re-directed the question to her, she often simply agreed with Reg. Details of their long marriage were shared, and they revealed Reg as the family's patriarch, the breadwinner and the decision-maker. In her efforts to stay abreast of the conversation going on around her, details within the conversation often were omitted and filled in by others, and words often proved elusive to come up with in mid-sentence and were glossed over. When asked how her memory was going, Reg answered and Rosie repeated it:

Researcher: *How is your memory?*

Rosie*: No problems, not really no I've got to write a few things down*

Reg*: No your memory banks are not too crash hot*

Rosie: *No, they're not crash hot no*

Reg*: That's an understatement* (3: 6-10, p.1).

Rosie relied on the other members of her family to prompt, and 'fill in the gaps', but she is aware that the story is no longer exclusively hers, no longer an act of her imagination. This frustrated her:

Reg: *Tell the lady about the incident in Sydney with the cat. What's his name?*

Rosie: *Oh don't ask me the cat's name Reg*

Reg: *Yes, you know it as well as I do* [terse tone]

Rosie: *I can't remember it. You will ask me these things*

Reg: *The cat brought in a dead rat with a look that said 'Look what I've brought in Mum!'*

Rosie: *When was this Reg? Yesterday or the day before?*

Reg*: When? Oh I don't know school holidays sometime*

Rosie*: I can't remember that's for sure* (3: 96-106, p. 5).

While Rosie relied heavily on others, Veronica demonstrated a fierce independence despite limited insight regarding risk associated with her condition. While acknowledging that she had dementia, she resolutely pursued her love of driving. Living alone in the quiet bush outside Melbourne, my first visit to her small unit left me with lasting impressions. Her home was at the back of a long row of units and it felt very isolated, being a drive away from shops and public transport. I pondered that at some time in the future, she may lose her driving licence, and that she would be reliant on others for company—perhaps becoming even more isolated. I was also struck by Veronica's vulnerability. It unsettled me—as my field notes read:

'After confirming my visit by phone an hour before, I arrived at Veronica's home at 11am. She was in her nightgown and somewhat surprised to see me. The thought that I could have been an unwelcome stranger crossed my mind. I was intentionally quick to establish my credentials and show her my student card for identification'.

In the following interview it was immediately apparent that everyday life had become shambolic, as lapses in memory were profoundly affecting Veronica's day-to-day life. She was barely able to manage, her refrigerator was over-filled with food and each day she would take off in her car to shop and buy more. Her reduced insight into having dementia ruled it out as the reason for the problems she was having living independently: *I don't feel as though I've got Alzheimer's at all now* (3: 82-83, p. 7). Following my first visit, she was granted a new driving licence, and she nominated the driving test as a risk for her:

> Veronica: *Well, I had to go for the driver's test, so that was a bit risky*
> Researcher: *Were you worried?*
> Veronica: *No, not really it was alright but I made a mistake. When I got back here* [laughing]. I *turned in really quickly. It was a dangerous thing to have done really* [laughing]. *That was scary. It was like a bat out of hell and that was scary' cos* [*sic*] *it was getting dark too* (3: 329-333, p. 11).

The field notes from my second visit read:

> 'I arrived to find Veronica confused, had poor recall and was verbally repetitive. On listening to the tapes later her speech was mumbled, muffled even. When transcribing on the same day, I struggled to decipher some of the conversation as her voice tapered off or she had word finding difficulty. Other instances of language disruption included her struggle to 'get going' with her thoughts. I often repeated the question, rephrasing it and then simplifying it. I was surprised that she was still driving, but she says that she 'does nothing today that is risky'.

Similarly, William used his stories of risk to make sense of the present day, and to sustain his identity. This re-storying of erstwhile events and people from his past affirmed him as a risk-taking, daring and somewhat pugnacious character and he revelled in their telling:

I was in Fitzroy and coming down a lane and it was pretty rough
times then. They used to fight with guns and shoot each other up
the street and being a sticky-nose I got up in the tree in the
paddock next door. And I'm sitting waiting up there like and me
[*sic*] *brother come round. He dragged me out of the tree and he*
broke me [*sic*] *collarbone when I hit the ground* [laughing]
(2: 66-71, p. 3).

While his wife Susie frequently corrected his version of events, he disregarded this for he was the custodian of his memories and his memory loss meant that he shared them any way he wished. With this transition to a person living with dementia, he became an historian of his life and there were times when he: *just had to hope for the best* (1: 208, p. 10).

The transitional effects of dementia were seen within the stories of the participants. They were acknowledged or denied; or a person could be oblivious to them, but the inexorable reality was that the effects of dementia were ongoing, and will be continually felt, rebutted or not, with the progression of time.

Stigma was a significant issue and concern for the participants living with dementia−whether real or perceived. It was one of many painful changes associated with diagnosis and both Harriet and Dan were aware of it. They reluctantly accepted that a new identity had been forged as a person with dementia and acknowledged that others may view them differently now. This was abrupt transition, initiated by changes related to an arbitrary diagnosis conferred by others—people who they had never met before—strangers.

Dan was certain that he was treated differently at the CDAMS clinic: *You get the label—that gets me. When somebody's done something—I'm sorry, I'm a bit funny* (1: 452-453, p. 19). His clinical encounter at CDAMS for assessment had been a demoralising experience: one where his wife was not permitted to stay and where Dan floundered when he was on his own for several hours. With his schooling being severely disrupted by war, the cognitive assessments at the Cognitive Dementia and Memory Service [CDAMS] required reading and writing skills beyond his capability.

He became agitated when recalling this experience: *Like being in a Nazi place you know* (2: 235-236, p.16), and the pace of his diction quickened. His thoughts and feelings within the dialogue evoked his residual feelings of resentment and hurt:

> Dan*: Well I don't like to be taken for a ... I probably got angry about*
> *well I didn't get angry with that lady I just thought*
> Researcher*: But you felt angry?*
> Dan*: Well I just thought ... she must have thought I came off the*
> *train,*[4] *the midnight train. Because it's not fair to say to somebody*
> *you go through all that. Oh that was wonderful and that was lovely.*
> *Oh you're doing very well. That's not right. They shouldn't say that*
> *and if you've never been in these things la-de-da you know like*
> *doing windows*[5]*and other things, such silly business I've never*
> *done that and I thought she's taking the mick*[6]*... sorry taking the*
> *piss so I'm sorry* (1: 410-411, p. 17).

Harriet was also cognisant of others' perception of those living with dementia, but her response was different: *I go about like a normal person. It doesn't worry me and if somebody thinks that er* [*sic*] *I'm so dumb over something* [laughing] *or anything like that, I don't care* (4:159-161, p. 7). This attitude was a testimony to Harriet's steadfast resolve to live her life to the fullest:

> *I'm not one who says 'Oh I've got this or that sort of thing'. It might*
> *kill me you know. I may not be able to do what I'm doing now. I*
> *think you've got to close your eyes to that and think that every day*
> *you've got is a* [word finding difficulty], *you know you should be*
> *enjoying it, you should enjoy every day you've got*
> (2: 179-183, pp. 9 -10).

---

[4] 'Coming off the train' is a colloquial expression which generally means a change to an abnormal or malfunctioning situation.

[5] The 'windows' to which Dan refers are the tick boxes within the multiple choice questions as part of the CDAMS assessment. The la-de-da reference possibly means that the tests were for people he considered to be more intelligent than himself.

[6] 'Taking the mick' or 'taking the piss' is an expression meaning to mock, tease, ridicule, or scoff at another person.

Harriet managed the transition wrought by the diagnosis of dementia in her particular way, acknowledging change and rationalising that: *The more you think about these things, the more you get depressed. And I'm not depressed, 'cos* [*sic*] *I join in things and talk to people* (3: 26-28, p. 2). Her skills of making 'the best of things' is a well-honed one, and she applied them now to the increasing uncertainty and worry associated with having a recent diagnosis of dementia.

The transition associated with dementia may be sudden and dramatic, and result in constantly unpredictable situations for all the people involved. Dan concurred with this: *Yeah I was on me* [*sic*] *own and I just went ... I freaked out, I was absolutely terrified. I couldn't drive. I didn't know what was going to happen. She* [wife] *wasn't here and so I just collapsed* (4: 323-324, p. 16). Dan nominated being alone as his greatest fear in the future, and sitting beside this tall, reed-thin man with his voice timorous and his hands shaking, I felt immense compassion for him. Transition for Dan was fraught with high drama, and witnessing its effects on him was affecting me also. We gave each other time to compose ourselves before this conversation continued. His preferred identity as a tough and uncompromising man demonstrated his strength of character but this had been dramatically reduced to a vulnerable person with dementia, reliant on his wife in his moments of challenge and despair. A lifetime of considerable experience was being called upon now and applied to difficulties such as memory loss which had come up in the lives of the participants—difficulties which challenge and could defeat the hardiest of people.

6.7.2. Age: a minor theme within transition
Once you get a bit older you get a bit more brains I think
(Rosie 1: 331-332, p.15)

Transition, the primary theme, continued with the minor theme of *age* which was precipitated by the sudden change in circumstances imposed by a diagnosis of dementia. It illustrated that transition in one context can "catalyze further life changes" (Schumacher, et al., 1999, p. 4), and as time went by the participants increasingly felt the effects of *age.* Ageing is a process of losses and gains over time, a transition precipitated by variances in one or more domains of a person's life. The conversations spoke of the effects of age in functional, affective, social and

cognitive domains—irrespective of also having a progressive illness. This minor theme contained two meaning units *ageing* and *age and dementia.*

The participants commented on *age* and the physical toll it was taking on them. Florence explained: *I still walk with a limp and I'm older, and that's always going to happen, isn't it?* (4: 390-391, p.17). Jessie's love of walking was curtailed due to the risk associated with fluid in her legs. The same fate had befallen Harriet who had been proud of her walking laps around the facility day and night:

> *I know what my body used to feel like and I know what it feels like now. I know I'm deteriorating myself. Nobody needs to tell me that−I know it meself* [*sic*], *but it doesn't worry me. I don't think 'Oh I've got this and I've got that–what am I going to do'?*
> (2: 72-75, p. 14).

Reaching the age of 85 was a complete surprise for Harriet:

> *I'm 85 this year and that ... well I wouldn't have thought that I'd get up to 85. I don't actually feel old. I know what everybody is saying and I know the body is changing, but I don't sort of feel 'Oh I'm an old woman I'd better not do this and not do that'* [laughing]. *I do everything that I want to and I push myself a bit and I like you know if somebody says 'Would you like to go on a trip?' Yes I'd like to go on a trip' but if I'm not feeling good then I'll say 'Well I'll give it a miss this time' and I'm happy with that* (4: 18-26, pp.1- 2).

While Jessie also scoffed at the idea of age slowing her down, she conceded the risk associated with dancing:

> Researcher: *You don't see age as a barrier, do you?*
> Jessie: *No I don't think of it—it's that's not a problem*
> Researcher: *How old do you feel?*
> Jessie: *I'm eighty-three I think. I don't know the thing is I can do most things you know*
> Researcher: *I know*

Jessie: *I can do most things and most people say 'Do you really*
still do that?' I'm not a person who says Oh no I can't do that
Researcher: *So what I … so how old do you feel?*
Jessie: *Oh say late sixties perhaps 'cos* [*sic*] *I've always danced. I*
love to dance. I don't dance anymore (4: 200-209, pp. 17-18).

Despite a diagnosis of dementia Veronica used *age* as a scapegoat when she drove
through the night lost and disoriented: *My Alzheimer's now that's OK yeah, good.*
Although I made a mess of it today [laughing], *but that's not Alzheimer's* (3: 24-25, p.
2). The incident frightened her however and she began to withdraw: *You're not the*
same as you get older—you need to be a bit more circumspect (3: 258-259, p. 9).
Residual fear from the risk of being lost in her car left Veronica chastened, and she
determined to be more careful next time.

Chicks had a mother who lived into her nineties but this was not something that she
looked forward to. While she 'defied' her age with her presentation, she readily
associated her memory loss as a 'natural' part of ageing: *Yes, well I forget things,*
but most people my age start to forget things anyway (2: 304-305, p.14). The
physiological co-morbidities associated with increasing age, such as Jessie's
oedematous legs and Harriet's osteoarthritis 'slowed' the participants down, and was
another reminder that nothing can ever be taken for granted as you get older.

Losses associated with ageing carried associated risks, and for Harriet they included
being on your own and becoming isolated. She nevertheless accepted the risks
associated with the many transitions in her life, including the loss of her father when
she was young, caring for her invalid mother and moving to Australia from England
with her husband and young son. While the move into an aged care facility was
unexpected, she embraced it:

Well I've changed where I live you see. I was in my own place in
the village and with my health going downhill a little bit. When the
doctor said there was a vacancy here I didn't argue with her I took
it—and I've been happy ever since (3: 101-104, p. 5).

Harriet saw that this transition was associated with age and dementia:

> *You could become restless or upset about things that you wouldn't*
> *have done. Um, I've got over that stage you see and I don't care*
> *what happens, it doesn't worry me at all. I mean if I had to go to*
> *hospital, I'd go to hospital I wouldn't worry about it. I don't want to*
> *go to hospital but it wouldn't be anything that I'd object to if I had to*
> *go. I like to be realistic* (4: 151-155, p. 6).

Once she settled into her facility, Harriet set about helping others as she had always done: *I really like helping people. If I see somebody on the floor, I say 'Now don't move' and I go and get help* (3: 116-117, p. 5). Harriet drew on her life experience in order to manage this change in her living arrangements, and this allowed her to adapt to it and move forward, thereby maintaining continuity within her life.

Veronica and Harriet both nominated the risk of moving into institutional care as being their greatest risk, for neither wanted to leave their beloved home:

> Harriet: *It's getting that way that I really should be thinking of*
> *moving into a retirement village I think. I don't know. Where do I*
> *go?* [laughing] *I don't know if I could stand to be in one of those*
> *places* (1: 217-219, p. 10).
> Veronica: *Oh I wouldn't want to go to a nursing home* (3: 310, p.
> 10). Later when visiting her in her facility and reminding her of this
> previous comment she smiled: *And here I am* [loud laughter]. *It's*
> *not really a nursing home though. There's all different types, yeah,*
> *you've seen the whole complex, have you?* (4: 306-308, p.15).

For several of the participants, old age was a proud achievement: *eighty-four in November, born in 1930 so I'm doin'* [*sic*] *pretty well aren't I? Yep, I can do most things for meself* [*sic*] *... showering, washing* (Jessie 4: 8-10, p. 1). For others it was seemingly a time to pull back—but only when your husband was listening! Every three years, Rosie and Reg would climb up on ladders and hop onto the tin roof of their house, working their way down painting from the roof to the weatherboard exterior. She was proud of this achievement, and while her fluctuating awareness

would have allowed her to keep painting, her protective husband vetoed any thoughts of continuing to do so:

> Rosie (to Reg): *Oh yes* (laughing) *I can remember being up on the roof, on the back porch the last time. Do you remember that? You know that last back porch that we put up to paint? With the ladders, climbing the ladders, oh you can't remember but I remember getting out there and painting*
>
> Researcher: *When I was here last time I asked you about when it comes time to paint your house again, do you think that you will do it?' and you said to me that you most likely would 'we'll paint the house a bit at a time'*
>
> Rosie: *Yes*
>
> Researcher: *Would you still do that?*
>
> Rosie: *Yes*
>
> Reg: *Ah no I I veto that*
>
> Rosie: *Well I could climb too high*
>
> Rosie: *Reg can't climb the ladders but*
>
> Reg: *Oh I can I was good on heights all me* [*sic*] *life. But no, seeing my wife up there on the ladder. What would happen if she came off? And I thought oh no you mustn't paint high up*
>
> Rosie: *Oh no I've never been up*
>
> Reg: [interjecting over Rosie]: *VETO VETO*
>
> Rosie: *No I have been up on the porch roof many years ago when I was a lot younger but I wouldn't do it now*
>
> Researcher: *So that's changed?*
>
> Rosie: *Yes, these days yeah. I need to be very careful*
>
> Researcher: *So age stops you from doing things that you used to do?*
>
> Rosie: *Yes sometimes and there again if I didn't do it all at once and did some one day and not the whole thing not any more* (4: 53-76, pp 3-4)

The transitional effects of age and dementia on awareness and insight into personal safety and decision making can be seen in this conversation between Rosie and her

husband Reg. It raised questions about Rosie's safety if she was living on her own, like Florence.

Within a short time frame of two interviews, Florence went from being confident living alone, to having serious concerns about the consequences of social isolation. In the first instance she boasted that she was: *Never lonely. I don't know I fiddle around in the garden. Not this weather, but I've been on me* [*sic*] *own a long time now* (3: 9-10, p. 1). But now she was fearful:

> *No-one here bothers to call in or anything. I could be lying here*
> *dead. 'Oh, her car hasn't—Oh, I haven't seen her for a while'. Like*
> *that place over there—there's no car there—so I know they're*
> *away. But if they saw my garage closed they wouldn't know if I*
> *was in here or not* (4: 141-144, p. 6).

Florence loved to drive to the gym, to play cards and to visit the shopping centre*: Yes I'm outgoing. I like to talk to people* (1: 309, p.13). Getting older was compounded by memory loss and a loss of confidence, and this also set limitations on her ability to drive:

> Florence*: I'm alright driving. I'm not scared driving. I wouldn't drive*
> *up the hills or anything. I go to Gwen's. I go around this area. I go*
> *over to my daughter's*
> Researcher: *Have you had to re-sit a driving test? Could that come*
> *up?*
> Florence*: I dunno* [*sic*]. *No one has suggested it, but I wouldn't*
> *know how far you have to park from a curb. I know all the road*
> *rules give to the right and all the rest of it. But actually I couldn't*
> *park between two cars, to come in backwards. I'd drive to the next*
> *place. Can you do that?* (3: 80-88, p. 3).

The tenuous nature of her driving licence was a significant blow to her self-esteem and emotional wellbeing, and a potential threat to other domains of her life.

Transitions demand new strategies to address risk associated with old age, which was made more complex by the uncertainty of living with daily life experiences of dementia. While lifelong skills such as driving a car were under threat, existing relationships, roles and responsibilities also underwent transition and became fluid and changing. Wives became carers and drivers, and that did not sit well for Dan: *I feel very bad you know. I say to Mary—'cos* [*sic*] *she has to do all the driving* (2: 357, p.17). Life for Florence had changed profoundly: *Oh I don't know. I'm not out as much as I used to be, 'cos* [*sic*] *a lot of my friends are getting older as well* (4: 172-173, p. 8). This social withdrawal gave way to a sombre outlook: *Well life's a bit drab now* (3: 237, p. 12).

The transitional effects of ageing had already begun to be felt by all the participants, and were accepted reluctantly, but philosophically: *You know if I've got two or three years, fair enough. If I don't, fair enough because it doesn't worry me. 'Cos* [*sic*] *I'm not fear, fearing* fear [*sic*], *I have no fear of death* (Harriet 2: 187-189, p.10). When dementia and its effects combine with ageing, an already sense of decline can go faster, further disrupting the taken-for-granted continuity of life. Dan lamented his diagnosis and referred to dementia as 'this': *I've ever really wanted to do is to be normal. And then I caught 'this'* (3: 272-274, p. 8).

With its attendant losses and subtle shifts, *age* was of increasing influence within the primary theme of *transition* in this study. It assisted in shaping the meaning of a diagnosis of dementia for the participants as it accompanied them on their journey— both affecting and being affected by dementia.

6.7.3. Risk: a minor theme within transition
I just roamed the streets ... never any fear um [laughing out loud]
never any fear it's a wonder I'm still here today
(Chicks 1: 39-40, p.3)

Risk infiltrated all elements of the primary theme of *transition*—its minor themes and meaning units. Their interconnectivity enhanced the trustworthiness of the study. Within this third minor theme of *risk* the participants explored the vicissitudes of their lives, and there was uncertainty surrounding the concept of risk throughout the

conversations. A reluctance to make change, wrought by the implications of a present and a future living with dementia had rendered the participants unable, or unwilling to take risks now. This reluctance to make change was due to many different factors—of particular note was a change in their view of the future. Risk was a feeling, a premonition but it could also be applied to a certain time or an event. Four meaning units underpinned the universes of meaning surrounding risk: *risk and dementia, risk today, future risk, and denial of risk.*

6.7.3.1.   The transitional nature of risk following a diagnosis

The following personal reflections acknowledged change in the lived experience of risk for the participants following a diagnosis of dementia—instant change which was initiated at the point of diagnosis. For several of them, living with dementia had a profound impact on their risk-taking:

Dan: *No, I don't take no* [*sic*] *risks now*
Researcher: *Why is that?*
Dan: *Well probably it's the disease*
(4: 172-174, p. 9).

Strongly associated with the recantation of risk in the lives of the participants was the presence of fear—fear of dependency and isolation. This manifested in many ways for them, and was palpable at times. While Harriet repeated over and over that she had no fear of dying, she was however afraid of losing her independence. That would be like a death for her:

Not fear, fearing fear [*sic*]*. I have no fear of death and if I got to the stage where I couldn't do for myself—umm you know you've got to be fed and you've got to be washed and everything you rely on. You know I don't want that—it'd get me down. I'd sooner die. That would be like death to me* (2: 189-192, p.10).

Veronica scared herself getting lost in her car, and she talked about it often: *I went like a bat out of hell and there was no incident, thank God. I sure as hell wouldn't want to do that again* (3: 340-342, p. 11). Her acknowledgement of the inherent risk

within this episode was a realisation that her ability to drive safely was changing, and that new strategies were required to handle everyday familiar experiences such as driving.

A firebrand like Dan who was afraid of nothing, and fought the unions and corrupt bosses in search of a 'fair-go', readily nominated being left alone in the house now as his greatest risk:

> *The thing is you've got to understand ... what's it called?*
> *Alzheimer's. Yeah. I got caught with it. Yeah I was on me* [*sic*] *own*
> *and I just went … I freaked out. I was terrified. I couldn't drive. I*
> *didn't know what was going to happen* (4: 336-339, p. 17).

This fear is reminiscent of Florence's experience of being on her own all day. Without calling on her friends she is disengaging from life, and this is like a social death for her:

> Florence: *Oh I dunno* [*sic*]. *You're not the same as you get older*
> Researcher*: No? What changes?*
> Florence*: Oh I don't know I'm not out as much as I used to be,*
> *'cos* [*sic*] *a lot of my friends are getting older as well*
> (4: 169-173, pp. 7- 8).

Growing up, Harriet had: *Moved around from pillar to post* [7] *quite a bit with my mother* (1: 48-49, p. 3). As a consequence, she had embraced risk from an early age and she continued to do so into her adulthood. Travel was a lodestar for her, and she and her husband became intrepid tourists:

> *Oh yes, we went right up to the top. We had a caravan, we bought*
> *a caravan. Well early on we used to go away for weekends and*
> *holidays just sort of locally in Victoria, but when we retired we*
> *stretched our wings and went right to the top and it was lovely. I*

---

[7] Pillar to post is a colloquial expression which means to always be on the move.

can recommend that to anybody. You never know Australia down
here. I like to find something that is, that I haven't seen before
(2: 55-60, p. 4).

When moving into her unit, Harriet continued to love getting about and was regular attendee on bus outings. But now she was unsure:

I don't know really ... I don't know how, now I've got this dementia
um [sic] how that's going to go um [sic]. I'm hoping that it doesn't
develop too quickly. And if it doesn't develop too quickly, if they go
from here for a day's outing I'd like to go, you know. I wouldn't
think well I really can't go. But now I can tell my body's probably,
my body's more tired than my brain (2: 292-296, p. 15).

William however wanted to keep on taking risks. His identity was bound up with being a risk-taker, and it was revised many times. He was a bottle-shop attendant, a cobbler, an orphaned boy on the streets, a bike-rider and a sportsman: *I played cricket 'til I was fifty-seven at Collingwood* (1: 251, p.12). He was immensely proud of all these roles, and he clung to them. Lately however he had lost the skills to manage them. Getting up ladders, fixing plumbing and driving the caravan down to Barwon Heads were distant memories. His wife Susie explained: *Climbing up a ladder with a chainsaw… if he could get it, he'd do it. They've* [his grandsons] *taken them* [his chainsaws] *from him now* (2: 108-109, p. 4). This was a sorry reflection on a man who took risks in order to get what he wanted out of life: *See, what I wanted in life always took a few risks, yeah* (2: 300, p. 11).

Each participant had a unique subjective 'lens'—a place from where they told and retold their stories related to risk. From such positioning the participants explained what risk meant to them. Nursing a swollen knee and in considerable pain after another fall, Veronica declared that risk was now out of the question: *No I look after me* (2: 245, p. 9) ... *I think that I am the biggest risk to myself, these days* [laughing] (2: 172, p. 7).

The word risk was not in Florence's lexicon: *Yes, so I just go along with the flow and I don't do anything like that. So you've probably come to the wrong person* [laughing] (1: 77-78, p. 4) however, she loved to tell the story of going to England with her friends, having little money and no job. This was not considered a risk by Florence— her acknowledged risk would have been to stay at home on her own: *You see, us four girls had been friends forever, but I wasn't going to be the one left behind you see* (1: 18-21, p. 2).

For those participants who were aware of the clinical implications of their diagnosis, there was a range of emotions. Harriet exemplified this: *I didn't think that I would get dementia, and I realise now that I've got it, but I really can't accept that I've got it* (4: 88-89, p. 8). Harriet had rationalised her diagnosis, but did not accept its implications, as having dementia was a painful and risky prospect to consider—particularly on her own. Her transition was ongoing and incomplete due to her refusal to accept her diagnosis, but with the passage of time she reflected on her fluctuating memory and began to pull back from her usual activities: *I know I'm sick—I know what I've got and you know what I've got. And as much as I'd like to go for a holiday, I think it would be more sensible to stay* (3*:* 131-133, p. 6). After some existential questioning of her life, she was better able to make some sense of her condition, enabling her to begin the process of adjustment:

> *I've had quite a life where I've had experiences and that's taught*
> *me a lot. I had the experience of a good job and I enjoyed it and*
> *but if something goes wrong with—I don't know what I can battle*
> *with. It doesn't matter. I can do that but I sometimes think I'm sorry*
> *that it's come to that* (3: 196-200, p. 9).

Life for Harriet had become a 'battle', irreversibly changed and extremely uncertain.

By taking 'the bull by the horns' Dan reacted to his diagnosis, for he simply knew no other way of dealing with adversity: *So you've got to* [*come to*] *grip*[*s with*] *yourself and your mind—which I have been trying to do very hard. I'm beginning to remember it* [clenching fist] *and keep it tight* (4: 226-227, p. 11). Struggle and privation from an early age helped shape Dan's strong belief in a better world, and it taught him the

value of human life and honest toil: *If you work hard in life you get your rewards. We've done very well with cars and other things I mean nobody gives you anything. You have to put in the time to work* (2: 273-274, p. 13). He was keeping the past ever-present, serving as an exemplar of what was required now, but all the hard work in the world would not change his diagnosis. His memory was a solace to him, and it embodied his love for his family and his identity as a man of principle, and he was not letting go of it: *A man's gotta* [*sic*] *hold onto this* [shaking a clenched fist] *what I've got now* (3: 57, p. 2). Like Harriet, Dan accepted the challenge, but was also philosophical about the transition that he was experiencing. He used the word 'battle' as Harriet had done before him.

> Dan: *Well when you get er ... er the* [*sic*] *what's it called?*
> Mary (wife): *Alzheimer's*
> Dan: *It's a disease that doesn't touch you for quite a long while*
> *and then all of a sudden you get hold of a glass and say you want*
> *a glass of water you forget it* [pointing] *from here to there. And then*
> *when you go to sleep and the whole day you forget. I think myself*
> *in the last six, to eight, nine, ten weeks it's been a bit of a battle* (3:
> 6-12, p. 1).

Acknowledgement of the risk associated with the transition to living with dementia was strongly evidenced in the stories shared. Florence and Veronica did not mind a diagnosis too much, as long as they both could continue to drive a car. Episodic memory loss had 'blunted' the impact of a diagnosis for them, and they were oblivious to ongoing changes in their ability to drive safely.

Rosie lacked awareness of the consequences of risk when driving and living with dementia, but her husband Reg saw it clearly:

> Rosie*: Yes, I still drive*
> Researcher: *OK*
> Reg*: No, no you've got that wrong*
> Rosie*: Well I haven't*
> Reg: *No, you've got that wrong she no longer drives*
> Rosie*: Well I no longer ... I can drive*

> Reg*: You can drive of course but she's no longer driving*
> Rosie*: No longer driving from place to place as much as I used to*
> *I've given it away sort of thing*
> Reg: *No they took her licence away from her and when you look*
> *at what's on the road today it's just amazing that she would be*
> *allowed to drive* (2: 81-92, p. 5).

Bearing witness to this squabble in the small lounge room was revealing. Rosie continued to assert her right to drive, and her husband Reg overruled her judgement. She acquiesced, but it was done half-heartedly, and at the first opportunity she raised the issue of driving again:

> Researcher: *So you don't use your car now*?
> Rosie: *Not a lot, no. Not a lot, no. Unless I meet the ladies*
> Reg: *No, we no longer use it AT ALL*
> Rosie: *Oh well if I went to see the ladies today I would use it*
> Reg: *No, you WOULD NOT USE IT*
> Rosie: *Well I could Reg 'cos I can still drive*
> Reg: *No you cannot use it Rosie, do not argue the point*
> Rosie: *Where I can go I can walk anyway so it doesn't matter*
> (2: 98-105, pp. 5-6)

I felt sympathy for Rosie as her choices were summarily dismissed by Reg without further explanation. With fluctuating insight, she was confused, but she did not dwell on it and quickly moved on when I re-oriented the conversation back to the research question of *risk*. On that occasion, driving the car exemplified transition for Rosie, and it was a painful moment which was brushed aside as she deferred to Reg's judgment—as she had done all her married life.

For William, the effects of dementia had been evidenced some time ago, and a recent diagnosis was a formality. While he was oblivious to living with dementia now, the cost and consequences of a diagnosis and its transitions were being felt keenly each day. As time went on, his losses were mounting. A chainsaw and caravan were significant, symbolic reminders of a past life, and William was struggling to reconnect

his life prior to his diagnosis with his present one. He had to let his future life take care of itself now, for he was no longer in charge:

> *Me [sic] grandson was goin' [sic] crook[8] the other day. We got a water tank down the back. I put it up. I got up and put it up meself [sic] but it just wasn't right. So I got me [sic] grandson. I said 'I put the pipe in but I'm not getting any water' so he looked up and he said 'No' he said 'You've got it in the wrong place'. So he just got up, he's pretty tall and he pushed it across and he said 'Good now the water tank's full'* (2: 148-153, pp. 5-6).

When William was a young man, fighting back was his preferred method of survival on the streets:

> *Yeah, you learn to protect yourself* (1: 85, p.4), but not any more:
> *Things have changed ... you look at it different ways—even now if you go to do something you can change your mind, but only to a certain point. No, I wouldn't be confident enough to do it—in fact I'd be frightened* (2: 71-73, p. 3).

William kept on trying to take a risk. However all the things that he loved to do were being withheld, or literally taken away. Lacking awareness into why he could no longer drive, use his chainsaw or tow the caravan down to Barwon Heads he was furious and he felt: *useless* (3: 292, p.10).

> William: *I've just lost two caravans and I've been driving them all around Queensland everywhere*
> Researcher: *Oh really?*
> Susie: *This story's not true*
> William: *How long ago is that Susie?*
> Susie: *Since you drove the caravan?*
> William: *Twelve months*
> Susie: *It would be two years*
> William: *'Cos I'm not allowed to drive it*

---

[8] 'Going crook' is a vernacular term for getting angry, or upset.

Susie: *They weren't his caravans*

William: *Now I've had two caravans down at Barwon Heads. Now*
I've got, I've lost both of them. Someone's knocked them off

Susie: *No, that is not true*

William: *Yeah*

Susie: *Not true* (3: 214-218, p. 8).

William's deep sense of loss and disenfranchisement was felt by his wife Susie and by me, and it was a sad and sobering experience. He had positioned himself as the man who loved travelling to Queensland and his beloved Barwon Heads for annual holidays, and these wonderful memories assuaged the painful reality of his losses.

Losing the right to drive a car was overwhelming, and this further added to William's frustration: *Now why have they stopped me from driving a car? The doctor done it* [*sic*]. *I never had a smash or anything in a car, but I'm not allowed to drive a car* (3: 202-203, p. 7).

Transition continued for the participants and with it an unfolding sense of loss. After a hectic life which involved travelling the world Veronica admitted: *I don't think I've got the oomph that I had back then. Boy, am I glad I did it, when I did. It has given me so much* (4: 77-82, p. 5). Future risk-taking, or the 'not taking of risk' in the future was broached by other participants also, and the overwhelming consensus was that taking risks would not be countenanced nowadays: *'Cos* [*sic*] *when you're older, you're not as agile or as quick as in the past* (Veronica 3: 338, p.11). She continued:

Veronica: *Well I think you need to see risk differently as we get*
older
Researcher*: Why do you think that is?*
Veronica*: Um, because you're older. Well you're older in years and*
you're older in what you've done (3: 261-264, p. 9).

Risk-taking had been a bellwether for Dan: *We took our chance, but you have to work. Nobody's going kissy-kissy and do it for you* (2: 255-256, p. 12). He admitted that his risk-taking days were over for a different reason: *Well no, I can't take many risks I'm at home all day aren't I? See me* [*sic*] *brain's gone now* (2: 351, p. 16). On a

more private note, he readily identified his excessive drinking as the biggest life risk. The doctors had attributed his dementia to this, and it was a private sorrow for him: *I made one mistake in life* [knocking his fist on the table]. Was this [banging on his head] '*cos* [*sic*] *for 23 years I used to drink* [banging on table] (2: 324-325, p. 15). This was the most dramatic moment, deeply personal and emotionally charged. Dan's raspy voice was such an intimate instrument—bringing to the surface poignant and painful memories and the accompanying histrionics punctuated this sad and sorry recollection. A long silence followed as we all gathered our thoughts and Dan his strength to continue.

Nowadays the will to fight had abandoned him: *I think you get more frightened when you get older—especially when you're elderly* (3: 341, p.10). When asked about any further risks to be taken, Dan was adamant: *No I don't want to get the trouble again* [lowered voice tone] (2: 524, p. 24). Dan had endured 'trouble' in his life, and in this statement he was referring to his workplace injury, but could have included his street fighting as a young man, and his drinking. Within these instances, risk was bound up with elements of fear and anger, and also regret when talking of his drinking days.

The denial of risk in his earlier life had left Dan perplexed—even after fifty years. His wife Mary would not allow him to open his own business, and he talked about it twice in a whisper: *But Mary did not want to. I don't know she wouldn't, she wouldn't go into it and that was that* (3: 383-385, p.11). One can only speculate as to what Dan's response may have been then, but it was long ago now. He rationalised that it was probably for the best as: *See Mary's got a real brain, she could have done anything. Sometimes I wonder why she married a mug like me* [laughing] (3: 86-87, p.11).

Risk was seen within the participants' life stories, but within the primary theme of *transition* it had been re-evaluated by them. A diagnosis of dementia had changed their attitudes toward taking risk, citing the uncertainty of the present day, and a future that for Jane was simply inconceivable: *I don't see any future* (2: 178, p. 8).

6.8.   Reflections on the primary theme of transition

Transitioning to living with dementia was inevitable—whether it was denied or accepted by the participants. While dementia presented huge challenges—both real and potential—the meaning of the change determined how big or small that challenge would be. For those who acknowledged cognitive and physical changes, it was seen as something that ultimately can work out for the best, and the challenge was accepted:

> But it's got to the stage now where I know that I can't do a lot of
> things, so I've just got to expect it. I'm eighty-five and your body is
> obviously not going to do what you did when you were sixty-five
> (Harriet 2: 280-282, p. 14).

While acknowledging her diagnosis, Veronica disregarded its implications, and the incident in her car held potential risk for her and for others. It was illustrative of the disruption that the effects of this progressive condition can wreak in everyday circumstances in routine settings for people living with dementia. For Veronica this incident was a watershed moment, a ruction in her life, and a time to reflect on her present circumstances of transitioning to a person living with dementia. She was now in care, and was able to sum up the transition in her life succinctly: *I don't know I just seem to go from one thing to the other. Things evolve you know* [laughing], *I mean like being here—I got no idea how I got here* (4: 177-179, p. 9). She acknowledged and accepted transition with her customary stoicism, grace and quiet resignation which seemed to be part of her life skills honed years before as a young initiate in the convent.

Transition for Dan however, had become a crisis where his whole world was turned upside down—where certainty becomes uncertain, and where things usually under control, now become uncontrollable. While he accepted his diagnosis, he could not countenance losing his cognition: *You see the brain goes—your brain goes and a new one takes over and it's all our yesterdees* [*sic*] (3: 37-38, p. 2). He had 'seen' dementia's impact on a family relative, and he looked to his wife Mary for validation:

'*Scuse* [*sic*] *the word dopey*[9]. *It seems that a lot of people go right off and I ain't gone right off yet love, have I?* (3: 42-43, p. 2). This particular stance determined the strategy that Dan employed—of fighting with every intention of beating his diagnosis: *I've been trying to frighten that* [dementia] *away every day and it's a war between Alzheimer's and the normal Dan* (3: 42-43, p. 1). He remembered the feelings he experienced when being told he had dementia: *When that happened* [a diagnosis], *I've never been terrified by anyone in my life—in punch ups or things like that. But when that happened I thought 'Oh well I've had it now'* (3: 173-175, p. 6).

In his reflective moments however Dan displayed perceptivity about the progression of his dementia, and spoke of transition: *As you go on, it does get badder* [*sic*]— *there's no two words about it* (4: 246, p. 12). After a crippling back injury at work and ten years on WorkCover[10], Dan worked his way back to health. In a cruel twist of fate, his diagnosis had hijacked his journey back to wellbeing and normality: *Well the trouble is now I've done all these years, trying to stay well. Now I've had a couple of bad times and that's all, now all that's changed* (3: 71-72, p. 8).

Transition had been acknowledged and accepted by Harriet in her new facility:

> *Well I really haven't got any decisions because I know because of*
> *my health and my age I need to live here. And I'm not going to cry*
> *out and say 'Oh I don't want to live here. I want to be off'. You've*
> *got to be sensible and if you've got a good place to stay and*
> *everybody's nice, I'm happy* (4: 122-125, p. 5).

While Chicks acknowledged physical changes, she resisted the challenges that transition to living with dementia will bring. She clung to a reality that was both unrealistic and one which would become unsustainable. Unlike the others, *transition* was not seen as something that can ultimately work out for the best, and she will continue to define her story strictly on her own terms. Whether resisting, challenging or accepting a diagnosis, *transition* is inexorable however, with its attendant losses and gains, and this was evidenced in the stories of the participants within this study.

---

[9] To be dopey is to be stupid.

[10] WorkCover is an Australian Commonwealth insurance scheme for workers injured in the workplace.

Transition was understood in this analysis as the passage within the everyday lived experience of risk for the participants living with dementia. Following a diagnosis, everyday life assumed an insecurity and unpredictability where the only certainty was the remembered past. Here the lived experience of risk loomed large within the stories, and permitted the participants now living with dementia to realign their present with the same aspirations and goals as in the past. This paved the way for the continuity of life's patterns—past, present and perhaps future possibilities for risk-taking.

6.9.   The primary theme of resilience: defining the boundaries

The term *resilience* (meaning 'elasticity' or 'vigour' from the Latin *resilire,*) originates from physics describing the ability of a material to change shape, and then return to its original form (Amann, 2015). Resilience has credence within the fields of medicine, mental health and science, with a resultant lack of consensus on a definition which fits all these disciplines (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014). Nevertheless, resilience has a number of common characteristics. These include the ability to absorb and then recover from an abnormal event; being ready and prepared to face threats and events which are abnormal in terms of their scale, form or timing; an ability and willingness to adapt to a changing and sometimes threatening environment; a tenacity and commitment to survive; and a willingness of communities and organisations to rally round a common cause and shared set of values (McAslan, 2010).

In the pursuit of an explanation that reflects the analytical interpretation an understanding of a core component of resilience provided some guidance. Resilience is built upon personal characteristics intrinsic to the individual such as experience, and typically includes traits such as optimism, adaptability and acceptance (Amann, 2015). These traits may be found in macro contexts such as economic and political systems, and in the micro contexts of family and environment. They are in constant flux, and this dynamic matrix determines how a person responds to an adverse event on a given day and at a particular time (Southwick, et al., 2014). For the participants in this study, their resilience built up over a lifetime is challenged by a diagnosis of dementia.

Resilience as a theme is interwoven with *transition* through the threads of meaning within a lifetime, and was seen within the conversations of this study. While there is no single agreed-upon definition of resilience within the literature (R. Allen, Haley, Harris, Fowler, & Pruthi, 2011) despite its many applications; the concept of resilience provides a useful framework for understanding *how* people cope in a changing world, while facing many of life's uncertainties and challenges. The primary theme of *resilience* is analysed in the following section and integrates the minor themes and meaning units of which it is composed.

The following section analyses the two minor themes of *resilience*: *ways and means of doing things* (which was abridged to *ways and means*) and *loss*. Within this analysis, *resilience* defied a singular definition, elusively presenting different forms in individual ways in a multiplicity of contexts. Within the two minor themes there were many meaning units, and they will be uncovered and explored within the data.
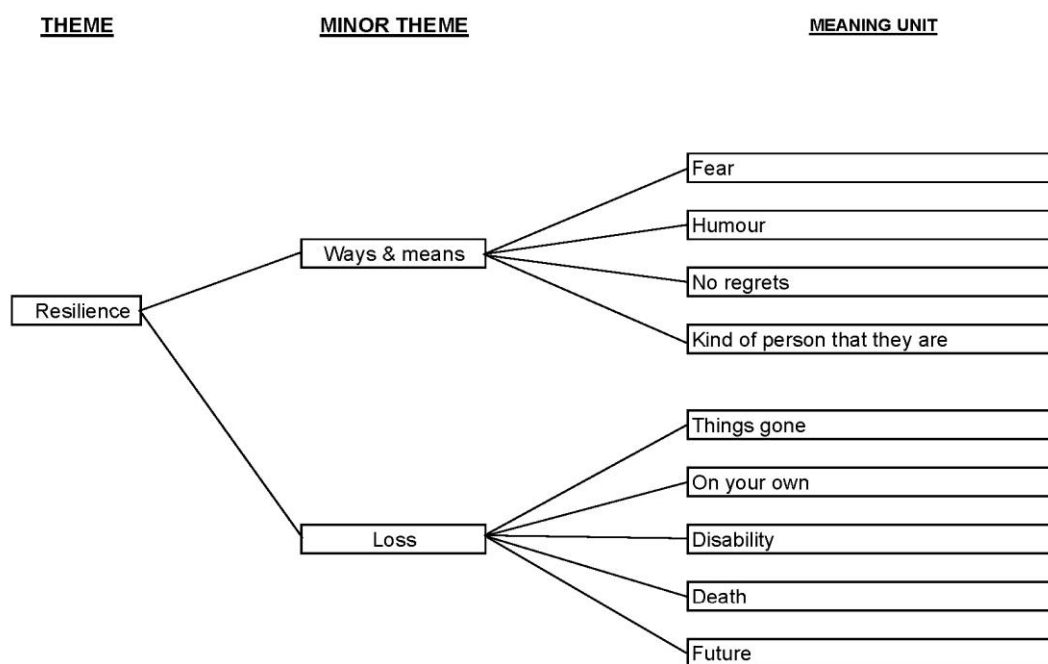
THEME	MINOR THEME	MEANING UNIT

Figure 6.4 The primary theme of *resilience* and its attendant minor themes and meaning units

This matrix conceptualises the breakup of the theme of *resilience* into minor themes and meaning units. Their interconnectivity is visible once again whether going from the parts to the whole, or vice versa.

6.9.1. Ways and means: a minor theme within resilience

> *I think you've just gotta (sic} get up with life, you know. Whatever*
> *happens. Not let it worry you (*Jessie 1: 213-214, p. 11)

Ways and means was seen in the attitudes, values and character traits within the participants' stories that were shared with me. It can be summarised as the 'tools' used by the participants to build their gutsy and determined ways of being-in-the world, and it defined *who* they are, and *what* they stood for. This minor theme also provided the tools for transitional change. There were four meaning units which made up the context of *ways and means*: *fear, humour, no regrets* and *kind of person that they are,* and all demonstrated resilience while living with dementia. Stories of life experiences demonstrated a quality of spirit that permeated the stories of adventure, risk and lots of laughter. These traits assisted the participants to cope and build lifelong resilience. It shaped their response to risk and adversity, and determined how they managed learning how to live with dementia. Within one conversation, Veronica commented nine times on aspects of the *ways and means* which she had in her resilience 'kit'. One outstanding example which she continually returned to was her bush upbringing on the family's dairy farm. This country life instilled in her the importance of hard work and family, and exemplified the kind of person she was:

> *It was a very natural life, if you know what I mean—close to the*
> *earth sort of thing. We were all busy because we didn't have*
> *electricity or anything like that. You know you did your own*
> *separating of the milk with the cream and working hard. Then you*
> *go and feed the pigs and things like that. Have you ever been on a*
> *farm?* (1: 41-43, p. 3)

Harriet was a private, self-sufficient and independent woman running her own life: *Oh no, I make my own decisions if it's a personal thing. I don't discuss it with strangers—*

I'm very close to my own heart (3: 151-152, p. 7). She was successful at managing the changes in her life, and there had been many:

> Harriet: *My mother she reared me to stand on my own two feet*
> Researcher: *But you're pleased about that*
> Harriet*: Oh yes I am 'cos* [*sic*] *my father was away and she was on*
> *her own and she brought me up to be self-reliant*
> Researcher: *Yes*
> Harriet: *And not to expect anybody to be there or to get everything.*
> *You've got to be prepared to do things yourself. She was a very*
> *good advisor on what I should be doing for my own good*
> (4: 97-104, pp. 4-5).

William coined the title of this minor theme. It began with the anecdote of the shots being fired nearby, but was emblematic of many other hair-raising escapades:

> *Yeah you learn to protect yourself. You go in and you try to punch*
> *him. You can't do it cos* [*sic*] *you're too small and so if you get*
> *them in a neckie*[11] [raising his shoulder and putting the opposite fist
> through the opening] *you throw them up in the air. It's hard for 'em*
> [*sic*] *to punch you when they're going through the air*
> (2: 2, pp. 29-32).

These rich and colourful anecdotes summed up his ability to survive in Fitzroy, an industrialised suburb of Melbourne which was both socially diverse and heavily populated with workers looking for jobs and a future for their families. During the Depression when William was growing up, Fitzroy had high unemployment and was considered a slum—a haunt of criminals and prostitutes:

> *This was a true story up in Fitzroy. But there was a whole lot of*
> *people* [*who*] *lived there it was during the time of the war and so*
> *the funny part I still remember* [laughing] [*is*] *that I went around to*
> *get some stuff this night and I came back. And I'm coming back in*
> *and there was another bloke and a girlfriend, a prostitute in the*

---

[11] This is a colloquial term for getting someone in a neck hold or a neck lock.

passage way like and I went to walk past and he grabbed me
hand. He had a £2 note and he said 'Keep it and keep on walking'
[laughing]. *He was going to bed with a woman* [laughing]. *Those*
things stick in your mind yeah (2: 35-4, p. 2)

William's life overflowed with stories of his guile and quick-wittedness in order to avoid trouble. They were rowdy and rambunctious stories both in their telling and their content. Working in a hotel drive-in bottle shop, he described an incident when an aggressive customer got out of his car, jumped the queue, and was looking for '12 rounds' [12]:

There was the bloke, he was fighting twelve rounds and I turned
round and said 'Well you just wait your turn' and that's what it was.
And he got out of his car and walked up. He walked up I was
behind the counter and he said 'I, I'm here first' and I said 'No, you
get back in your own place and then we'll serve you'. At that time it
would have been the best thing in the world or the worst thing in
the world if he went bang [clenching his fist and raising it as with a
punch] *because I would have been flat on the ground and didn't*
know if I cared about that (1: 8-17, pp.1-2).

Many of William's escapades worked out well for him: *Yeah I was pretty strong, and fit, and yeah I did learn a little bit of boxing. I know how to look after meself* [*sic*] (1: 114-115, p. 6). His ability to manage and resolve conflicting situations held him in good stead, and assisted him in building self-resilience. At times however this was sorely tested, as exemplified in his recall of the bottle-shop incident: *I was scared stiff...I was petrified* [laughing] *put it that way. 'Cos* [*sic*] *twelve rounds I don't want any troubles like that* (1: 18-19, p. 2).

In his long life, Dan recounted many instances where he dealt with personal challenges and anguish, such as the acceptance of both his sons' long-term mental health issues. He was immensely proud of his boys, and on settling in Australia he

---

[12] Looking for 'twelve rounds' is a colloquial expression meaning looking for a fight. William had done some boxing as a young man, and this would have been a phrase coined to describe being in a boxing ring and fighting for twelve rounds-the usual length of a bout unless one person is knocked out, or injured before then.

defended them: *My sons would have fought for Australia. They have been called pommy bastards—that's all bullshit. My two sons took out Australian citizenship, Mick was born here. They're Australian through and through* (1:159-162, p. 8). But there were setbacks along the way: *Our youngest son he had a lot of trouble with the brain. We got through all that. There's Mick he's forty-five, then there's Jamie. He was in the prison system for twenty-five years that didn't go well. I told him to get out of there. He went a bit wonky[13] in the end* (2: 418- 422, pp. 19-20). When asked about his future wishes, his only thoughts were for his wife Mary and his boys: *Oh if I had a lot of money I'd probably put one of my sons—two of my sons to be alright* (4: 360-361, p.18).

Dan had resilience instilled in him by his father long ago: *My Dad said you can't afford to be frightened* (1: 382, p. 16). Despite being: *knocked over a few times* (4: 112, p. 6), he had the capacity and tenacity to address life's challenges without fear. He often described himself as a stayer: *We were stayers, because Mary* [wife] *was a stayer. If you're not a stayer you're not gonna* [*sic*] *get anywhere* (2: 203-204, p. 9).

A diagnosis of dementia however tested Dan's lifelong fearlessness in the face of adversity: *I was terrified the other week. I was crying me* [*sic*] *bloody eyes out* (2: 383, p. 16). A diagnosis was an existential crisis for Dan as he had watched a family relation struggle with dementia. However this journeyman who had fought the unions, threatened bosses, defended workers and worked sixteen hour days in a factory resolved to fight on: *I can't do anything about it, but I can try. I remember maybe two or three hours later. I work through it, and the people haven't taught me that—I taught meself* [*sic*] (2: 549- 551, p. 25). Previous risk-taking and adventurous behaviour however had been left behind, as fear and doubt had crept into his everyday life leaving him reliant on his wife Mary for everyday support:

> Researcher: *Dan can you tell me what is a risk for you today?*
> Dan: *Well, being on me own I s'pose* [*sic*]. *When we been out shopping* [*sic*] *and Mary says 'You can stay there' but I always keep me* [*sic*] *eye on her*

---

[13] Wonky is a slang expression for shaky or unsteady. It may refer to physical or emotional unsteadiness.

Researcher: *That would be the biggest risk for you?*

Dan: *Oh yeah. Oh I wouldn't stay here. I wouldn't top meself or*
anything like that but

Researcher: *So if Mary's away you feel completely at sea?*

Dan: *Oh yeah, you've got to have something to hang on to*

Researcher*: And being on your own can be?*

Dan: *That's the finish* (4: 332-340, p. 17).

Dan's experience of dementia and his reluctance to embrace risk-taking now was echoed in the stories of other participants who became reflective about what they could and could not do. Chicks feared losing her independence, and chose death as a preference: *Oh look if anything happened to me and I couldn't look after myself—I just hope that I just don't wake up some morning* (2: 299-300, p. 13). Harriet also wanted to live life on her own terms: *I have no fear of death and if I got to the stage where I couldn't do for myself umm*[*sic*] *you know you've got to be fed and you've got to be washed and everything you rely on, you know I don't want. That'd get me down I'd sooner die* (2: 189-192, p. 10). Both women were fiercely independent, and having control in their lives also meant hopefully having control over their death also.

Within the context of changing life circumstances, Harriet and William's hope to 'become wiser' acknowledged that they had lost their nerve to take risks now. With her usual equanimity, Harriet reasoned: *Yes, yes you've got to be wise. You can't do things that you did earlier on* (3: 196-197, p. 8). William had become fearful and lost his nerve and when asked if he would stand up for himself, he replied:

William*: I don't know but I don't think so*

Researcher*: Why's that?*

William*: I'm not fit enough, I'm not tall enough. The kids today now*
are a lot taller

Researcher: *Oh*

William*: And a lot faster* (1: 85-89, p. 5).

He declared: *Oh well, as you get older, you might get wiser,*
hopefully, hopefully [laughing] (3: 326, p. 12).

This realisation incorporated an acceptance of transition and a wisdom borne of experience, pragmatism and resilience across multiple domains of life, as he attested:

> Researcher: *If Susie wasn't here would you climb the ladder*
> *William?*
> William*: No*
> Susie: *Oh I think he would*
> William: *No I wouldn't be confident enough to do it*
> Susie: *Well there you go. I'm glad you said that*
> William: *No. I'm not game enough to do it. I'm scared now. And*
> *you forget Susie, but I'm getting old too* (2: 141-148, p. 6)

Humour permeated the experiential stories of resilience when living with dementia. William loved to laugh, and this stood him in good stead in what had been a sometimes difficult life. His humour was optimistic—a defiance in the face of events in which others might find little to laugh about:

> *No, I was not a fighter and another time when I lived down in*
> *Fitzroy which was pretty rough at the time I used to go out where*
> *Mum had the place and I used to go out the back gate, up the lane*
> *and get the milk and this bloke used to give me a belt on the head*
> [smacking the back of his head with his hand]. *Every time I went*
> *up there he'd belt me on the back of the head and take the milk off*
> *me and ah that wasn't too good. So I thought about it and said 'I've*
> *had enough of this' so I walked over and he come running over*
> *and he went to whack me and I'd just gone up and learned to do*
> *judo. So I when he threw the punch at* me [punching a clenched
> fist into his other hand] *I just grabbed him by the arms and threw*
> *him through the window* [laughing] (1: 17-30, p. 2).

This allowed him to reminisce about conquering life's adversities, and provided clues about managing the present and the future, despite his recent losses. Sometimes, laughter can offer an escape—a partial break in a difficult conversation about the

losses and limitations that are currently being imposed on the person. Harriet tells of her exploits in her facility:

> Harriet: *Sometimes I like to pull the legs of the sisters. Sometimes I like to pull their legs and I think they've got a name for me or something, I'm not too sure. Oh yes, she's at it again* [laughing] *or something, but I like to pull somebody's leg. It's better than sitting around with er* [*sic*] *what's it called?*
> Researcher*: Alzheimer's*
> Harriet: *Yes. I'm accepting it because I know that there's nothing I can do about it. See I think that there is a serious side of life that can get you down and there's the other way of looking at life that you don't let it get you down—and I'm on that side. And it's not stopping me from being cheeky though* [laughing] (4: 164-167, p. 7; 4: 205-208, p. 8).

On several occasions within the conversations, humour defused otherwise awkward situations, and it was a relief for all of us. Here Dan was talking about his son Mick who was unwell:

> *We had to take a risk with Mick 'cos* [*sic*] *he had a nervous breakdown and we had to bring him home. He's been in a special place up there for about nine years and he drives his car. We just got a new car—we gave him our car so we don't worry about it. Mick worries about me and I tell him not to worry about it. If you go, you go—but I'm not going! Into the box, I mean!* [laughing] (3: 389-392, p. 11).

Mary, Dan and I—we all laughed heartily.

Warm humour and laughter trickled through the friendly banter with Florence and her old school friend Gwen who was present at all the conversations together: *I haven't got a boyfriend—wouldn't know what to do with it* [*sic*] *if I did* [laughing] (1: 193, p. 9). Humour can be seen as a human strength and most of the participants saw the funny

side of life. When discussing her career, I sought more details of her working life from Veronica, and her comment was followed by sustained laughter:

> Researcher: *So you were a teacher and a nun?*
> Veronica: *Yeah, I'm not a nun now*
> Researcher: *No?*
> Veronica: *I am a NONE* [spells this out while we both laugh]
> (2: 300-303, p. 11).

Jessie loved men, and having buried two husbands her gentle humour centred on the men in her facility as this anecdote suggested:

> Researcher: *Last time I was here you had had two proposals of marriage. Have there been any more proposals since I last saw you?*
> Jessie: [sustained giggling]: *Well I still have a man here, he brings me sweets and things, and I talk to him*
> Moira: [daughter]: *I'm not too sure which one this is. It's not Alby, is it?*
> Jessie: *No this is another one* [more giggling]
> Jessie: *And the only time I see him is at meal times. Every time I come in I see him at the table on his own, and then I'm two tables down. And that's when Elaine* [woman on the same table] *says to me 'Oh when are you getting engaged? and then married?* [more giggling]' (4: 234-244, pp. 10-11).

Jessie clearly loved this subject, and her daughter joined in the fun:

> Meg: *Well if I come in here one day and you've gone I'll know that you have eloped. Just make sure that he has plenty of money* (4: 247-250, p. 11).

Perhaps the importance of having 'no regrets' can be appreciated more fully in the examination of in reverse, regret. Regret was mentioned on four occasions within all thirty-two interviews, and signified feelings of profound remorse and sorrow. Regret

often implies a fault in personal action where things could have been done differently, and for Dan this was the case with his drinking. He referred to his daily beers as the one mistake that he made in his life for the doctor had attributed his dementia to his late night drinking. With this regret is an awareness of lost opportunity:

> *With young people today, if you don't mind me saying, is that they*
> *don't go for a lifetime. We got born, you've seen the war, you've*
> *been in the army, you've seen rough stuff. Today half of 'em* [*sic*]
> *haven't seen anything. See we got married, came half way around*
> *the world in an old tin bucket for a boat and then you're just worry*
> *free … but then I got this* [*dementia*]
> (2: 524-529, p. 24).

Harriet moved into care before she 'felt ready', but when a suitable vacancy came up she listened to the advice of her doctor and heeded it: *So from that point of view it didn't upset me, and I thought well it might be as well—while I've got this opportunity to take it. I think it's just sensible* (2: 258-259, p.13). While she missed her unit with her husband's artwork and tapestries throughout, she remained positive. In the nursing home, she continued to help others and pursue every opportunity that came along: *Where I've always tried to look on the bright side of life and if I've wanted to do something um I I I* [*sic*] *forget about myself and I do it. Because I've always thought while you can do things, do them* (2: 277-279, p. 14). Once committed, there was no looking back for her: *I think so. I've no regrets* (1: 8, p. 1). This was a *ways and means* of maintaining and building resilience, and for other participants who were also looking forward this was also possible due to a lack of regret. When reflecting on her immigration to Australia, I posed a question to Jessie:

> Researcher: *So your lesson to one of your grandchildren—if they*
> *were thinking about doing something like that, what would you say*
> *to them?*
> Jessie: *I'd say think about it and* [*ask them*] *what do you really*
> *want to do? You've got to decide. You can't say 'oh you'll have to*
> *go' and then come back. You've got to decide and then you've*
> *done the right thing* (2: 36-40, p. 2).

Jessie's fearless response exemplified decision making without regret which has the potential to uphold and build resilience−irrespective of the outcome.

This minor theme is summed up by Jane: *I'd like to go back to France but I don't think it's worthwhile. I expect most of my friends are dead now 'cos* [*sic*] *they were mostly older than I was* (2: 185-186, p. 8).

6.9.2. Loss: a minor theme within resilience
Loss impacts on a person's resilience and for people living with dementia it confers additional burdens such as stigma. Within the conversations, loss was filled with regret and sorrow, but renewal and optimism were also seen. When playing a joke on a nurse, Harriet recalled: *I couldn't help laughing it was so funny—so you see I haven't lost my sense of ... joking* (4: 200-201, p. 8). Expectations of 'things will only get worse' often accompany a life-threatening illness such as dementia, but within this study a dignified resignation and acceptance of loss was realised. Jessie had lost two husbands and then an old friend to whom she became close, but stoically she carried on: *Well you have to accept things. Do you know what I mean? I had to make another life for meself* [*sic*] (4: 52-53, p. 3). Moving into care was easy enough but finding companionship proved difficult:

> *I try and keep busy* [lowering voice]. *Most of 'em* [*sic*] *here they'll*
> *go into their room and sit. I'm not that type−I like to go out and*
> *meet people. I find there's a few that sit around but not a lot really,*
> *no. Lorraine she sits at my table but every time I pass her she's*
> *sleeping* [laughing] (3: 65-68, p. 3)

This anecdote[14] highlighted the importance of 'place' for people as they age and their social world begins to shrink. Jessie's past was filled with family and friends—most of whom are now gone, and she had been hopeful of greater engagement with others in her new facility. She remained positive however: *Oh maybe a couple of things like, I may have been disappointed in, but most things go well I enjoy most things like* (3: 64-65, p. 3).

---

[14] Van Manen assigns the term 'anecdote' to a statement or story which can reveal the true nature of a person.

When asked about loss in her life, Jessie replied: *Aye well, I don't go out dancing and yeah I always did and I don't work now—that's two things gone* [laughing] (4: 257-258, p.11). Her loss of paid work had been reluctantly accepted, but the curtailment of her dancing was largely due to a lack of opportunity. This was a blow to her self-esteem as she still wished to dance:

> Jessie: *Age does not bother me. I'm not a person who says 'Oh no, I can't do that'*
> Researcher: *So how old do you feel?*
> Jessie: *Oh, say late sixties perhaps, 'cos* [*sic*] *I've always danced. I love to dance but I don't dance anymore*
> Researcher: *If there was a dance going on here, you'd probably still be doing it wouldn't you?*
> Meg (daughter): *Yeah when there have been occasions here Mum's got up and danced. What she does do is still very good*
> Jessie: *I'm still pretty good*
> Meg: *Yeah, but you're not up there jitter bugging and that*
> Jessie: *No, but I can still do the waltz and the quickstep. Oh yes I love that and I think that's something that you never lose. That's right yeah, I love the dancing. They don't usually do much of it around here and what could I do? I couldn't go out at night and come back in here like no I'd never do that unless there was something on that the family was picking me up and taking me to. But never, ever would I go on me* [*sic*] *own* (4: 10-21, pp. 9-10).

This loss had an important social dimension for Jessie. She loved people, and she had made the choice to move into care because she was lonely: *Yeah well I knew that it was going to be better to be with people* (2: 121, p. 5). The losses of role, privacy and control inevitably occur in care, but Jessie was relying on the bonus of being with others to offset them.

Jane was one of several participants who came to Australia to live, but her losses were greater as she had made the journey in her old age, attempting to start her life all over again:

Researcher: *Do you think that you coming to Australia was a risk?*

Jane: *It was. Different language, different understanding of life, living a different way*

Researcher: *You've lived in many places—you've done it before*

Jane: *Yes* [slowly] *but not at this age, of course. And I haven't met many people about this age. There's one group that Kim* [daughter] *got me onto. They're very nice people, but I didn't find them* [to be] *extremely exciting. Nor did they find me* [exciting], *I think* [long delay] (1: 116-122, pp. 5-6).

Jane's bitter regret at having no choice but to come back to Australia deepened as she was moved into care without consultation, and this fuelled her disappointment and disillusionment:

Researcher: S*o this is one of the changes that have not been so good?*

Jane: *Yes I think we all regret it* [speech very slow and considered]. (Here *we* is referring to her family)

Researcher: *Regret?*

Jane: *Being put in this place*

Researcher: *Do you think that everybody here feels the same way?*

Jane: *Yes, a little bit of regret* (2: 115-120, p. 5).

Compound losses such as these left Jane with few options and few personal resources with which to counteract them.

The meaning unit of *things gone* reflected the resilience of the participants. While there were many people and things acknowledged as 'gone', none had the impact that the loss of driving a car had for the participants. Driving a car allows a person to have dominion over their life, and the arbitrary removal of this right inflicts reliance on others for transport at a time when independence is being threatened on several fronts. Rosie had not accepted her loss of a driving licence, and if she had her way she would still be driving: *No longer driving from place to place as much as I used to,*

but I can still drive (2: 88-89, p. 5). Florence had insight into her situation which was becoming tenuous: *It's not the driving, it's the memory. It's not the driving at all—I love to drive* (4: 339, p.14). There was a presentiment of change when she announced: *I'm actually quite set and satisfied with my life while I can still drive* (3: 118, p. 4).

Dan accepted the loss of his licence, but it was a blow to his masculinity: *I feel very bad you know. I say to Mary she has to do all the driving—'cos* [*sic*] *I get a bit pissed off with it, to give her a rest* (2: 358-359, p. 17). William was furious at losing the right to drive a car: *Now why have they stopped me from driving a car? The doctor done it* [*sic*]*. I never had a smash or anything in a car, but I'm not allowed to drive a car … and that makes you feel useless* (3: 202-203, p. 7).

When the participants had insight into their changed situation, they acknowledged and accepted loss in their lives, but having reduced awareness resulted in a different response. William had lost his role as a 'fixer' around the house, and he begrudgingly accepted this after a time. The loss of his bath was different however: *Now me bath's gone and so am I* (3: 86-87, p. 4). His arthritis and poor balance made it unsafe for him to bathe now, and the last time I saw him he was in considerable pain. His losses were mounting fast and when he raised the issue of riding his bike again, his wife said:

> Susie [wife]: *Oh, no you don't—*to which he replied
> William*: I've been hearing that a lot lately* (3: 123, p. 6).

Loss remained a reminder of 'something gone', or changed, and was more acceptable if a person was able to rationalise the reasons for that loss.

On your own was a powerful meaning unit within *loss,* and a recurring concern for several participants in this study. Margaret, Florence, Harriet, Jane and Rosie commented on it, and it was tinged with sadness, fear and for Jane, bravery: *I don't see why I'm brave. Perhaps going out on my own with no husband, but thousands do it* (2: 230-232, p. 10). It was a reminder of loved ones who had gone—or moved away—and it left Florence feeling alone. When invited to a family friend's party she

felt like an outsider: *Because when you're on your own, you're on your own. Although she's one of my best friends it's breaking into that family situation—do you know what I mean?* (4: 81-82, p. 4). Being alone became less important with the progression of dementia, but it shook her confidence:

> Florence: *I'd like to be about twenty years younger, but then what difference would that make? I'd still be on me [sic] own and that would be worse wouldn't it? I'd have to get myself another bloke [laughing]*
> Researcher: *If you were twenty years younger is that what you would you be doing?*
> Florence: *No, no I don't need a man around once you've lived on your own for a long time* (4: 193-198, pp. 8-9).

Being *on your own* had important benefits for one's independence however, and Florence readily acknowledged this: *And I think living on your own makes you more aware of the things that you can do—that you've got to do because you can't rely on your husband to do it* (1: 286-287, p. 13).

Having a dependent disabled child constitutes significant loss for any parent, and it posed a burdensome dilemma for several of the participants as they were getting older, and adjusting to a diagnosis of dementia. After they were married, Florence and her new husband moved to Nauru, an island north of Australia in the Pacific Ocean. They had hopes of secure work and building a future, in order to come back to Australia and buy a house of their own: *Well when we married, I mean, I never had much money and he had probably less* (2: 50-51, p. 3). While living there, a son was born in Australia, and then a daughter Megan was born in Nauru. Florence recalls her birth:

> *I wanted to come home and then I got pregnant again and I decided I'd stay there. And of course they bring the baby in and I looked at this baby and thought she looks a bit different and she was Down's syndrome. So I rang the buzzer and the nurse came in and I said to her 'This baby looks like a Down's syndrome child' and she said 'Oh yes she might only look like one but she mightn't*

be one' and I thought God fancy looking like one and not being
one anyway… it was a teary sort of time (1: 151-157, p. 7).

Going to Nauru changed everything: *No, no we wouldn't have got ahead without*
Nauru— 'cos [sic] *then I had a disabled kid. I couldn't work. We didn't know just how*
she was going to turn out (2: 351-352, p. 15). Listening to the anecdote of Megan's
birth, it was a 'teary sort of time' for Gwen, for me and for Florence, but her usual
optimism shone through: *Anyway I got over it. That girl's forty-two or something now,*
forty-three? (1: 157, p. 7).

Now a widow, visiting Megan's facility weekly in her car was proving difficult:

I don't see her terribly often. I used to see her and take her out but
that's too hard now. It's too late in the game [laughing]. *She hasn't*
got the nouse to say 'Oh where's Mum—my Mum hasn't been over'
(3: 161-163, p. 6).

Florence nominated her daughter as being future risk for her: *Don't know what's*
going to happen about her [Megan] *because Tom* [son] *lives in Brisbane and if*
anything happens to me (3: 177-178, p. 6). When Dan thought about his future, he
was also fearful for his two sons and he fretted about them: *Oh if I had a lot of money*
I'd probably put one of my sons, two of my sons to be alright (4: 360-361, p. 18). Both
Dan and Florence had voiced concerns about the future care of their children, and
this was a legitimate worry as they began to face uncertainty in their future too.
Veronica had a disabled brother with cerebral palsy, and she watched as her mother
was worn down with the toll of looking after him in their large family:

We had Michael who taught us so much. It was hard for him. He
was still intelligent, but he couldn't put the words together. I don't
know how we, we sort of had a language but he'd see things and
know things before we would. And he coped with all his losses well
(1: 341-344, pp. 19-20).

The ultimate loss is often associated with 'death', but this did not worry Dan: *The only thing that I'm gonna* [*sic*] *look forward to is getting in the box* (2: 497-498, p. 23). His concern was not for himself, but his family—the ones being left behind:

> Dan: *But one thing I do know...Mary's covered...Mary's covered*
> Researcher: *Yep*
> Dan: *And* [tearfully] *she'll always be alright and nobody can take what she's got* (4: 165-167, p. 8).

An interaction such as this was a reminder of the tenuous nature of life, and how an arbitrary diagnosis such as dementia can change everything. It was an experience that will never leave me.

Harriet was also facing an uncertain 'future' and like Dan she was unafraid:

> *I don't know how long I've got. I know* [um] *that this will get me in the end—I'm quite sure of that. But I don't know when it is and I'm not looking. In fact I don't care when it is* (2: 185-187, p. 4).

When asking about her 'future', Veronica said she wanted to go home, but this was unlikely to happen:

> Veronica: *I'm tossing up whether I'll go back to Portland. I need to talk to Kate* [sister] *about that. Actually she's the only one there now and I've got my grave in Portland−save the funeral costs* [loud laughing]
> Researcher: *Oh*
> Veronica: [laughing]*You've got to laugh. I've paid for it so−well everybody has to do that, don't they?* [laughing]
> Researcher: *What else does the future hold?*
> Veronica: *Um, ah, well I think I'm retired actually*
> Researcher: *You're not working anymore?*
> Veronica: *No I haven't, not recently* (4: 289-298, p.14)

Jane was aware of ethical issues relating to loss which occurred when she moved into aged care, and she saw no future at all—certainly not one that she would want to have, or one that she had any control over:

> Jane: *I'm not making decisions anymore*
> Researcher: *Who is making the decisions?*
> Jane: *I think my daughter mostly and her husband... I don't know.*
> *All very strange*
> Researcher: [after a very long delay] *What about the future Jane?*
> *What do you see happening in the future for you?*
> Jane: *I don't see any future. I don't really know* [very slowly] *I don't*
> *really know what the future is—what lies ahead of me*
> (2: 174-180, pp. 7-8).

Being involved in choice and decision making regarding one's future has significance for everyone, but when living with the threats posed by dementia, this involvement has particular moral and ethical implications. Recovering from multiple losses can prove insurmountable, and it did for Jane. She was now in chronic pain, she could no longer walk independently and she was unhappy. Resilient people are able, and willing to adapt to changed circumstances, but Jane had neither the agency nor the inclination to do so now.

Loss signified the progression of dementia, and in sharing their stories the participants explored the effects of loss and its implications for their everyday life, both now and into the future:

> Rosie: *Oh my memory goes on and off, it's not as good as it used*
> *to be* [laughing]
> Reg: (husband): *Understatement*
> Rosie: [laughing] *It's not as good as it used to be*
> Researcher*: So how do you manage that, does it let you down?*
> Rosie*: Oh well I write a lot of things down, and if I want to go*
> *shopping or something and I think oh I've got to get that and I don't*
> *write it down, and I go to the street and it's not there. So I get*

home and have to go back again. So now I have to write things
down

Researcher: *Did you write down that I was coming today?*

Rosie: *No, because I remember you said that you were coming*
today [Our first meeting was arranged by phone three times. It took
three trips to Reservoir before I found Rosie at home. Telephoning
was not a guarantee of success then but Rosie does not drive any
longer and is less mobile]

Researcher: *So you write everything down and that works well?*

Reg*: Losing the piece of paper—that's the problem*

Rosie*: See I no, I haven't put something down here but see I put*
things in different places. Instead of putting it in the same place
where I like in the kitchen—that's what I must do—put it always in
the same place (4: 115-123, p. 5).

Coping can be defined as efforts to prevent or reduce the negative impact of stress
on a person, and it is an integral component of resilience. It was a strategy
mentioned frequently by the participants. Similar terms were used: 'managed', 'it
worked out', 'just got on with it', 'accepting things' and 'went on'*.* Pearl summed up
her approach to life: *I just got on with whatever was happening, didn't I?* (1: 164, p.
7). Many of the participants shared this coping style, and readily faced the adversity
as it came up: *You need to know your own limits, and if you know your own limits*
then you can go and do anything (Harriet 3: 145-147, p. 6).

A lifetime of experience was embedded in the stories told, and it was seen to be
applied to difficulties that came up later in life, countering the hardship and assisting
with coping:

My mother was very er [*sic*] *not strict but informative you know—*
'just think before you do something' and if you can do something
for other people. But she didn't have to tell me 'cos [*sic*] *I was*
always doing something for other people. She reared me to stand
on my own two feet (Harriet 4: 94-97, p. 4).

Experience such as this is invaluable for Harriet as she confronts a future with ageing and a diagnosis of dementia.

Positive emotions can play a part in coping and in related psychological and physical wellbeing, even during stressful times (Lavretsky, 2014), and they were seen in abundance within the stories. Qualities of altruism, optimism, loyalty, acceptance, personal responsibility and looking out for others were evidenced, and they also contributed to the participants' resilience.

In his job as a shop steward Dan worried about the workers:

> *And another thing these people they came from Yugoslavia and Greece. They were treated like dirt. If you ever worked in a rubber factory sixteen hours a day it's not worthy. Cos [sic] I know guys who are finished after sixteen hours a day. You gotta have eight hours rest and eight hours play and eight hours work. And they used to work so hard* [change in voice tone] (1: 53-58, p. 4).

For Jane a multitude of losses had left her feeling helpless and unable to cope. Her negative emotional state did not bode well for her future. She was saddened at being old: *You see I've got old now, so old...It's not a happy life when you get old like this* (1: 36-37, p. 3), and when asked to comment on old age she retorted: *No, it's FOUL...no it's a thing to be missed out, if one could ... how marvellous* (2: 211, p. 9).

A person can be physically 'frail' and resilient; but chronic arthritic pain was diminishing everyday life for Jane, and she did not have the resolve or the energy to go on. But this was not always the case. As a gutsy young woman, she had worked at Bomber Command during World War 2*: I remember taking the car up to London during the bombings. You didn't know if you'd drive back, but you got used to it and it didn't worry you anymore* (1: 5-6, p. 2). But as an ageing widowed woman, her only choice was to return to her daughter in Melbourne to be cared for. My field notes at the first meeting read:

'I was invited to meet and have lunch with Jane for the first time on a very hot day in an outer suburb of Melbourne. Jane was slow to come out of her room, but she was on a wheelie frame and in pain. When introduced, she was quiet and reserved, but when asked, agreed that she would like to take part in the study. Over lunch she ate little. When her daughter had left for the day and the conversation was completed, I escorted her back to her room. She asked me to come again. I said that I would be seeing her in six months, but she said that she liked me, and would like me to visit before that. I sensed that she was lonely, with a grandson coming in the evening to cook for her, and a daughter juggling many things in her life, including a full-time job'.

Personality or mindset is also considered to be important in adapting to stress and building resilience. Jessie's positive outlook stood her in good stead for the upheaval and uncertainty of a diagnosis. This attribute offers an array of adaptive benefits, both for everyday life and in response to stressful events: *Anyway, I enjoyed it, whatever it was* (1: 164, p. 7). This is the kind of person she was, and many of the participants shared a similar anecdote—which gave me a picture of *who* and *what* they were. They tried, they managed and they assumed responsibility for their own lives. Dan accepted that his drinking was the cause of his diagnosis, but his survivorship was seen in his determination to enjoy the good things in his life now—particularly his family: *Oh, I'm pretty good, OK I don't intend to let this disease get me down—I've got too much to...I like me* [*sic*] *grandchildren you know* (4: 4-5, p. 1). This resilience has been forged on both Dan's strengths and his weaknesses (Lavretsky, 2014), and it has come to the fore at a time when it is needed the most. Harriet said:

> *I'm not sitting here and moping and thinking if I'm going to die*
> *tomorrow or something like that. I know with this disease*
> [dementia], *ah it takes you. It can do and look at Hazel Hawke.*
> *She died in her fifties and I mean I'm eighty-five* (2: 317-320, p.
> 16).

6.10. Reflections on resilience as a primary theme

Being resilient in the face of a diagnosis, with a capacity to buffer change can be seen as an active response to an increasingly complex life. Dan was 'retraining' his memory, and on the advice of his doctor he was 'training' his body too:

I've trained my legs into a car and when I want to go out I tell Mary
'I'm going up to so and so park'. Then I'm going in a big long walk
right around the street, and I know runs and areas I can walk to. I
just sit down on this big seat in the park and now and again I have
a little bottle of water and I'll have a drink and then I come back (3:
208-211, p. 6).

This inner fight was an acquired skill that Dan had honed during World War Two and it was summoned again. This was a lifelong strength that held Dan in good stead, and played a decisive role in his lifelong resilience.

Resources which build resilience include attachment relationships—the closeness of friends and/or family. Jessie appreciated her devoted children: *I do alright which is good, and I've got Meg and the kids. Oh no, I'm quite happy* (1: 80-81, p. 5). Dan reminisced fondly of his father and role model:

It's like my Dad. I loved him like the earth. He was a man who was
not afraid of anyone… As he used to say you can only get a
certain amount of money—if you seen [*sic*] *an opening you go for*
it. If you don't, they close it on you (2: 41-43, p. 7).

When talking about life's 'ups and downs', William compared it to having a bet on the horse:

Researcher: *So you have to take what life deals out to you don't*
you?
William: *What else can you do? Same as when you back a*
racehorse [laughter)*] put your money on and sometimes you get it*
back and sometimes you don't [laughing]
Susie: [wife]:*That's his hobby on Saturday. If there's a race on, he*
has a bet. Hasn't been winning anything lately but he has his days
William: *But I always get something back* (1: 241-246, p. 11).

Within this study, an interplay between personal predisposition, experience and environment was evidenced. This interplay tested individual weaknesses and strengths in everyday life, and it highlighted the things that were most important to the participants—things that were likely to enhance their resilience rather than weaken it.

The primary theme of *resilience* defied a singular definition and remained elusive. Resilience then, was not an inherent personal characteristic or a fixed attribute, but a dynamic process, seen within the stories of the participants living with dementia. There were anecdotes of risk-taking bound up with both vulnerabilities and strengths—Dan with his disabled sons, Harriet and her curious nature that motivated her to travel and Veronica with her determination to keep driving. For the participants, resilience was the 'engine', figuratively speaking, which facilitated the process of transition and adaptation to living with dementia. It was dynamic and shifting when dementia posed a risk to the normal expectations of transitional change. Resilience in turn shaped the response to dementia bound up in lifelong strengths and qualities which the participants called upon to manage a recent diagnosis. It was an attribute built up over a lifetime that sustained the continuity of their life journey while living with dementia. The analysis demonstrates positive adaptation to adversity over time, including the ability to incorporate both vulnerabilities and strengths following a diagnosis of dementia.

The process of the lived experience for the participants with a recent diagnosis of dementia included transitional change reflected upon in the minor themes of age, risk and thinking. This 'new' everyday living reflected shifts and change requiring adjustment— which in itself posed certain risk. Resilience provided the 'raw material' to shape the response and cope with these shifts and changes; risk which had been taken over time as the participants confronted a future with dementia. The primary theme of resilience provided and will continue to provide, the impetus to manage this change and reflected its essential connection to risk.

At the end of this exhaustive and in-depth analysis, it is a worthy reminder of van Manen's comment (1990, p. 79) that the concept of theme is "rather irrelevant" and

is merely the means to get at the phenomenon that we are interested in. It supports Stead's contention that stories are the *record of the day* and the preservation of stories of risk by the participants ensures their place in time and history. The two primary themes of *transition* and *resilience* are singular and independent and inextricably linked. Transition was unfolding in the lives of the participants, and it was managed by the resources where resilience enabled them to move forward, learning about loss and the power of humour in living with dementia.

CHAPTER 7

PHENOMENOLOGICAL REFLECTION

'I have a ring, a string of pearls, a locket and a gold heart. These I wear. The papers are piled around my desk, tied with the thread she made, along with the notebooks I kept of our conversations during that strange last summer. Through this patchy evidence I piece together the story of Poppy who was born in 1924, daughter of China and Jack, wife of Richard, lover of Marcus, mother of May and Phoebe and me. That is how we mark a woman, by her kin and progeny. But it doesn't tell me who she was.

(Drussila Modjeska: *Poppy*)

As Modjeska sought to develop a deeper understanding of *who* Poppy was in the above citation, this study's aim was to grasp the essential meaning of the lived experience of risk. Van Manen reminded me that phenomenological reflection is difficult, for to understand the lived experience of risk is to come to "a reflective determination and explication" of its essential meaning (van Manen, 1990, p. 77). An intensive analysis of the text began over again and a deep reflection uncovered further meanings. Within the text, the themes and the meaning units allowed me to get closer to the lived experience—effecting intimate contact and deeper understanding.

Gadamer provided guidance for this phenomenological reflection in his concept 'fusion of horizons' when he said: "[t]he horizon of the present cannot be formed without the past" (1996, p. 306). My focus on the participants' deeper understandings began with the lived experience of risk and its recalled memories, and was reflected upon in the present—the 'now' (van Manen, 2014, p. 57). For Heidegger (1962) this interpretation of meaning is not an act of subjectivity, nor is it the objective explanation or neutral description. It is an engagement with the participant, their data and the wider socio-cultural context within which these phenomena may occur. Importantly it is also a return to my exhaustive field notes where changes and considerations were noted in order to embody that engagement. Such intense scrutiny in the search for meanings—some of which may be hidden, is well suited to

address the complexity of the research question. My task was then to interpret its "livingness—the living moment of the experience" (van Manen in Higgins & van der Riet, 2016, p. 6).

7.1.   The findings of the study

The four major findings of this study reflect the two core themes of resilience (findings one and four) and transition (findings two and three).

1. The participants had all taken significant risks in their past lives for both extrinsic (contextual) and intrinsic (personal) reasons and linked the past to the present living experience.

2. The participants expressed fear, anxiety and uncertainty following a diagnosis of dementia. This was expressed in terms of:

> ➢ future expectations of responsibility and obligation; and

> ➢ a reluctance to embrace risk that previously was seemingly part of 'life'.

3. Following a diagnosis of dementia, risk was withheld by 'others' in the 'best interests' of the participant.

4. After a process of transitional adjustment to a diagnosis of dementia, the participants rallied and were determined to live life to the full.

The following section returns to a phenomenological reflection on the first finding where significant risks were taken by the participants in their past lives for both extrinsic (contextual) and intrinsic (personal) reasons. The lived experience of risk was explored at a time when the participants were harnessing their considerable personal resources in order to 'tackle' the transitional effects of living with dementia.

7.2.   Lived experience of risk: a reflection on the past

For the participants—their values and principles were reflected in the study's themes and embodied within their stories of risk. The participants had all taken significant risks in their past lives and this was the substance of the study's first finding. In a time of great uncertainty and doubt following a diagnosis of dementia, stories of risk were told, enhanced and promptly dismissed as 'normal'—something you 'just did'. The concept of risk however assumed an importance far greater than stories of migrating to Australia; being chased by a bully in the street; or moving into care. This

was risk that was embraced—an embodied risk, irrespective of outcome. When looking back on their lives, risk was seen as something the participants really wanted to do—and they did:

> Veronica: *Um probably done what I wanted to do* (4: 173, p. 9)
>
> Pearl: *Yes, yes, I've done what I wanted to do that's for sure*
> (1:100, p. 5).

But not everything worked out for the best. William reminded me that when things go wrong: *You, you've got to take the upper hand. You can't wait for somebody else to fix it for you. That's just natural* (2: 59-60, p. 3). When reflecting on the titles of several of the meaning units—'loss', 'kind of person that they are', 'coping' and 'managing', the meaning of risk for the participants became clearer. It was natural and it was, as Dan remarked: *life* (1: 351, p. 11).

In order to test this definition of risk, I turned to the experiences of the participants. Jane grew up in Europe and moved to London to work in Bomber Command when World War 11 broke out. She had memories of being in an official car which later was found to have a bomb planted underneath it. She referred to this: *You got used to it, and it didn't worry you anymore. I don't know anything else* (1: 6-7, p. 2). Other particular instances of 'risk' taken by the participants included a fight in a neighbour's backyard; falling out of a tree while watching a gunfight; entering and then leaving the seminary; and doing a naturopathy course in your fifties and attending naturopathy's first conference in China. These experiences of risk were shrugged off by the participants as being 'normal'; as just something that you did. Despite their variability, the meaning of risk as an embodiment of 'life' was its essence for all the participants.

7.2.1. Banking resilience for a rainy day

Research suggests that the individual's life story is an important factor in determining the manner in which the individual will cope with a current crisis (Angus & Bowen-Osborne, 2014; Angus & Bowen, 2011; Egeland, Carlson, & Sroufe, 1993; McMillen, 1999).This position was endorsed in this study. Throughout their lives of change and disruption, the participants highlighted that skills of coping, adjusting and accepting

prevailed when challenging situations arose. Personal resilience was operationalised in response to significant encounters involving risk such as living in wartime as a child, or a threat to personal safety. These experiences and the participants' responses to them, resulted in the maintenance of an authentic life of meaning and satisfaction—a 'bouncing back' (Donnellan, Bennett, & Soulsby, 2015). It was a means of 'banking' resilience for what may lie ahead.

Resilience to stress and adversity appears to be central to optimal health and function in ageing where long life resilience is seen as a dynamic developmental process in which we actively participate (Baltes & Baltes, 1990; Lavretsky, 2014). We all bring our attitudes, expectations and feelings from our experiential past to our new emerging experiences and this 'know-how' stands us in good stead to face the present stress and hardship (Egeland, et al., 1993). The capacity for resilience develops over time in the context of environmental support, where external assets such as loving and respectful— relationships and community resources impact on resilience building (Windle, 2011). Its dynamic nature however indicates that resilience is not fixed, as new vulnerabilities and strengths arise from changing life circumstances such as receiving a diagnosis of dementia. As a consequence, being resilient at a particular time does not predict later resilience (Sroufe & Rutter, 1984). After her fright in the car following her diagnosis, Veronica said: *it's OK to be fearless but like if you were just laissez faire going all over the shop*[15], *but you have to pull your head*[16] *in sometimes* (3: 168-169, p. 6).

The developmental process of resilience can be seen in the conversations where the negative consequences of later life events were ameliorated as a result of the participants' enduring ability to negotiate hardship and adversity. Their wellbeing and quality of life was enhanced as a consequence of their risk-taking, and a building up of personal resilience ensued. The 'banking' of resilience for Chicks began in her carefree childhood: *I just roamed the streets, never any fear um* (laughing out loud) *NEVER FEAR it's a wonder I'm still here today* (1: 40-41, p. 3). Gadamer's fusion of horizons allowed me to think about this statement and fuse it with my own horizon—

---

[15] This is a colloquial expression which means going all over the place.
[16] Pulling you head in means to stop and think and be more cautious.

or particular history and culture, and this facilitated my interpretation. Chick's bold statement was that she was a risk-taker, independent, fearless and able to tackle anything. Throughout her life, these qualities held her in good stead, and built resilience. Her unsuccessful marriage with a man she had only just met demonstrated a defiant streak—particularly when being told what to do*: I was like if someone said do this I'd think— oh well, that's what you think* (1:100-101, p. 6).

Chicks formed the present adaptive approach to her current circumstances from her past experiences and this was the understanding from where her 'essence' lay: *Yeah you've got to adapt if you're in trouble. Like I was in a bad situation and I just had to get the kids out. I had to get out. I mean what was gonna [sic] happen?* (2: 335-337, p.15). This declaration affirmed her resilience and revealed the experience of risk's "livingness" for her—and it was still exhilarating after seventy years. Her rich story was embellished with detail and colour and considerable flourish, and this was what she wanted to remember, and importantly she presented it to me.

7.2.2. A reflection on transition: 'everything changes in life anyway'

The reactions to risk-taking following a diagnosis of dementia are bound up in the primary theme of *transition*. While transition is a part of life for everybody, for people with dementia it stalks their day-to-day life, imposing changes as it subtly erodes lifelong abilities. For the participants, their experiential journey of transition began long before their diagnosis, but it had now 'picked up pace'. Memory loss, fatigue, fear, momentary insight and general disorientation were common experiences expressed by the participants, and they were managed in manifold ways. Life had to be reconciled as it was, and for several of them they remained upbeat, positive and optimistic. They reached out and re-connected with family and community and employed a range of cognitive and behavioural coping strategies in order to live a 'normal' life. This allowed them to make sense of their diagnosis and carry on with their lives—despite the unwelcome imposition of the effects of dementia. For example, when Florence was unable to locate her car in a large car park, she tied a coloured ribbon to its aerial for subsequent shopping trips. The adjustment to having a diagnosis was not as smooth for others, one of whom declared war on Alzheimer's and another who simply did not believe the diagnosis at all, blaming a 'stupid woman' at the CDAMS clinic: *When I went for the test the bloke said 'God I don't*

*know why you're doing this'.[*taking a MMSE*] And I said 'Well it's that stupid woman who doesn't know what it's about* (Chicks 2: 268-270, p. 12).

In this longitudinal study, transition is linked to the participant's perceived past, producing continuity, and linking the past story to the present. These are "coherent, yet continuously revised, biographical narratives" (1992, p. 5), which provided the rich data for this study. The conversations reflected long journeys undertaken by the participants—reliving past experiences alongside the present living experience of a journey of uncertainty, fear and challenge. Transition for Harriet was subtle acknowledgement: *When the little Chinese girl* [nurse] *came in, was it yesterday? She said 'Do I want any help?' and I needed that help. I couldn't manage that and I thought, I mean, I can't be too independent* (4: 322-326, p.13). Transition could also be cruel: *You got all your brain, but half of it goes and you don't know where it's gone to. And you can never find it* (Dan 4: 396-397, p. 20). For Chicks transition was dismissed as 'normal': *Everything changes in life. I mean the weather's changed. The whole of Australia has changed* (2: 332-333, p. 15). As time went on however this transition became a disruption, a foe, a 'thing to be denied'.

For others, transition became a reluctant acceptance of change: *I didn't think that I would get dementia, and I realise now that I've got it but I really can't accept that I've got it* (Harriet 4: 88-89, p. 8). Over time Harriet acknowledged her transition: *I can tell that I am going down, I can tell—I'm not stupid* (2: 269, p.14). She sought ways to live with the inevitable changes happening in her life: *I'd like to be able to think better. That holds me back quite a bit. But er* [*sic*] *nothing worries me. If I can't do something, then I just accept it and go and do something else* (4: 271-273, p.11). While Veronica acknowledged her diagnosis of dementia: *I hit my head and I think that's how the Alzheimer's got started in the brain* (2: 178, p. 7), the effects of reduced awareness took longer to acknowledge*: Umm* (sigh) *my memory. Now that's OK, yeah good. Although I made a mess of it today* (laughing), *but that's not Alzheimer's* (3: 24-25, p. 2).

Transition is not a linear process. It was frequently associated with awareness which is often variable and fluctuating as people living with dementia move through shifting levels of avoiding, exploring and understanding their diagnosis. These notable shifts

were seen within the conversations: *I don't feel as though I've got Alzheimer's at all now* (Veronica: 3: 182-183, p. 7) and: *Well I've never noticed it* [dementia] *to be quite honest* [laughing] (Harriet: 3: 81, p. 1). These assumed positions have been associated with coping styles (Clare, Roth, & Pratt, 2005), self-identity (Sabat, 2002) and environments and interactions (Langdon, Eagle, & Warner, 2007). These variable positions reflect the complexity of transitioning to a person with dementia. Whatever their reasons for not acknowledging their diagnosis, Harriet and Veronica were buttressed by their personal resilience and were determined to be happy and positive. Intermittent perceptiveness brought wisdom:

> Researcher: *Were your mother and father risk-takers?*
> Veronica: *Yeah, getting married in the 30's. Times were uncertain.*
> *My Dad bitterly regretted not going to war. He did his training, but*
> *he had to stay and keep a lot of farms going. He was upset* (2:
> 325-327, p.15).

Nevertheless, living with dementia brought fundamental changes to the lives of the participants, and was bound up in transitional change—and there was no going back.

The lifelong strength of managing risk and change were inherent in forms of resilience which assisted in reconciling change and managing the transition of an inexorable passage toward a life fraught with the effects and limitations imposed by dementia.

7.2.3. The roller coaster ride of a dementia diagnosis

While a diagnosis was shared by all the participants and defined them as a group, its implications were different for each of them. Interplay between personal predisposition, experience and environment was discerned in the participants' responses to risk in the stories told, and this continued in their varied reactions to a diagnosis of dementia. This interplay tested individual strengths and weaknesses in everyday life, and it highlighted what was most important to the participant—what was likely to enhance their resilience rather than weaken it—making them stronger (Lavretsky, 2014). For example, Harriet's solitary childhood forged independent, coping behaviours which were still apparent in her mid-eighties. An only child, she

had bronchial pneumonia when she was four, and spent a lot of time in bed: *Then you don't get the chance to mix with people* (1: 56, p. 2). When her parents died prematurely her independence was thrust upon her: *You have to fight your own battles; you've got to carry on yourself* (2: 134-135, p. 6) and as an older woman living with dementia, she craved for social connection: *probably I create my own loneliness* (2: 139, p. 7). Harriet's perspicacity enabled her to reflect on her lived experience as to *why* she may be presently feeling lonely and to accept circumstances that she was unable to change.

Family was the measure of all things for Dan. His loving and supportive home environment nourished and cared for him, walking alongside him in his journey with dementia. His strong sense of self was no longer dependent on what he did, but rather what he stood for. This can be seen in his acceptance of new roles on which he based his identity. Significantly he realised the importance, pleasure and value in being a husband, father and grandfather and this was the source of his resilience.

Dan's family buttressed his emotional response to his diagnosis and stabilised his everyday life. He referred to his wife Mary as an *anch*or and a *compass* and someone who he does not let out of his sight: *You got to have something to hang on to* (4: 345, p. 17). This sensitive and emotional man reacted angrily to his diagnosis, desperate to hang onto what he had: *Oh ye* [*sic*] *yeah to hold onto this* (clenched fist) *what I've got now… But it still goes* [memory] (3: 57-58, p. 2). Within this study, Dan's personal struggle with dementia was graphically described, enacted and rallied against as his attempts to hang onto his memory illustrated. It was a dramatic and eloquent declaration by Dan and the stability which his family provided was in stark relief to his emotional response to his diagnosis.

The section which follows encapsulates the participants' responses to their diagnosis of dementia and constitutes the study's second finding. It has a hermeneutic focus which allowed me to embrace the dialogue within the stories, to fuse my horizon with that of the participant, and to reach a shared understanding about the impact of a diagnosis of dementia.

7.3.   A diagnosis of dementia: a challenge to resilience

Research focusing on the critical juncture of receiving a diagnosis has mixed findings (Clare, 2003; Harman & Clare, 2006; Pearce, et al., 2002). Reactions to a diagnosis range from grief and denial (Aminzadeh, Byszewski, Molnar, & Eisner, 2007), to a confirmation of suspicions and an end to uncertainty (Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006). A finding common for them all is the dilemma of people with dementia, who have to balance their desire to maintain a prior sense of self [therefore, attempting to minimize the impact of change], against the need to re-appraise and re-construct their self in accordance with the effects of illness (Aminzadeh, et al., 2007). My study's second finding emphasised the participants' negative reactions to their diagnosis of dementia including shock, disbelief and sorrow. This finding has also been established in other research (Campbell et al., 2016; Langdon, et al., 2007; Lishman, Cheston, & Smithson, 2016; Manthorpe, et al., 2011) where people have reported feeling overwhelmed by these initial feelings—rendering them helpless and alone. After this 'bombshell' has been assimilated, dementia's progressive effects go on to cause frustration and further upset (Bamford et al., 2004; Carpenter & Dave, 2004).

In this study, a diagnosis of dementia had a dramatic, emotional impact on both the participant and their family, and attested to the emotional load which a diagnosis represented. Dan expressed fear of being alone: *It's terrifying. If Mary* [wife] *is not there I collapse* (3: 145, p. 5). Harriet was still in shock after several months: *This is the last thing* [dementia] *that I would have thought that I would get* (1: 225-226, p. 10). These anecdotes support the research literature which illustrates that the disclosure of a diagnosis of dementia was a fearful and uncertain experience for the participants, where adjustment can be a gradual process of realization (Vernooij-Dassen, et al., 2006) or a lengthy period of acceptance (Alzheimer Europe, 2009).

Alternatively, denial acts as a coping strategy which delays the adjustment to having a diagnosis of dementia. In the study of Pearce, Clare, and Pistrang (2002) denial was seen to be part of a cyclical process of slowly turning to face the situation, rather than accepting it immediately. When justifying her right to a limited driving licence, Chicks defiantly and repeatedly defended her position: *If there was an accident it wouldn't be my fault because I know, and I watch and I don't take risks* (2: 260-261,

p. 12). Levenson and Miller (2007) explain that these defensive feelings sometimes manifest as anger and aggression, making this both a highly stressful and confusing time.

It is also a time when relationships may deteriorate due to the associated stress and upset, and the need for ongoing emotional, social and practical support is critical (Vernooij-Dassen, et al., 2006). Without this support people with dementia may lose hope and motivation to keep trying to maintain a 'normal' self—a self they fear losing to memory loss (Beard, 2004). Among the benefits of support for people living with a diagnosis is the promotion of a sense of safety at an otherwise uncertain time and two participants attested to this. Veronica was 'rescued' by her neighbour next door when she became lost: *I feel safe here when you've got neighbours close by… I feel really happy here with neighbours who notice things* (2: 317- 318, p. 12). After his wife [Mary] went to the hairdresser Dan was stricken with fear: *I couldn't even exist without Mary now* (2: 415, p.19) and his neighbours have also stepped in to help*: Our friends over there I can go there now if I get a bad set on*[17] *you know. I'm terrible, terrified. They look after me yeah* (3: 150-151, p. 5). These are circumstances where fear, anxiety and uncertainty prevail and threaten many personal aspects of the participants' lives while living with dementia.

While resilience has been interpreted as a dynamic process (Ryff & Singer, 2008) which may shift according to circumstance (E. Edwards & Hall, 2015), it was seen to initially be countered by a diagnosis of dementia in this study. On the receipt of a diagnosis Dan explained [using the word terrified for the second time]: *When that happened—I've never been terrified by anyone in my life, in punch ups or things like that but when that* [a diagnosis] *happened I thought 'Oh well I've had it now'* (3: 175-176, p. 6). This statement summed up the second finding from the data analysis—that a diagnosis of dementia rendered all of life's certainties, uncertain.

7.4.   The uncertainty of future risk

This study was conducted at a critical time of transition to 'becoming' a person living with dementia—a time of grappling with a diagnosis and facing a future that was yet

---

[17] A bad set on means if everything is going badly.

to be revealed. The word 'future' was therefore clouded in uncertainty and doubt for all the participants. When asked about risk-taking now, the participants unanimously declared they would no longer consider it. For dementia created doubt and insecurity, and this made risk too 'risky' now. Previous risk-taking was undertaken long ago with the certitude of one's convictions; with the inalienable right to strive for something better in life. A diagnosis of dementia however resulted in a loss of confidence to try new things and make decisions:

> *No, not really you can't* [make a decision] *'cos* [*sic*] *you gotta* [*sic*]
> *have two sides of a brain and you can't. Half of it goes and you*
> *don't know where it's gone to and you can never find it* (Dan 4:
> 395-397, p. 20).

This uncertainty was not a foundation on which to take risk. Relenting on risk-taking exemplified a process of transition and change. The following two stories personify the transition from 'taking risk' as a part of 'life', to becoming more circumspect in everyday life.

Rosie and her husband Reg did their own house maintenance and a regular job was the painting of the house inside and out. She conceded that climbing up on the roof was out of the question now: *I don't think I'd try it now. Once you get a bit older you get a bit more brains. I think well I don't do silly things. Maybe when I was younger I probably did more* (1: 330-334, p. 15). By her own admission Harriet had always been cautious: *Well I'll take risks to an extent. I don't just go jumping into anything. I think about things very carefully then I'll go ahead* (2: 141-145, p. 8).

She had taken risks throughout her life but risk had been redefined by ill health and now a diagnosis of dementia: *I'd love to go back up to Cooktown...I've got some sense to realise now that I've just got to pull my horns in and stay 'er* [*sic*] *more or less locally* (2: 155-157, p. 8; 2: 166-168, p. 9).

Identity was eroded by the disappearance of roles—as a breadwinner, a driver, a payer of bills and a fix-it man around the house. These roles were not conferred, but earned over time, and they were treasured reminders of another life. Their loss was

especially painful. Overall these changes amounted to losses which threatened everyday life as the participants knew it. Together with the ongoing cognitive changes associated with dementia, the participants' agency and ability to continue living life as before had been undermined.

7.4.1. Implications for future risk: 'Like entering new territory'

While the taking of risk was reflected upon in the stories told, implications for future risk were reflected in other subtle ways. Chicks for example, used 'age' as a determinant for avoiding risk: *I'm not going to take a risk—AT MY AGE TAKE A RISK? (*2: 270-271, p. 12). Her statement reflected the paradox between taking risk (independence) and the need to counterbalance it by its avoidance (loss of independence).This was quite 'normal for her age' declared Chicks—and there would be no slip-ups.

Veronica reflected on her diagnosis when she said: *I suppose it's like entering new territory* (4: 205, p. 10). Risk had changed for her and rather than take her chances*: I sorta* [*sic*] *go more with what evolves. With what comes up* (4: 203, p. 10).

Other participants like Harriet took a cautious 'wait and see' approach, where future risk was defined as a lack of control of one's life. She explained

> Researcher: *You said to me last time that a fear that you do have*
> *is when you get to a stage where you can't do for yourself*
> Harriet: *Yes, 'cos* [*sic*] *that would be taking my independence*
> *away, 'cos* [sic] *as long as I can do things for myself I don't mind.*
> *But I'm not looking forward to the time that's when probably I can't*
> *do these things. I'm a funny one* [laughing] (4: 278-283, p. 11)

Harriet feared dependence and the inability to do what she 'needs to do'. She articulated this as: *taking my independence away.* I interpreted this statement in two ways. It suggested that within a progressive illness, abilities decline or diminish over time, and that things we do and take for granted may become out of our grasp. Harriet's statement also implied a 'taking away' without consultation, and this had serious implications for her. She doesn't mind what other effects dementia may

hold—as long as she can 'do things' for herself. Just what Harriet meant by independence was unclear, but within her low-needs facility it likely referred to her capacity to do tasks of daily living without assistance. She wanted to remain a person capable of doing everything for herself but accepted that a time will come: *when probably I can't do these things* (4: 282, p. 11), 'things' which were seen by Harriet as fundamental to her independence.

Harriet's summation of the situation was that she was: *funny* and I inferred from this that she thought that she was different—due to the strength of prevailing societal attitudes and stereotypes. The study by Galvin (2004) of first-person anecdotes of people living with a disability who resisted having their independence taken from them by others, spoke of being labelled 'aggressive' and 'difficult'. They related instances of care which disallowed their autonomy which in turn impacted on their perceptions of self, and this has also been encountered by people with dementia (Brooker, 2004; C. Clarke, 2001; Ward-Griffin, 2001). Harriet was expressing her needs in the above reference—needs which surround autonomy, the freedom of choice and action. She is hopeful 'she will be able to do what she wants to do' in the days ahead. This is the challenge for others—to support and enable decision making about risk which is built upon the strengths, abilities and preferences of the person with dementia—and not their deficits or others' preferences. Dan also expressed his fear of losing control of his life once again. His previous life experience was plagued by illness where he struggled to be 'in charge of his life' following a workplace accident. He had spent ten years recovering from an injury to his coccyx, and he spoke of the frustration and disappointment that had robbed him of being 'normal' and enjoying the next phase of his life:

> Dan: *Well the trouble is now I've done all these years er* [*sic*] *trying*
> *to stay well now I've had a couple of bad times and that's all. All*
> *I've ever really wanted to do is to be normal.*
> Researcher: *I understand*
> Dan: *And then I caught this* [dementia] *and that's what made me*
> *crazy* (3: 271- 274, p. 8).

7.4.2. Future risk: 'who will look after them when I am gone?'

Parental care-giving is a job that lasts a lifetime. When a child has a disability that role becomes more complex and difficult. The longitudinal study of Pejlert (2001) examined this scenario within a hermeneutical phenomenological framework and its first-person narratives revealed ongoing grief, sorrow and guilt associated with having a disabled child. Ageing parents experienced a coming-to-terms with the difficulties of raising a disabled child, persisting in the care-giving role while striving to look after themselves as well. In my study thirty per cent of the participants had an adult child with a disability in their family, and a deep fear persisted for their family member's future when they were gone. They expressed the same profound fear surrounding their diagnosis of dementia. For these ageing parents of dependent, disabled adult children, the question of responsibility arises: '*Who will look after our adult child when we can no longer do so?' 'Who will look after them when we are gone?'* Florence for example, replied: *Don't know what's going to happen about her* [Megan] *because Tim* [brother] *lives in Brisbane and if anything happens to me* (3: 178, p. 6). This was a heavy burden of unknown risk for Florence and the others to carry at a time when she was facing a battle of her own.

Looking into the future held no credence for Dan, but he never stopped thinking about the future for his two boys. While fighting the effects of dementia and facing its uncertainty, Dan's wish was for his two sons with mental health issues—his 'boys': *to be alright* (4: 366, p. 18).This selfless mindset saw him dismiss his present difficulties and hope that his sons would be fine. Unlike Florence on her own, Dan's wife Mary will continue to look after their welfare when he is no longer able to do so, and this was of some comfort to him.

There is emerging research on the experience of dementia from the perspective of children living with a parent with a diagnosis (J. Allen & Oyebode, 2009; Barca, Thorsen, Engedal, Haugen, & Johannessen, 2014; Deist & Greeff, 2015).There is no research however on the experience of parenting following a diagnosis of dementia, including parenting children with a disability. Search terms 'parent with dementia', 'dementia and parent', 'parent' and 'dementia', 'disabled children' 'children' and 'disability' and 'dementia' were used interchangeably across the library's electronic data bases including Academic Search Premier, CINAHL with full text, Medline with

full text, PubMed, and Sage Journals, The library databases were also browsed by subject including Arts and Humanities, Australian databases, Biomedical Science, Health and Medical Sciences, Nursing and Social Sciences. Google Scholar was also activated with no results. The findings in this thesis have identified a gap in the existing literature and it is an area for further research.

7.4.3. A diagnosis of dementia can erase the future

For several of the participants it was impossible to imagine a future at all following a diagnosis of dementia. The diagnosis carried with it an abiding concern that something somehow was wrong, and this made change either necessary or unavoidable now. This meant that future risk-taking was unthinkable where typical responses ranged from: *too late in the game; at my age, take a risk; no; the kids are stronger and fitter than me nowadays.* With a diagnosis of dementia, life as it was had stopped. But what of the things that made it worth living? The things for which, life had meaning and continuity? Do they just stop also? Was this like erasing the present? Harriet summed up the situation that reflected the attitude of all the participants: *I don't know really … I just don't know, how, now I've got this dementia um I'm hoping that it doesn't develop too quickly* (2: 297-298, p. 15). When asked about his future, Dan looked at the bigger picture: *I'm not really worrying about living or dying* [laughing]. *I've come this far and an old English expression: Who gives a shit?* (2: 554-556, p.26). Through his outward bluster, Dan expressed his fear and frustration at being powerless in the face of a diagnosis.

Jane did not see a future for herself at all. Her reluctant journey to Australia to live with her only child had been a bitter pill for her to swallow. With her husband and most friends gone, she saw no alternative but to leave her beloved home in France. Now in an aged care facility, she did not open her eyes at all throughout our second conversation together. She deeply regretted: *being put in this place* (2: 118, p. 5) as it felt like the end of the road for her. She rationalised that a future in which she was no longer making the decisions affecting her life was simply no future at all. This indeed, was the end of the road.

The removal or denial of taking risk was dramatically evident within the conversations of this study and it caused the participants great upset and trauma

from which they did not recover. This was the third finding of this study which is discussed below. It has policy and practice implications—both moral and ethical, for carers, professionals and organisations alike.

7.5.   Whose life is it, anyway?

7.5.1. The personal cost of dementia

Among the many transitions following a diagnosis of dementia, the third finding is that the participants frequently felt that they no longer had control of their life—irrespective of their capacity to express preferences and wishes. A diagnosis carries with it a label which may rob the participant of roles and responsibilities; many of which they were still capable of performing in their daily lives. Until an official diagnosis was made, many of the participants were still driving, parenting children with special needs, supporting husbands and wives in daily life, volunteering and helping others. These roles were now called into question—and became uncertain. Risk so deeply associated with *life* was suddenly taken away by others.

7.5.2. The clinical gaze

This removal of risk began with the arbitrary removal of agency—or voluntary action seen in different contexts within the data. Constraints were imposed from the beginning of the transition to living with dementia—the visit to the CDAMS clinic. When undergoing assessment, a biomedical 'gaze' (Foucault, 2003) involved a series of tests which privileged cognition and reflected Post's hyper-cognitive society" (1998) and this placed Dan for example, at a disadvantage. With a severely disrupted education, this was an inappropriate assessment of his cognition, discriminating against him and ultimately disempowering him.

In a study of the role of memory clinics, Moniz-Cook & Woods acknowledged that disclosure is a major intervention (1997) where the information needs to be individualized, taking into account the person's particular perception of their difficulties as well as the concerns of families (Woods, 2001). This was a position endorsed by Campbell et.al. (2016) whose study participants called for transparent information, for example the need to share the meaning and function of the neuropsychological tests. Dan's greatest fear was to be alone in this strange and

intimidating environment and his wife was not permitted to be present for his assessment. Knowing *who* Dan 'was' and providing emotional support for him was critical for a successful CDAMS clinic visit. It was an experience which haunted him throughout the time span of this study. This situation is an example of what is referred to as "negative positioning" (Österholm & Samuelsson, 2015) where Dan was situated in a position of feeling less competent and where his ability in negotiations regarding his care was further negatively impacted upon without the support and presence of his wife.

Foucault's term 'biomedical gaze' identifies the dehumanising separation of the body from the person (identity) and Dan felt this keenly. After many months it still rankled*: Because it's not fair to say somebody—you go through all that. Oh, that was wonderful and that was lovely. Oh you're doing very well—that's not right. They shouldn't say that* (1: 405-407, p.17). This encounter with the 'gaze' of professionals was an insult to Dan's intelligence and it was not a true reflection of *who* he was.

He felt the condescending attitude of some allied-health staff and it assailed his self-respect and dignity: *I thought she's taking the mick*[18] (1: 409, p.17). The experience made him feel diminished and unworthy, and he likened the CDAMS clinic to a: *Nazi place* (2: 335-336, p.16). Dan returned to his visit to the CDAMS clinic several times within the conversations, and it pained him on each occasion.

My role as a researcher took me into the CDAMS clinics for several reasons. Initially I presented the study and its procedural steps to the staff, and later I became involved in approaching and speaking to the clients with a view to their participation. For me as a researcher these clinics were hectic and noisy and rather impersonal, and my observations were not compounded by the anxiety of an upcoming assessment—which the participant may have been experiencing. This raised questions about the optimum environment in which to conduct the cognitive assessment of people who are confronting a diagnosis of dementia. Fluctuations in awareness may occur for them and this alienating environment was not the 'safe context' (Dewing, 2002; Hellström, et al., 2007) for providing support and assessing

---

[18] Taking the mick is a slang expression for making fun of someone or something.

people for a diagnosis of dementia. This finding attests the need for more flexible and mobile forms of clinics whereby assessments can be conducted in a congruent environment.

7.5.3. Paternalistic attitudes: who owns the risk?

A criterion for taking part in my study was that the participants were alone when interviewed. At a time when people with dementia are seeking to be heard (Abramson, 1990; T. Adams, 2005; Buchanan & Middleton, 1995; Hughes & Baldwin, 2006; Hydén & Orulv, 2009; McCormack, 2002), this criterion aimed to prioritise the 'voice' of the person with dementia. However, taking part in research can be seen by 'others' as risk-taking and within my study Pearl's daughter insisted on being present in the one conversation that I shared with her mother—despite Pearl: *not being fussed at all* (1: 3 p.1). Paternalistic attitudes by 'others' in research participation (Sherratt, Soteriou, & Evans, 2007) may silence or muzzle the voice of those living with dementia, and result in views or preferences which do not reflect their views. Pearl's daughter subsequently had an active presence throughout the conversation, reminding her mother and me of details which she considered salient to the study. She withdrew her mother without her consultation following one conversation—essentially withholding her mother's right to make her own decisions. This action encapsulated the third finding in this study.

Upon reflection in my field notes the conversations conducted with Rosie were beset by her husband Reg's overriding presence and opinions. He insisted on having the last word, often openly contradicting Rosie. I recorded my discomfort on several occasions, of which this is one:

> Today upon arrival Rosie appeared flustered and 'on edge'. She had
> been searching for her medication container in the belief that she had
> not taken her morning 'meds'. Her husband Reg was quick to remind
> her that he was in charge of this—that he always checked and did not
> make mistakes. Since we last met, Rosie had also lost her driver's
> licence, and I had the sense of accumulating losses for her.

7.6.   Repositioning of risk: a challenge for others?

The challenge for others remains to support people to *live with* and *manage* their condition, to become advocates for the pursuit of their personal goals and dreams, including risk. Positive risk-taking is about making good decisions and taking calculated and reasonable risks—not leaving things to chance (S. Morgan & Williamson, 2014). This repositioning of risk has significant legal and ethical implications for all stakeholders, impacting on dementia policy and practice. It has resulted in enterprises such as Dementia Adventure (www.dementiaadventure.co.uk) which practise positive risk-taking and allow people with dementia to follow their goals and dreams.

7.7.   Does your care plan tell my story?

 A dynamic risk assessment necessarily includes the voice of the person with dementia and highlights "the gains for the person's physical, psychological and emotional wellbeing" (Titterton, 2005, p. 83), when risk is permitted. More critically an assessment must consider the consequences for the person if the risk activity does not go ahead. The following excerpt from William's story reflects the way that risk was summarily withheld by 'others' following a diagnosis of dementia. He provided a stark reminder of the consequences: *See I used to come home from football after doing all me training and then hop into a hot bath. And I've done that for years* (3: 81-84, pp. 3-4). His bath held cultural significance for him and its loss disregarded the lived experience of the man who had soaked in the bath after a game of football or a long day in the field playing cricket. This was a man for whom a shower would never do. Morgan & Williamson (2014, p. 11) argue that "taking risks will not always be about helping people to change and strive for the new", but rather they may be more about familiarity with the past (as in William's situation with the bath) and using personal strengths and abilities. William's personal strengths could be seen in abundance around the house, but they were presently being denied. A wheelbarrow, a chainsaw and ladders were emblematic of *what* he did and *who* he was and *what* he stood for. Despite increasing ill-health, William felt these losses keenly, which was less about his garden tools and more about the existing abilities on which his identity had been built. This withholding of possible implications had serious implications for his psychological wellbeing, and with the resultant loss of self-

confidence a lowering of expectations and motivational levels may also occur (Manthorpe, et al., 1997).

7.8.   Withholding risk: who has the right to decide?

For all of us—including the participants in this study "few daily actions carry the psychological and social significance of driving" (Scheidt, 2013, p. 699). Florence knew this well:

> *I'm actually quite set and satisfied with my life while I can still drive.*
> *It will be different when I can't drive. Well I'd like to be still driving*
> *for a while. When do they stop you? Do you have to do something*
> *wrong?* (3: 103-104; 118-119, p. 4).

'Traffic medicine' has evolved significantly since the1990s. This term refers to the seeking of a balanced view of a person's ability to drive, rather than attending only to labels such as dementia or age and cancelling the licence to drive outright. This emphasis is now placed on preserving mobility rather than an unfair attribution of risk (Breen, Breen, Moore, Breen, & O'Neill, 2007). While misconceptions exist about the relationship between older age and accidents (Cooper, Tallman, Tuokko, & Beattie, 1993), over the course of an illness such as dementia, the risk of an accident is significantly increased (Breen, et al., 2007).

For people with dementia, driving is "highly emotive" (C. Andrew, Traynor, & Iverson, 2015, p. 2737), as it confers competency, respect, dignity and independence at a time when these human rights are under threat by a recent diagnosis. This challenge to personhood for people with dementia may be seen in research which highlights the negative implications of driving cessation. Depression (Fonda, Wallace, & Herzog, 2001), decreased socialisation (Mezuk & Rebok, 2008) and impaired physical functioning and health status (J. Edwards, Lunsman, Perkins, Rebok, & Roth, 2009) are all noted while on a personal level, ceasing driving can limit access to family, friends, and services and is an independent risk factor for entry to a nursing home (Breen, et al., 2007). In the face of these negative outcomes, helping drivers with dementia to stay on the road as long as it is safe to do so is important, as it preserves their overall wellbeing (Wang & Carr, 2004). It raises the issue

however of assessment and suitability to drive, and what criterion for competency are essential for safe driving, irrespective of a diagnosis of dementia (C. Andrew, et al., 2015).

Driving a car is a learned embedded skill which is "relatively automated" (Duchek et al., 2003, p. 1343), like riding a bike or singing songs from the past—skills that often remain salient in the most advanced stages of dementia. The participants who had been drivers all saw themselves as drivers still— it was not something they relinquished even without a licence! Rosie rationalised this: *Well I no longer ... I can drive. No longer driving from place to place as much as I used to. I've given it away sort of thing* (2: 86-88, p. 5). The difficulty however may not be driving, but in the deterioration of navigational skills. Florence, for example loved driving, but she knew that it had become more difficult, and explained: *It's not the driving, it's the memory— it's not the driving at all. I love to drive* (4: 339, p. 15). With an estimate of 200,000 Australians who have dementia who are currently driving, this number is projected to reach 730,000 by 2050 (Deloitte Access Economics, 2011). The following questions are salient:

How do we allow people to continue driving, and stay safe?
How do we ensure the safety of other people?

The policies related to driving eligibility varied in each of the study's three CDAMS clinics. Pearl's immediate and arbitrary cancellation of her driving licence at her CDAMS clinic visit was not reflected in others' experience. Upon receiving their diagnoses, several of the participants were given the option to re-sit a driving test, and they declined. Veronica was driving when I first met her, and after being lost in her car overnight, her guardian arranged for her to re-sit her driver's licence. Veronica related a part of this experience:

I made a mistake when I got back here [laughing]. *I turned in really quickly. It was a dangerous thing to have done really* [laughing]. *It was scary. I was like a bat out of hell and that was scary, it was getting dark too* (3: 331-333, p.11)

She proclaimed that her driving test was the riskiest thing she had ever done: *Yes, and the roads are busy, aren't they? They come at you from lots of different angles now* (2: 118, p. 8). These examples demonstrated the inconsistency in CDAMS approach towards driving with a diagnosis of dementia.

As seen in this study, the loss of the right to drive can have catastrophic effects on a person, and this identified the need for a more comprehensive process for driving cessation for people living with dementia. Initiatives include closer links to regulatory bodies, and improved communication and increased support for families/carers. This may also result in a more integrated and consistent approach by CDAMS clinics, making the difficult issue of driving with dementia somewhat easier and more transparent.

7.9.   Business as usual: living with dementia

The following section reflects on the ways and means of ameliorating loss and living a good life, albeit not the one lived before a diagnosis of dementia. It encapsulated the fourth finding in my study.

The adjustment required to living with a dementia diagnosis is a complex process and this raised the following questions:

  How do people with dementia overcome their first reaction to a diagnosis?
  How do they return to some semblance of their old life and begin to enjoy themselves once more?

7.9.1. The importance of memories

While struggling with change and loss in their lives, the participants in this study rebounded and looked 'on the bright side' of life again. When asked about how he was going Dan replied: *Oh pretty good, OK. I don't intend to let this disease get me down I've got too much to ... I like me* [*sic*] *grandchildren you know* (4: 4-5, p. 1). Such personal resilience had a regenerative capacity and allowed Dan to enjoy life again. Writing, talking or joining a support group are all ways in which people living with dementia overcome negative reactions to a diagnosis (German Ethics Council,

2013) and Dan revelled in telling his story of his long and wonderful life: *Anyway, I've said my truths* (2: 564, p. 26).

All the participants drew strength from their early life experiences, and their wellbeing and quality of life was enhanced as a consequence of their risk-taking. Dan summed this up: *We were stayers ... if you're not a stayer you're not gonna* [*sic*] *get anywhere* (2: 203-204, p. 9). He stood alongside other postwar immigrant workers in the factories, and their exploitation by the bosses steeled his resolve, resulted in his role as a union official and made him grateful for what he had: *Well it don't* [*sic*] *all come out like that you know, some people will fall along* [*sic*] *by the wayside* (2: 74-75, p. 13). He had fought so long and so hard that a diagnosis of dementia seemed like just another hurdle, and he took control again: *And I can't do anything about it, but I can try. I remember maybe two or three hours later. I work through it and the people haven't taught me that. I taught meself* [*sic*] (2: 549-255, p. 25). Here there is a sense of momentary resignation, and then the adjustment to the situation and his resilience reasserted itself.

Harriet's pragmatism was a personal strength that assisted her in managing adversity in life events, and in seeing things clearly: *You need to know your own limits, and if you know your own limits, then you can go and do anything* (3: 140-142, p. 6). Her story of being an only child with loving parents was a great consolation to her now, and with it came the conviction that she could manage her new situation. This was Harriet's personal resilience which allowed her to build on the positive aspects of her life.

7.9.2. *The importance of interpersonal relations: past and present*
 Great satisfaction and succour continued to be derived from those remaining, long-standing, interpersonal relationships. Parents long since gone still, however, evoked powerful memories of unconditional love, their life lessons were not forgotten and they served as role models. Dan reminisced: *It's like my Dad—I loved him like the earth. He was a man who was not afraid of anyone* (2: 41-42, p. 7). While counting her blessings with a loving family, Jessie cautioned however: *The family's good, they come and take me out like, but you're on your own—you're always on your own* (2: 58, p. 3). Enjoying the company of others was important for Jane and Florence, but

they were also on their own and were at risk of being lonely. Andrew and
Rockwood's study (2010) highlighted links between increasing social vulnerability
and cognitive decline and this finding has implications for Jane and Florence and
their long term health and wellbeing.

Florence experienced changed friendships after her diagnosis and a close friend had
recently died. These events impacted negatively on her self-esteem and confidence:
*My friend that died and there was Gwen and her friend. So there was four but now
there's three and I'm on the outer, stuck on my own* (4: 485-486, p. 21). While able to
manage challenging circumstances, resilient people can still be vulnerable (Van
Regenmortel, 2002) as exemplified by Florence. Paradoxically the a*cceptance and
openness of feeling alone and vulnerable* may be another important source of
strength (Janssen, Regenmortel, & Abma, 2011). This was not the experience for
Florence whose increasing isolation diminished her confidence and her motivation to
try new things and venture out socially.

7.9.3. Laughter is still the best medicine

The restorative powers of shared humour and laughter (Berk, 2001) mitigated the
effects of a recently diagnosed illness and strongly endorsed the saying that
'laughter is the best medicine'. The role of sensitive and positive humour was
critical for the participants to adjust to a life living with dementia. When a joke was
told or a funny story was shared within the conversations, there was a raised
consciousness of us all being in this situation together; a sharing of something very
deep, a privileged moment. The laughter was accompanied by smiling, quite often
eye contact and, afterwards, a sense of release; certainly on my part and, I suspect,
on the part of the participants (MacKinlay, 2001). Harriet told yarns of her life with
others in her facility and then summed it all up: *I like to pull the legs of the sisters …
see I haven't lost my sense of er* [word finding difficulty] *joking* (4: 201-202, p. 8).
In his studies, Gordon (2014, p. x) has suggested that humour is much more than a
light and amusing mood. It is a "genuine human capacity", a way of knowing and
understanding which can provide us with unique insights about human existence.
Importantly the relationship between friendship, intimacy and humour provides the
space to talk about more serious issues through the medium of humour. When
talking about being on her own, the quick-witted Florence shared this humorous

thought with her friend Gwen and me several times: *I haven't got a boyfriend—wouldn't know what to do with it* [*sic*] *if I did* (laughing) (1: 193-194, p. 9). This was a marvellous moment of spontaneous mirth to which Gwen retorted: *He'd just be another problem for you to sort out I reckon* (1:195, p. 9). The light-hearted banter is underscored by the pain of loss and has much to tell us about how Florence is dealing with her husband's death and her daughter's Down's syndrome. Within funny conversations held over tea and biscuits—we all laughed. This merriment allowed us all to cope with poignant moments such as this when we feel that life is uncertain—or unfair—and it enriched our experience of being together at that time, and in that place. Such loss, laughter, and connection are integral to being human.

Jessie loved to flirt. Her longing for male companionship had been unsuccessful so far but it did not stop her from continuing to check out the men in her facility: *Well I still have a man here, brings me sweets and things, and I talk to him* (4: 236-237, p. 10). This is a continuous joke between her daughter Meg and herself, and Jessie giggled like a young girl when she continued: *No it's not Alby, this is another one. Every time I come in I see him at the table on his own and then I'm two tables down and that's when Elaine* [woman on the same table] *says to me 'Oh when are you getting engaged?' and then married?* (more giggling)' (4: 236-242, p. 10). This is light-hearted relief between a daughter and a mother who craves male company and attention. It is also an example of the use of humour by Jessie to remind others of things that are missing in her life—things that are still important to her as she reached her eighty-fifth birthday.

Stressful life events however may also provide opportunities for personal growth (Hardy, Concato, & Gill, 2002), particularly when a person has *banked* resilience with which to call upon. Personal meaning is then sustained through the inner resources which resilience provides and this permits continued growth—even in the face of loss and pain (Lavretsky, 2014). Dan's frequent physical rehabilitation over ten years had reaped rewards of regained independence, but that was under threat again. It posed future risk bound up in life experiences which clearly determined attitudes towards imagining a future living with dementia.

Threats and losses however, were counterbalanced by reaching out to others, or by creating new identities, or roles. The study of Vernooij-Dassen et al.,(2006) demonstrated that within social relationships people with dementia attempt to 'hold on' to their roles—they want to remain valuable to others. Harriet and Jessie were examples of this as they continued to help others in need when they were able. Dan reinvented himself by becoming a dog walker, a gardener and a newspaper collector as the new routine of his life took shape. This was self-directed transition which had called upon existing resilience, and permitted a sense of control and generativity in day-to-day life. It included the realignment of goals which the participants made— from the 'tackling' of life head-on, to the acceptance of life as it now was. These anecdotes summed up the essence of the fourth finding that resilient people such as the participants determined to make the best of it and actively create meaningful lives while living with dementia.

This chapter returns to this study's aim that is to grasp the *essence* of the meaning of risk for the participants living with a recent diagnosis of dementia. The fusion of horizons reflected joint engagement while their data and the wider socio-cultural context provided the platform to reflectively interpret the complexity of the research question: *What is the lived experience for a person with a recent diagnosis of dementia?* My task to interpret the livingness of this experience has been richly rewarded.

CHAPTER 8

SUMMARY AND IMPLICATIONS FOR PRACTICE

Then I felt too that I might take this opportunity to tie up a few loose ends, only of course loose ends can never be properly tied, one is always producing new ones. Time, like the sea, unties all knots. Judgements on people are never final, they emerge from summings up which at once suggest the need of a reconsideration. Human arrangements are nothing but loose ends and hazy reckoning, whatever art may otherwise pretend in order to console us.

(Iris Murdoch: *The sea, the sea*)

At the conclusion of a phenomenological thesis such as this, there is no conclusive argument, or a set of ideas, or even a list of themes (van Manen, 2014). Rather the reader will be oriented to that aspect of lived experience in which the phenomena of the *essence* of risk dwelt in the lives of the participants. It is here where there are possibilities for a reflective engagement with practice.

This begins with a brief summary of the thesis and progresses to once again utilising van Manen's more recent text 'Phenomenology of Practice' (2014, p. 15). This chapter will proceed to elucidate what van Manen refers to as *on* and *in* practice to "address and serve the practices of professional practitioners as well as the quotidian practices of everyday life" (2014a, p. 15). More specifically it refers to the practice of phenomenological research and writing in its preparation for practice through tactful and reflective ideas for action.

8.1.   A summary of research: phenomenology and the exploration of risk

Within this hermeneutic phenomenological methodology, the phenomenon of risk has been presupposed by the researcher, recalled, reflected and re-imagined by the participants and articulated through the human science method of van Manen (1990). The methodology's contribution to this study's validity is acknowledged at a time when researcher reflexivity and openness supports the study's trustworthiness. This in turn ensures integrity within the research findings which is critical to the

potential impact that the findings may have on practice and policy. From the outset of the study (see Chapter 1.6 *Implications of the study*), this was a key consideration and confirmed the researcher's motivation to improve care practices and hence the everyday lives of people living with a diagnosis (see Chapter 8.4 *Implications for practice*). This methodology, together with its concepts and understandings provided the insight and direction in the chosen method to explore fully the phenomenon of risk within the everyday lives of people with a diagnosis.

The study's longitudinal design captured shifts in meaning over time of the lived experience of risk of people who had received a recent diagnosis of dementia. This concept of risk was an exemplar to view autonomy and the right to exercise choice and make one's own decisions whenever possible. It sits within a body of research which views dementia and risk as social constructions—fluid, complex and multi-dimensional.

This study also revealed that following a diagnosis of dementia, risk was being withheld by 'others'. When others assumed that the abilities and strengths of a person were no longer intact, they deprived them of their agency and motivation to keep trying to maintain a 'normal' self. Within the contours of a progressive illness, variable abilities such as insight often rendered an arbitrary and final assessment by others. These one-off assessments often determined an unapprised distortion of the reality of the situation for the participants and denied them their dignity—the dignity to take a risk. The resultant resentment and anger at the arbitrary denial of choice, and ultimately dignity may have been ameliorated for the participants with a more consultative and sensitive approach where mutual goals of wellbeing were to the fore in risk-taking decisions.

8.2.   The emergence of two primary themes

The study's longitudinal nature clearly identified with the primary theme of *transition* as a diagnosis of dementia threatened to rupture routine life and turn the participants' worlds upside down. Generally, a reluctance to make change within the uncertainty of a diagnosis rendered them unable, or unwilling to take risks. It became part of a new form of medicalised risk profile for the participants. It was also a time for mustering *resilience* to cope with the threat to everyday life posed by dementia.

An uncertain future; a time of upheaval; the time to restructure lives to compensate for age-related losses as well as those losses compounded by a diagnosis of dementia. Alongside the 'bombshell' of a diagnosis was the participants' acknowledgement of the effects of ageing and the transitional changes wrought on their lives. Losses such as friendships, the right to drive and pastimes such as dancing inflicted a new reality on everyday life. Such losses posed risks of their own, imposing their own particular forms of adverse risk-taking by decreased social engagement and physical activity. This confluence represented the 'immediacy' of their world and resulted in the participants' present disinclination to take risk.

8.3.   Implications for the 'practice of living'

This hermeneutical phenomenological method of practice provided the interpretive depth to move beyond the taken-for-granted understandings of what it's like to live with dementia. It guided the study towards its goal of contributing new knowledge about the meanings associated with *lived* (past), *living* (present), and future taking of risk for the participants. Change was felt in these categories and required a calibration in everyday life to continue as 'normal'. The shifting reality of living with dementia realigned normative expectations and called for a 'steady as we go' attitude. The motivation to make this adjustment was forged in the *lived* experience of risk, where transitional points in a person's life called for personal strength and clear vision to adjust and go on. Within these points both positive and negative elements were contained at any one time and their 'weighing up' was a testimony to the participants' fortitude and character, and also their resilience. The participants' personal strengths—their *ways and means*—were being called upon to adjust and counter the transitional changes in everyday living and this meant coping with the loss associated with the shifts. *Transition* became part of everyday life, and the personal resources required to manage its shifting reality were bound up in *resilience*.

8.4.   Implications for practice

In the traditional sense of "implications for practice", this final section begins with the suggestion that actions provided by the professions and their associated parlance require particular skill sets or knowledge. Specialised skills and information however are not the sole prerequisite for making life better for people living with dementia.

Hermeneutical phenomenological practice challenges this misconception that excludes 'others' who are ably competent to provide support, and care about people with a diagnosis through empowering actions or deeds. Van Manen best describes this phenomenology of practice as a "thoughtful understanding of the meaningful aspects of having a conversation" which is of value to institutional providers, professional practitioners and those involved in the everyday living and care of people with dementia (2014, p. 15). It is as van Manen infers, about the tactful and reflective ideas for action for everyday practice.

8.4.1. Institutional forms of language

The use of language surrounding the practice of 'care' is an impetus for challenging conversations about attitudes and stereotypes. The practice of care has become emotive and value-laden, as the rhetoric often portrays people living with dementia as vulnerable and needy and this fosters images of disability and dependency (Basting, 2009; A. Bradshaw, 1995; A. Clarke, Hanson, & Ross, 2003; Dunham & Cannon, 2008; Gilroy, 2003; Pipon-Young, et al., 2012). This was counter to this study's findings where the participants were engaged within unique and evolving stories of risk and were determined to rebuild their lives as fully as possible following a diagnosis. This study demonstrated the importance of person-centred care where empowering actions or deeds have no power differential; nor is it an act conferred *upon* those who have a diagnosis. Caring can be seen as reflecting on the lifeworld of the participant; seeing them as a person and what they do—their "sociality" (Ashworth 2003, p. 220), the things that give their life meaning. In turn, our caring is enhanced and reflection allows us to see ourselves as 'carers'.

This negative social construction of institutionalised language challenges the unreflective practice of our humanity by asking questions of us as a society, as professionals and human beings. There is a need to acknowledge the heterogeneity of living with dementia that may benefit everyday life for the participants and facilitate the 'getting on and living life' following a diagnosis. It is imperative to reflect on practice, on *how* people with dementia are treated, *how* dementia is perceived and *how* dementia may be shaped as an inherent part of our contemporary life. It demands a response at a societal, institutional and interpersonal level. It demands action from each.

This study began and ended with the rich and illustrative stories that drove the data and enabled the participants to maintain a sense of *who* they are, *who* they have been, and *who* they want to be in the future. Their telling, their communication was multi-faceted—use of the voice [accents, sounds, tones, language] use of the body—[face, hands, feet] and props, all supplemented the spoken word. These communicative skills provided the platform for knowing the intimate, personal journey—the story where hurt and delight; disappointment and joy; sorrow and happiness merged towards, and understanding of personhood. The nature of care relationships shaped lives and responses to unexpected or adverse events and in turn furnished the carer with the contingency and the *grit* of a person's life. It was the sum of all that has gone before, and from where the pursuit of meaning, and the *shape* of caring may begin. Having dementia is part of their story, and caring for the person involves caring for the story.

8.4.2. The construction of dementia: revisiting the impact of stereotypical attitudes
Further to the language of care, this study found that the attitudes and stereotypes surrounding the word 'dementia' struck trepidation into the hearts of the participants because they had a deeply embedded fear that they would be seen as demented. Furthermore, its arbitrariness—the word 'dementia' may ignore the subjective and interpersonal aspects of living with a diagnosis (Angus & Bowen, 2011; Cayton, 2004) which contributes to misunderstandings about what it is like to live with a progressive illness such as dementia. In her study of the relatedness of dementia to stigma and discrimination, Milne refers to it simply as the 'D' word (2010).

Dementia has replaced cancer as the scourge of modern times (Van Gorp & Vercuysse, 2012) and this conception shapes our understandings and manifests our profound dread of the word 'dementia'. This view has grave implications as it undermines both the heterogeneity of the participants and their illness. A medical diagnosis is all that separates people living with dementia from the rest of us, but its consequences are profound. It has the ability to affect *how* a person's actions are interpreted, *what* choices they can make and it renders their identity as dysfunctional. The participants were aware of these damaging consequences, and reflected dread and fear on receipt of a diagnosis—declaring war on dementia and hoping that they won't 'go right off'. The dominance of a biomedical construction of

dementia is as a disease—an incurable disease—where people are seen as 'sick' and there has been attribution for the powerful stigma surrounding dementia (Kitwood, 1997a; Kontos, 2003; Lyman, 1989; Netten, 1993).

8.4.3. Reflecting the lived experience of dementia

Dementia is typically portrayed with bio-medical assumptions that underlie socially constructed concepts (Basting, 2009; Gubrium, 1986; Kitwood, 1997b; Kontos & Naglie, 2007). This reductionist construct also informs societal attitudes fuelled by the media's pervasive and negative portrayal about people with a diagnosis (Zeilig, 2014). Attitudes are thus shaped, and form the basis for social interactions upon which, rest the preservation of self and identity of people with a diagnosis. A process referred to as self-stigmatization (Milne, 2010) may result whereby stigma is absorbed by the person living with a diagnosis. So it was for some of the participants in this study. Understanding this, and the wider impact these attitudes have on health and wellbeing is an important way of ensuring that negative societal attitudes and practices are critically questioned rather than accepted.

A reappraisal of *how* dementia is constructed in society is urgently needed. The reluctance of the study's participants to consider risk-taking following a diagnosis reflected negative stereotypical societal perceptions. These attitudes hamper, and prevent the reappraisal and reconstruction required for the transitional challenges of living with dementia. The participants in this study demonstrated the many ways they negotiated risk throughout their lives. This built up a 'bank' of resilience and the social and psychological resources which made up their resilience had a positive effect on 'bouncing back' following a diagnosis.

Those living with dementia report the need to educate others, and they remain well positioned to overturn the inaccurate and damaging image of a diagnosis. The participants' narratives of living 'as normal a life as possible' and 'making the most of things' attest to readjustment following a diagnosis, a 'looking back from loss' and 'full speed ahead'. How to support those diagnosed to create meaningful lives includes the importance of participation and inclusion, rather than marginalisation and increased vulnerability. The findings of this study will encourage 'others'

including researchers and clinicians to engage with people with dementia as active agents to manage a new reality in the midst of an emerging and uncertain future. Their positive and willing participation in this research refutes the notion that people living with dementia are not interested in taking part in research and contributing to the well-being of others.

8.4.4. The diagnostic experience link to clinical specific practices

The participants had a range of experiences at the CDAMS clinic, some of which were negative. The clinics were busy, noisy, unfamiliar, depersonalised and intimidating environments. Feelings of nihilism—that 'nothing could be done' were experienced by the participants as they received their diagnosis. This may be due to the dominance of the medical model of dementia within the practices of CDAMS clinics. From the experiences of the participants in this study, a critical review of the 'practice' of diagnosis calls for a more person-centred approach to the performance of tests including the optimal environment in which to conduct assessments tailored to the client's particular abilities and strengths. Underpinning the importance of improving the CDAMS experience is the need for people living with dementia to participate in research (Hellström, et al., 2007) and provide feedback on their subjective experiences of diagnostic centres.

8.4.5. The ethics approval experience

Upon approval from the university ethics committee, my application to access clients for this study from three CDAMS clinics resulted in further ethics requirements–all of which were different in their procedure and practice. A National Ethics Application Form (NEAF) together with a Victorian State Module were designed to streamline the process of gaining ethics approval, but CDAMS ethics approval was a further complex and rigorous process. While this situation reflects the importance of protection for vulnerable people and the complexity of an organisation such as CDAMS, a counter view is that a sound research project predominantly relies on the integrity of the researcher (Pesonen, et al., 2011) rather than a regulatory framework (Jokinen, Lappalainen, Meriläinen, & Pelkonen, 2002; Smith, 2008; Ulrich, Wallen, & Grady, 2002). Ethics approval thus remains a priority in a study such as this while there is room for its requirements to be more streamlined and centralised.

This study demonstrates that people living with dementia value the opportunity to talk, reflect on, and ultimately accept and come to terms with their diagnosis. This was supported by other studies such as Anderson (2007) who highlighted the relational and generative nature of language and knowledge when we talk with each other; how it gives meaning and understanding to our interrelated lives. Benbow and Kingston (2016) confirmed Anderson's view, stating that producing a narrative is a valuable and engaging experience for people with dementia and carers, and is likely to contribute to the difficult and emotional task of centering the person in the careful explanation of the diagnostic outcome.

8.4.6. The research selection process

This study's participants were selected by the CDAMS clinic staff, and consent for participation was often given by a family member or a close friend. This diminishes the participants' independent decision-making. Dewing (2002, p. 161) resolves this dilemma by "inclusionary consent" which is situated within a relationship based on an ethics of personhood.

This study demonstrated the need for active researcher involvement as part of the team in the recruitment process, which may result in a more informed and empowering consent process for the research participant. It may also eliminate the need for the consultation and consent of others, particularly when people with a recent diagnosis are more than likely to be able to decide about involvement for themselves.

8.5.   Implications of this study

My study proposed implications at several levels. It sought the voice of the person living with dementia in all its "livingness" (van Manen, 2016, p. 6) as the subjective experience of living with dementia was the space which held the best opportunity for answering the research question. In all their dramatic power, the first-person stories told within this thesis were credible voices brimming with such 'livingness' which imposed the reality of living with dementia within the conversations. With stories that were honest and at times confronting, the participants raised their fears and concerns and hope for the future. These stories, and the voices within them, have

the capacity to shape concerns and needs for people living with dementia, and their articulation has implications at both a personal, professional and societal level.

Access to services and associated support for people with dementia will change with the consumer empowerment of consumer-directed care in both residential and community services in Australia. This care, with its onus placed firmly on the consumer, has serious implications for people if they are alone, have a cognitive impairment, or have long term conditions together with a progressive illness such as dementia. Support will be needed in terms of information about what consumer direction and choice might mean for consumers, and while the needs of this study's participants were relatively stable and enduring over time, within a progressive illness such as dementia, needs may change quickly and inevitably services must respond accordingly. There are inherent risks within this care model which need to be considered within the context of a risk analysis and lessons to be learned.

Access and equity are issues within services generally and dementia care services are no different. People who are marginalised on the basis of a chronic and disabling illness such as dementia face discrimination often based on the societal fears of the triple jeopardy that permeates professional practice and the availability of appropriate services and timely access to care. This inequality speaks to us as a community, as a society and as a democratic nation. It is complex, situated and political (Brannelly, 2016) and highlights the fight that isolated, marginalised and disenfranchised people have to achieve rights and citizenship as an issue of social justice.

Social citizenship can be created when communities develop initiatives which promote inclusion and engagement for all its citizens and Tronto's ethics of care (1993) is a guide to inclusive citizenship practices. This version of care ethics is private and public, moral and political, and intended to be a shared concern for all. Furthermore it supports the quality of life and well-being of everyone, including those disadvantaged.

There is my obligation that this thesis be presented to conferences and publications where stakeholders and service providers have the opportunity to hear the

participants' voices and respond to them. Gaps in knowledge have been identified and require the attention of all parties who care about people living with dementia and their well-being.

8.6.   Implications for future research

When keying in the words *risk* and *dementia,* the predominant response in search engines focused on the risk factors which are seen to cause dementia. Alternatively, the search revealed articles on the avoidance of risk within care practices. More recently theorists are asserting the right to take risk and the importance of autonomy within care practices and have included first person anecdotal responses to risk within their studies (T. Adams, 2001; C. Clarke, 2000). Throughout the review of published research, a gap in the literature was identified in the subjective experience of taking risk while living with dementia. This study is a clarion—calling on others to follow.

A further gap in the current literature pertaining to this thesis relates to the experience for people living with dementia of having disabled older children. An online search within VU, EBSCO and Google Scholar databases revealed no literature linking adult disabled children and people with dementia. Within this study, the situation presented as one of anguish for the parents in this study, and has the potential to adversely impact their ability to manage a diagnosis while juggling the responsibilities for adult children who are disabled. It is an important area for further investigation.

Finally, longitudinal qualitative studies are the exception in seeking the first-hand experience of those living with dementia. Of particular focus in this longitudinal study is the changing relationship to risk in the lives of the participants. The benefit of thisresearch design has been to monitor change and transition within the progression of dementia, together with changes in the lived experience of taking risk. Longitudinal studies such as this have manifold benefits and present important opportunities for future longitudinal work involving people and their lives in negotiating this chronic and disabling illness.

8.7.   A personal reflection

This journey has been a five year one. The highlight throughout was the privilege of working with the participants at an unexpected and daunting transitional juncture in their lives. They were warm, generous and singular in their relationships with me. This generous engagement allowed for an in-depth exposition of phenomena that has not previously been explored. It shed light on what it might be like for people to receive and adjust to a diagnosis of dementia necessary to 'becoming' a person living with dementia. Among the many adjustments—both present and future—were those made to the taking of risk. Within the uncertainty of a diagnosis, the participants were adjusting to a new life—a life which in the future may or may not include the *essence* of risk.

The process of meeting the participants over a period of two years highlighted their continued engagement in story-telling which remained an important form of communication. Within the stories the *essence* of risk continued to provide the platform to enable continued determination of autonomy and rights to make decisions about their lives. The lived experience of risk was bound up in memories— in funny times, dramatic actions and decision-making which unfolded over a lifetime teaching the participants valuable lessons and influencing *how* they lived their lives. It defined them. Taking risk was a positive experience for the participants because it was *'life'*. These stories of risk ushered the participants from the past through the present to an uncertain, but anticipated future. With all its attendant uncertainty, the present was no time to take personal risk but the future was yet to be determined.

While there was an expectation that things would continue to change, the importance that the participants placed on values, such as maintaining independence and not being a burden were articulated throughout this study. These values were powerfully demonstrated in quests for respect for autonomy and the right to make decisions—to take a risk—being upheld, despite the uncertainty and threat posed by a diagnosis of dementia. By understanding and respecting the values (often related to care), we uphold their personhood and have a positive impact on the experience of managing an illness such as dementia. Living life as before had been undermined by a diagnosis, yet adjustment and realignment to a new life of living with dementia

offered promise that life could be lived to the full. Envisioning the future, while managing the present, was ephemeral but vital to the participants' enduring identity in their transitional adjustment to living with dementia.

This thesis has embraced these voices and so demands that those involved in their support and care—*listen*—listen to their stories; stories deeply embedded in memory. It further demands consideration to allowing risk in the stories to come; thus upholding the *essence* of risk. This thesis contributes to building confidence in those who care alongside people with dementia to uphold and embrace the dignity of risk, the right to decision-making, and to honour the choices made.

REFERENCES

Abramson, J. (1990). Enhancing patient participation: Clinical strategies in the discharge planning process. *Social Work in Health Care, 14*(4), 53-71. doi: 10.1300/J010v14n04_06

Adams, C., & van Manen, M. (2008). Phenomenology. In L. Given (Ed.), *The Sage encyclopedia of qualitative research methods* (pp. 615-619). Thousand Oaks, CA: Sage Productions.

Adams, J. (1995). *Risk.* Oxford: Routledge.

Adams, T. (1996). Kitwood's approach to dementia and dementia care: A critical but appreciative view. *Journal of Advanced Nursing, 23*(5), 948 - 953. doi: 10.1046/j.1365-2648.1996.10613.x

Adams, T. (1998). The discursive construction of dementia care: Implications for mental health nursing. *Journal of Advanced Nursing, 28*(3), 614 - 621. doi: 10.1046/j.1365-2648.1998.00693.x

Adams, T. (1999). Developing partnership in dementia care: a discursive model of practice. In T. Adams & C. Clarke (Eds.), *Dementia care: Developing partnerships in practice* (pp. 37-56). London: Bailliere Tindall.

Adams, T. (2001). The social construction of risk by community psychiatric nurses and family carers for people with dementia. *Health, Risk & Society, 3*(3), 307-319. doi: 10.1080/13698570120079903

Adams, T. (2005). From person-centred to relationship-centred care. Generations Review, 15, 4-7. Retrieved fromhttp://0-search.ebscohost.com.library.vu.edu.au/login.aspx?direct=true&db=c8h&AN=2002052574&site=ehost-live

Adams, T. (2010). The social construction of risk by community psychiatric nurses and family carers for people with dementia. *Health, Risk & Society, 3*(3), 307-319. doi: 10.1080/13698570120079903

Ahern, K. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research, 9*, 407-411. doi: 10.1177/104973239900900309

Alaszewski, A. (2000). Risk assessment and management: Issues for policy and practice. Leeds: Nuffield Institute for Health.

Alaszewski, A. (2006). Diaries as a source of suffering narratives: A critical commentary. *Health, Risk & Society, 8*(1), 43-58. doi: 10.1080/13698570500532553

Alaszewski, A., Alaszewski, H., Ayer, S., & Manthorpe, J. (2000). *Managing risk in community practice: Nursing, risk and decision-making.* London: Balliere Tindall.

Alaszewski, A., & Coxon, K. (2008). Editorial. The everyday experience of living with risk and uncertainty. *Health, Risk & Society, 10*(5), 413-420. doi: 10.1080/13698570802383952

Alaszewski, A., & Coxon, K. (2009). Uncertainty in everyday life: Risk, worry and trust. *Health, Risk & Society, 11*(3), 201-207. doi: 10.1080/13698570902906454

Alaszewski, A., Harrison, L., & Manthorpe, J. (Eds.). (1998). *Risk, health and welfare*. Buckingham: Open University Press.

Alaszewski, A., & Manthorpe, J. (1998). Welfare agencies and risk: The missing link? *Health and Social Care in the Community, 6*(1), 4-15. doi: 10.1046/j.1365-2524.1998.00096.x

Albert, M., & Mildorf, B. (1989). The concept of dementia. *Journal of Neurolinguistics, 4*(3-4), 301-308. doi: 10.1016/0911-6044(89)90022-5

Ale, B. (2009). *Risk: An introduction*. Abingdon,Oxon: Routledge.

Allen, J., & Oyebode, J. (2009). Having a father with young onset dementia: The impact on well being of young people. *Dementia, 8*(4), 455-488. doi: 10.1177/1471301209349106

Allen, R., Haley, P., Harris, G., Fowler, S., & Pruthi, R. (2011). Resilience: Definitions, ambiguities and applications. In B. Resnick, L. Gwyther & K. Roberto (Eds.), *Resilience in aging* (pp. 1-14). New York: Springer.

Alvesson, M., & Skoldberg, K. (2000). *Reflexive methodology. New vista for qualitative research*. London: Sage Productions.

Alzheimer's Australia. (2016). Key facts and statistics for media. Retrieved from https://www.fightdementia.org.au/about-us/media/key-facts-and-statistics

Alzheimer's Australia. (n.d.). Memory changes. Retrieved from https://www.fightdementia.org.au/about-dementia/memory-loss/memory-changes

Alzheimer Europe. (2009). Facing the diagnosis. Retrieved from http://www.alzheimer-europe.org/Living-with-dementia/After-diagnosis-What-next/Diagnosis-of-dementia/Facing-the-diagnosis/(language)/eng-GB

Amann, E. (2015). *Resilience*. Germany: Haufe Lexware Verlag.

Aminzadeh, F., Byszewski, A., Molnar, F., & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging & Mental Health, 11*(3), 281-290. doi: 10.1080/13607860600963695

Anderson, H. (2007). A postmodern umbrella: Language and knowledge as relational and generative, and inherently transforming. In H. Anderson & D. Gehart (Eds.), *Collaborative therapy. Relationships and conversations that make a difference* (pp. 7-19). London: Routledge.

Andrew, C., Traynor, V., & Iverson, D. (2015). An integrative review: Understanding driving retirement decisions for individuals living with dementia. *Journal of Advanced Nursing, 71*(12), 2728- 2740. doi: 10.1111/jan.12727

Andrew, M., & Rockwood, K. (2010). Social vulnerability predicts cognitive decline in a prospective cohort of older Canadians. *Alzheimer's & Dementia, 6*, 319-325. doi: 10.1016/j.jalz.2009.11.001

Angus, J., & Bowen-Osborne, S. (2014). A self narrative of life-long disability: A reflection on resilience and living with dementia. *Dementia, 13*(2), 147-159. doi: 10.1177/1471301212455121

Angus, J., & Bowen, S. (2011). Quiet please, there's a lady on stage: Centering the person with dementia in life story narrative. *Journal of Aging Studies, 25*(2), 110-117. doi: 10.1016/j.jaging.2010.08.010

Angus, J., & Reeve, P. (2006). Ageism: A threat to "ageing well" in the 21st century. *Journal of Applied Gerontology, 25*(2), 137-152. doi: 10.1177/0733464805285745

Ashworth, A. (1990). *Meaningful, reasonable and normal. Making sense of the long stay geriatric ward, and learning some policy lessons.* Unpublished BA dissertation, University of Sheffield, Sheffield.

Ashworth, P. (2003). An approach to phenomenological psychology: The contingencies of the lifeworld. *Journal of Philosophical Psychology, 34*(2), 146-154. doi: 10.1163/156916203322847119

Ashworth, P. (2006). Seeing oneself as a carer in the activity of caring. Attending to the lifeworld of the person with Alzheimer's disease. *International Journal of Qualitative Studies on Health and Well-Being, 1*(4), 212-225. doi: 10.1080/17482620600967786

Australian Government. (2015). What is consumer directed care? Retrieved from http://www.myagedcare.gov.au/aged-care-services/home-care-packages/consumer-directed-care-cdc

Australian Institute of Health and Welfare. (2012). Dementia in Australia. Retrieved from http://www.aihw.gov.au/publication-detail/?id=10737422958

Australian Institute of Health and Welfare. (2016). Ageing. Retrieved from http://www.aihw.gov.au/ageing/

Bailey, C., Clarke, C., Gibb, C., Haining, S., Wilkinson, H., & Tiplady, S. (2013). Risky and resilient life with dementia: Review of and reflections on the literature. *Health, Risk & Society, 15*(5), 390-401. doi: 10.1080/13698575.2013.821460

Baldwin, C., & Capstick, A. (Eds.). (2007). *Tom Kitwood on dementia: A reader and critical commentary*. Maidenhead: McGraw-Hill/Open University Press.

Ballenger, J. (2006). *Self, senility, and Alzheimer's disease in modern America*. Baltimore: John Hopkins.

Baltes, P., & Baltes, M. (1990). Psychological perspectives on successful ageing: The model of successful ageing with compensation. In P. Baltes & M. Baltes (Eds.), *Successful ageing: perspectives from the behavioural sciences*. New York: Cambridge University Press.

Bamford, C., Lamont, S., Eccles, M., Robinson, L., May, C., & Bond, J. (2004). Disclosing a diagnosis of dementia: A systematic review. *International Journal of Geriatric Psychiatry, 19*(2), 151-169. doi: 10.1002/gps.1050

Barca, M., Thorsen, K., Engedal, K., Haugen, P., & Johannessen, A. (2014). Nobody asked me how I felt: Experiences of adult children of persons with young-onset dementia. *International Psychogeriatrics, 26*(12), 1935-1944. doi: 10.1017/S1041610213002639

Barnes, M. (1997). *Care, communities and citizens*. London: Longman.

Bartlett, R. (2014). Citizenship in action: The lived experiences of citizens with dementia who campaign for social change. *Disability & Society, 29*(8), 1291-1304. doi: 10.1080/09687599.2014.924905

Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies, 21*, 107-118. doi: 10.1016/j.jaging.2006.09.002

Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate: Towards social citizenship*. Great Britain: The Policy Press.

Basting, A. (2009). *Forget memory, creating better lives for people with dementia*. Baltimore: John Hopkins University Press.

Beard, R. (2004). In their voices: Identity preservation and experiences of Alzheimer's disease. *Journal of Aging Studies, 18*(4), 415-428. doi: 10.1016/j.jaging.2004.06.005

Beard, R., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging Studies, 23*, 227-235. doi: 10.1016/j.jaging.2008.01.002

Beauchamp, T., & Childress, J. (1994). *Principles of biomedical ethics* (4th ed.). New York: Oxford University Press.

Beck, U. (1992). *Risk society: Towards a new modernity*. London: Sage.

Beck, U. (2009). *World at risk*. Cambridge: Polity Press.

Behuniak, S. (2010). Towards a political model of dementia: Power as compassionate care. *Journal of Aging Studies, 24*, 231-240. doi: 10.1016/j.jaging.2010.05.003

Behuniak, S. (2011). The living dead? The construction of people with dementia as zombies. *Ageing & Society 31*(1), 70-92. doi: 10.1017/S0144686X10000693

Bell, V., & Troxel, D. (1994). An Alzheimer's disease Bill of Rights. *American Journal of Alzheimer's Disease and Other Dementias, 9*, 3-6. doi: 10.1177/153331759400900502

Benbow, S., & Jolley, D. (2012). Ethical perspective. Dementia: Stigma and its effects. *Neurodegenerative Disease Management, 2*(2), 165-172. doi: 10.2217/nmt.12.7

Benbow, S., & Kingston, P. (2016). 'Talking about experiences ... at times disturbing yet positive': Producing narratives with people living with dementia. *Dementia, 15*(5), 1034-1052. doi: 10.1177/1471301214551845

Benjamin, D., Fheffetz, O., Kimball, M., & Szembrot, N. (2014). Beyond happiness and satisfaction: Toward well-being indices based on stated preference. *American Economic Review, 104*(8), 2698-2735. doi: https://doi.org/10.1257/aer.104.9.2698

Benner, P., & Wrubel, J. (1989). *The primacy of caring, stress and coping in health and illness*. Menlo Park, CA: Addison-Wesley.

Berchtold, N., & Cotman, C. (1998). Evolution in the conceptualisation of dementia and Alzheimer's disease: Greco-Roman period to the 1960s. *Neurobiology of Aging, 19*(3), 173-189. doi: 10.1016/S0197-4580(98)00052-9

Berk, R. (2001). The active ingredients in humor: psychophysiological benefits and risks for older adults. *Educational Gerontology, 27*, 323-339. doi: 10.1080/036012701750195021

Berry, B., Apesoa-Varano, E., & Gomez, Y. (2015). How family members manage risk around functional decline: The autonomy management process in households facing dementia. *Social Science & Medicine, 130*, 107-114. doi: 10.1016/j.socscimed.2015.02.014

Blackstock, K. (2006). Living with dementia in rural and remote Scotland: Diverse experiences of people with dementia and their carers. *Journal of Rural Studies, 22*, 161-176. doi: 10.1016/j.jrurstud.2005.08.007

Bleicher, J. (1980). *Contemporary hermeneutics: hermeneutics as method, philosophy and critique*. London: Routledge.

Blumensteil, A. (1973). A sociology of good times. In G.Psathas (Ed.), *Phenomenological sociology: Issues and applications* (pp. 187-215). New York: Wiley.

Bogdan, R., & Biklen, S. (2007). *Qualitative research for education: An introduction to theories and methods*. Boston: Pearson.

Boller, F., & Forbes, M. (1998). History of dementia and dementia in history. *Journal of the Neurological Sciences, 158*, 125-133. doi: 10.1016/S0022-510X(98)00128-2

Bond, J., Corner, L., & Graham, R. (2004). Social science theory on dementia research: Normal ageing, cultural representation and social exclusion. In A. Innes, C. Archibald & C. Murphy (Eds.), *Dementia and social inclusion: Marginalised groups and marginalised areas of dementia research, care and practice* (pp. 220-237). London: Jessica Kingsley Publishers.

Bowen, S. (2006). *Dementia and the discursive creation of self*. Unpublished thesis. Victoria University. Melbourne, Australia.

Boyle, G. (2008). The Mental Capacity Act 2005: Promoting the citizenship of people with dementia? *Health & Social Care in the Community, 16*, 529-537. doi: 10.1111/j.1365-2524.2008.00775.x

Bradshaw, A. (1995). 'What are nurses doing to patients?' A review of theories of nursing past and present. *Journal of Clinical Nursing, 4*(2), 81-92. doi: 10.1111/j.1365-2702.1995.tb00015.x

Bradshaw, J., Saling, M., Hopwood, M., Anderson, V., & Brodtmann, A. (2004). Fluctuating cognition in dementia with Lewy bodies and Alzheimer's disease is qualitatively distinct. *Journal of Neurobiology, Neurosurgery & Psychiatry, 75*(3), 382-327. doi: 10.1136/jnnp.2002.002576

Brannelly, T. (2011). Sustaining citizenship: People with dementia and the phenomenon of social death. *Nursing Ethics, 18*(5), 662-671. doi: 10.1177/0969733011408049

Brearley, C. (1979). Understanding risk. *Social Work Today, 10*(31), 28.

Brearley, C. (1982). *Risk in social work*. London: Routledge & Kegan Paul.

Breen, D., Breen, D., Moore, J., Breen, P., & O'Neill, D. (2007). Driving and dementia. *British Medical Journal, 334*, 1365-1369. doi: 10.1136/bmj.39233.585208.55

Brinkmann, S., Jacobsen, M., & Kristiansen, S. (2014). Approaches to qualitative research. In P. Leavy (Ed.), *The Oxford handbook of qualitative research* (pp. 17-42). New York: Oxford University Press.

Brooker, D. (2004). What is person-centred care in dementia? *Clinical Gerontology 13*, 215-222. doi: doi.org/10.1017/S095925980400108X

Brooker, D. (2007). *Person-centred dementia care: Making services better.* London: Jessica Kingsley Publishers.

Brookmeyer, R., Johnson, E., Ziegler-Graham, K., & Arrighi, M. (2007). Forecasting the global burden of Alzheimer's disease. *Alzheimer's & Dementia 3*(3), 186-191. doi: 10.1016/j.jalz.2007.04.381

Bruens, M. (2013). Dementia: Beyond structures of medicalisation and cultural neglect. In J. Baars, J. Dohmen, A.Grenier & C.Phillipson (Eds.), *Ageing, meaning and social structure* (pp. 81-96). Bristol: Policy Press.

Bryden, C. (2005). *Dancing with dementia: My story of living positively with dementia.* London: Jessica Kingsley.

Buchanan, K., & Middleton, D. (1995). Voices of experience: Talk, identity and membership of reminiscence groups. *Ageing and Society, 15*, 457- 491. doi: 10.1017/S0144686X00002865

Burns, N., & Grove, S. (1993). *The practice of nursing research: Conduct, critique and utilization.* Philadelphia: W. B. Saunders Company.

Burzyński, J., & Burzyński, T. (2014). *Taming risk: uncertainty, trust and the sociological discourse of modernity.* Newcastle upon Tyne, UK: Cambridge Scholars Publishing.

Calder, R. (2014). Chronic diseases in Australia: the case for changing course. *Australian Health Policy Collaboration Issues Paper.* Retrieved from https://www.vu.edu.au/sites/default/files/AHPC/pdfs/Chronic-diseases-in-Australia-the-case-for-changing-course-sharon-willcox.pdf

Campbell, S., Manthorpe, J., Samsi, K., Abley, C., Robinson, L., Watts, S., et al. (2016). Living with uncertainty: Mapping the transition from pre-diagnosis to a diagnosis of dementia. *Journal of Aging Studies, 37*, 40-47. doi: 10.1016/j.jaging.2016.03.001

Caputo, J. (1987). *Radical hermeneutics: Repitition, deconstruction, and the hermeneutic project.* Bloomington: Indiana University Press.

Carpenter, B., & Dave, J. (2004). Disclosing a dementia diagnosis: A review of opinion and practice, and a proposed research agenda. *The Gerontologist, 44*, 149-158. doi: 10.1093/geront/44.2.149

Carson, A., & Fairbairn, G. (2002). The whole story: towards an ethical research methodology. *Nurse Researcher, 10*(1), 15-29. doi: 10.7748/nr2002.10.10.1.15.c5876

Cayton, H. (2004). Telling stories. *Dementia, 3*(1), 9-17. doi: 10.1177/1471301204039322

Chan, Z., Fung, Y., & Chien, W. (2013). Bracketing in phenomenology: Only undertaken in the data collection and analysis process? *The Qualitative Report, 18*, 1-9. doi: http://nsuworks.nova.edu/

Christensen, K., Doblhammer, G., Rau, R., & Vaupel, J. (2009). Ageing populations: The challenges ahead. *Lancet, 374*, 1196-1208. doi: 10.1016/S0140-6736(09)61460-4

Clare, L. (2003). Managing threats to self : Awareness in early stage Alzheimer's disease. *Social Science & Medicine, 57*(6), 1017 - 1029.

Clare, L., Roth, I., & Pratt, R. (2005). Perceptions of change over time in early-stage Alzheimer's disease: Implications for understanding awareness and coping style. *Dementia, 4*(4), 487- 520. doi: 10.1177/1471301205058304

Clarke, A., & Bailey, C. (2016). Narrative citizenship, resilience and inclusion with dementia: On the inside or on the outside of physical and social places. *Dementia, 15*(3), 434-452. doi: 10.1177/1471301216639736

Clarke, A., Hanson, E., & Ross, H. (2003). Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Advanced Nursing, 12*, 697-706. doi: 10.1046/j.1365-2702.2003.00784.x

Clarke, C. (1999). Family care-giving for people with dementia: some implications for policy and professional practice. *Journal of Advanced Nursing, 29*(3), 712-720. doi: 10.1046/j.1365-2648.1999.00940.x

Clarke, C. (2000). Risk: constructing care and care environments in dementia. *Health, Risk & Society, 2*, 83-93. doi: 10.1080/136985700111477

Clarke, C. (2001). Dementia care partnerships: Knowledge, ownership and exchange. In T. Adams & C. Clarke (Eds.), *Dementia care partnerships: knowledge, ownership and exchange* (pp. 5-35). New York: Balliere Tindall.

Clarke, C. (2006). Risk and ageing populations: practice development research through an international research network. *International Journal of Older People Nursing, 1*(3), 169 - 176. doi: 10.1111/j.1748-3743.2006.00027.x

Clarke, C. (2009). Editorial. Risk and long-term conditions: the contradiction of self in society. *Health, Risk & Society, 11*(4), 297 - 302. doi: 10.1080/13698570903045427

Clarke, C. (2010). Editorial: risk and long-term conditions—society, services and resilience. *Journal of Nursing and Healthcare of Chronic Illness, 2*(2), 85 - 87. doi: 10.1111/j.1752-9824.2010.01060.x

Clarke, C., & Keady, J. (2002). Getting down to brass tacks: discussion of data collection with people with dementia. In H. Wilkinson (Ed.), *The perspectives of people with dementia: research methods and motivations* (pp. 25 - 46). London: Jessica Kingsley.

Clarke, C., Keady, J., Wilkinson, H., Gibb, C., Luce, A., Cook, A., et al. (2010). Dementia and risk: contested territories of everyday life. *Nursing and Healthcare of Chronic Illness, 2*(2), 102-112. doi: 10.1111/j.1752-9824.2010.01040.x

Clarke, C., & Mantle, R. (2015). Using risk management to promote person-centred dementia care. *Nursing Standard, 30*(28), 41-46. doi: 10.7748/ns.30.28.41.s47

Clarke, C., Wilkinson, H., Keady, J., & Gibb, C. (2011). *Risk assessment and management for living well with dementia*. London: Jessica Kingsely

Clarke, P. (1996). *Deep citizenship*. Chicago, IL: Pluto Press.

Clough, P., & Barton, L. (Eds.). (1995). *Making difficulties*. London: Paul Chapman Publishing.

Cohen, A. (2001). Review of literature: Responses to "Empirical and hermeneutic approaches to phenomenological research in psychology, a comparison". *Gestalt, 5*(2). Retrieved from http://www.g-gej.org/5-2/reviewlit.html

Cooper, P., Tallman, K., Tuokko, H., & Beattie, B. (1993). Vehicle crash involvement and cognitive deficit in older drivers. *Journal of Safety Rescue, 24*, 9-17. doi: 10.1016/0022-4375(93)90047-Q

Cotrell, V., & Schultz, R. (1993). The perspective of the patient with Alzheimer's disease: A neglected dimension of dementia research. *The Gerontologist, 33*(2), 205 - 211. doi: 10.1093/geront/33.2.205

Courbage, C., & Liedtke, P. (2012). Global ageing: root causes and implications for key stakeholders. In P. Liedtke & K. Schanz (Eds.), *Addressing the challenge of global ageing, funding issues and insurance solutions* (pp. 17-32). Geneva: The Geneva Reports.

Crandall, L., White, D., Schuldheis, S., & Talerico, K. (2007). Inititiating person-centred care practices in long-term care facilities. *Journal of Gerontological Nursing, 33*(11), 47-56. Retrieved from http://www.healio.com/journals

Crease, R. (n.d.). Phenomenology and natural science. *Internet Encyclopedia of Philosophy*. Retrieved from http://www.iep.utm.edu/phenomsc/

Dartington, T. (2006). Editorial: managing vulnerability. *Dementia, 5*(4), 475 - 478. doi: 10.1177/1471301206069901

Dartington, T. (2007). Two days in December. *Dementia, 6*(3), 327 - 341. doi: 10.1177/1471301207081564

Dartington, T. (2010). *Managing vulnerability. The underlying dynamics of systems of care.* London: Karnac Books.

Davis, D. (2004). Dementia: sociological and philosophical constructions. *Social Science & Medicine, 58*(2), 369-378. doi: 10.1016/S0277-9536(03)00202-8

Davis, R. (1989). *My journey into Alzheimer's Disease*. Wheaton, IL: Tyndale House Publishers.

Deacon, B. (2013). The biomedical model of mental disorder: A critical analysis of its validity, utility, and effects on psychotherapy research. *Clinical Psychology Review, 33*, 846-861. doi: 10.1016/j.cpr.2012.09.007

Debesay, J., Nåden, D., & Slettebø , A. (2008). How do we close the hermeneutic circle? A Gadamerian approach to justification in interpretation in qualitative studies. *Nursing Inquiry, 15*(1), 57-66. doi: 10.1111/j.1440-1800.2008.00390.x

Deeg, D. (2013). New myths about ageing: The growth of medical knowledge and its societal consequences. In S. McDaniel & Z. Zimmer (Eds.), *Global ageing in the twenty-first century* (pp. 139-155). London: Ashgate.

Deist, M., & Greeff, A. (2015). Living with a parent with dementia: A family resilience study. *Dementia.* doi: 10.1177/1471301215621853

Deloitte Access Economics. (2011). Dementia across Australia: 2011-2050. Retrieved from http://www.fightdementia.org.au/common/files/NAT/20111014_Nat_Access_D emAcrossAust.pdf

Department of Health. (2010). Nothing ventured, nothing gained: Risk guidance for people with dementia. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/ 215960/dh_121493.pdf

Derrida, J., & Ferraris, M. (2001). *A taste for the secret*. Cambridge, UK: Polity Press.

Dewing, J. (2002). From ritual to relationship. A person-centred approach to consent in qualitative research with older people who have dementia. *Dementia, 1*(2), 157 - 171. doi: 10.1177/147130120200100204

Dewing, J. (2007). Participatory research: a method for process consent with persons who have dementia. *Dementia, 6*(1), 11-25. doi: 10.1177/1471301207075625

Dewing, J. (2008). Personhood and dementia: revisiting Tom Kitwood's ideas. *Older People Nursing, 3*(1), 3 -13. doi: 10.1111/j.1748-3743.2007.00103.x

deWitt, L., Ploeg, J., & Black, M. (2010). Living alone with dementia: An interpretive phenomenological study with older women. *Journal of Advanced Nursing,66* (8), 1698-1707. doi: 10.1111/j.1365-2648.2010.05295.x

Donnellan, W., Bennett, K., & Soulsby, L. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging and Mental Health, 19*(10), 932-939. doi: 10.1080/13607863.2014.977771

Douglas, M. (1992). *Risk and blame. Essays in cultural theory*. London: Routledge.

Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies, 44*(1), 131-142. doi: 10.1016/j.ijnurstu.2005.11.026

Downs, M. (1997). The emergence of the person in dementia research. *Ageing and Society, 17*(4), 597- 601. http://www.cambridge.org/.

Downs, M., Clare, L., & Mackenzie, J. (2006). Understandings of dementia: Explanatory models and their implications for the person with dementia and therapeutic effort. In J. Hughes, S.Louw & S. Sabat (Eds.), *Dementia, mind, meaning, and the person* (pp. 235-258). Oxford: Oxford University Press.

Draucker, C. (1999). The critique of Heideggerian hermeneutical nursing research. *Journal of Advanced Nursing, 30*(2), 360 - 373. doi: 10.1046/j.1365-2648.1999.01091.x

Dreher, M. (1994). Qualitative research methods from the reviewer's perspective. In J. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 281-297). Thousand Oaks: Sage.

Duchek, J., Carr, D., Hunt, L., Roe, C., Xiong, C., Shah, K., et al. (2003). Longitudinal driving performance in early-stage dementia of the Alzheimer's type. *Journal of American Geriatric Society, 51*(10), 1342-1347. doi: 10.1046/j.1532-5415.2003.51481.x

Dunham, C., & Cannon, J. (2008). 'They're still in control enough to be in control' : paradox of power in dementia caregiving. *Journal of Aging Studies, 22*, 45 - 53. doi: 10.1016/j.jaging.2007.02.003

Dupuis, S., Gillies, J., Carson, J., & Whyte, C. (2012). Moving beyond patient and client approaches: Mobilising '*authentic partnerships'* in dementia care,

support and services. *Dementia, 11*(4), 427-452. doi: 10.1177/1471301211421063

Durkheim, E. (1951). *Suicide. A study in sociology*. New York: The Free Press.

Eagleton, T. (1983). *Literary theory: an Introduction*. Oxford: Basil Blackwell.

Edwards, E., & Hall, J. (2015). Resilience in aging. Retrieved from https://nursingandhealth.asu.edu/sites/default/files/resilience-in-aging.pdf

Edwards, J., Lunsman, M., Perkins, M., Rebok, G., & Roth, D. (2009). Driving cessation and health trajectories in older adults. *Journals of Gerontology: Series A, Biological Sciences and Medical Sciences, 64A*, 1290-1295. doi: 10.1093/gerona/glp114

Egeland, B., Carlson, E., & Sroufe, L. (1993). Resilience as process. *Development and Psychopathology, 5*(4), 517-528. doi: https://doi.org/10.1017/S0954579400006131

Ehrich, L. (2005). Revisiting phenomenology: its potential for management research. Retrieved from http://eprints.qut.edu.au/2893/1/2893.pdf

Escandon, A., Al-Hammadi, N., & Galvin, J. (2010). Effect of cognitive fluctuation on neuropsychological performance in aging and dementia. *Neurology 74*, 210-217. doi: 10.1212/WNL.0b013e3181ca017d

Estés, C. (1979). *The aging enterprise*. San Francisco: Jossey-Bass.

Estés, C., & Binney, E. (1991). The biomedicalisation of aging: dangers and dilemmas. In M. Minkler & C. Estés (Eds.), *Critical perspectives on aging* (pp. 117-134). Amityville, NY: Baywood Publishing Company, Inc.

Feinberg, L., & Whitlatch, C. (2001). Are persons with cognitive impairment able to state consistent choices? *The Gerontologist, 41*(3), 374-382. doi: 10.1093/geront/41.3.374

Fink, E. (1970). The phenomenological philosophy of Edmund Husserl and contemporary criticism. In R. Olveton (Ed.), *The phenomenology of Husserl: Selected critical readings* (pp. 70-139). Seattle: Noesis Press Ltd.

Finlay, L. (2008). A dance between the reduction and reflexivity: Explicating the "phenomenological psychological attitude". *Journal of Phenomenological Psychology, 39*, 1-32. doi: 10.1163/156916208X311601

Finlay, L. (2009). Debating phenomenological research methods. *Phenomenology & Practice, 3*(1), 6-25. Retrieved from https://ejournals.library.ualberta.ca/index.php/pandpr

Finlay, L., & Gough, B. (Eds.). (2003). *Reflexivity: a practical guide for researchers in health and social science*. Oxford: Blackwell Publishing.

Fleming, R., Goodenough, B., Low, L.-F., Chenoweth, L., & Brodaty, H. (2016). The relationship between the quality of the built environment and the quality of life of people with dementia in residential care. *Dementia, 15*(4), 663-680. doi: 10.1177/1471301214532460

Flick, U. (2000). Episodic interviewing. In M. Bauer & G. Gaskell (Eds.), *Qualitative researching with text, image and sound* (pp. 75-92). London: Sage.

Flick, U. (2002). Qualitative research-state of the art. *Social Science Information, 41*, 5-24. doi: 10.1177/0539018402041001001

Fonda, S., Wallace, R., & Herzog, A. (2001). Changes in driving patterns and worsening depressive symptoms among older adults. *Journals of Gerontology: Psychological Sciences and Social Sciences, 56*, 343-352. doi: 10.1093/geronb/56.6.S343

Foucault, M. (2003). *The birth of the clinic*. London: Routledge.

Fox, P. (1986). Alzheimer's Disease: An historical overview. *American Journal of Alzheimer's Disease & Other Dementias, 1*(4), 18-24. doi: 10.1177/153331758600100408

Frank, A. (2004). *The renewal of generosity: illness, medicine, and how to live*. Chicago: The University of Chicago Press.

Fries, J. (2003). Measuring and monitoring success in compressing morbidity. *Annals of Internal Medicine, 139*, 455-459. doi: 10.7326/0003-4819-139-5_Part_2-200309021-00015

Gadamer, H. (1975). *Truth and method*. New York: Seabury.

Gadamer, H. (1989). *Truth and Method* (2nd ed.). London: Continuum Publishing Group.

Gadamer, H. (1996). *The enigma of health*. Stanford: Stanford University Press.

Gadamer, H. (2004). *Truth and Method*. London: Continuum.

Galvin, R. (2004). Can welfare reform make a disability disappear? *Australian Journal of Social Issues, 39*(3), 343. Retrieved from http://www.aspa.org.au/publications/ajsi.html

George, D., Qualls, S., Camp, C., & Whitehouse, P. (2013). Renovating Alzheimer's: "Constructive" reflections on the new clinical and research diagnostic guidelines. *The Gerontologist, 53*(3), 378-387. doi: 10.1093/geront/gns096

George, D., & Whitehouse, P. (2010). Dementia and mild cognitive impairment in social and cultural context. In D. Dannefor & C. Phillipson (Eds.), *The Sage*

book of social gerontology (pp. 343-356). Los Angeles, CA: Sage Publications.

George, D., Whitehouse, P., & Ballenger, J. (2011). The evolving classification of dementia: Placing the DSM-V in a meaningful historical and cultural context and pondering the future of "Alzheimer's". *Culture, Medicine & Psychiatry, 35*(3), 417-435. doi: 10.1007/s11013-011-9219-x

German Ethics Council. (2013). Dementia and self-determination. Berlin: Deutscher Ethikrat.

Giddens, A. (1990). *The consequences of modernity*. Cambridge: Polity.

Giddens, A. (1992). *The transformation of intimacy: sexuality, love and eroticism in modern societies*. Cambridge: Polity Press.

Giddens, A. (1999). Risk and responsibility. *The Modern Law Review, 62*(1), 1-10. doi: 10.1111/1468-2230.00188

Gilgun, J. (1999). Mapping resilience as a process among adults with childhood adversities. In H. McCubbin, E. Thompson & J. Futrell (Eds.), *The dynamics of resilient families* (pp. 41-65). London: Sage.

Gill, L., & Cameron, I. (2015). Innovation and consumer directed care: Identifying the challenges. *Australasian Journal on Ageing, 34*(4), 265-268. doi: 10.1111/ajag.12222

Gilliard, C., & Higgs, P. (1998). Ageing and the limiting conditions of the body. *Sociological Research Online, 3*(4), 4. doi: http://www.socresonline.org.uk/

Gilroy, R. (2003). Why can't more people have a say? Learning to work with older people. *Ageing and Society, 23*, 659-674. doi: 10.1017/S0144686X03001351

Giorgi, A. (1970). *Psychology as a human science: A phenomenologically based approach*. New York: Harper and Row.

Giorgi, A. (1994). A phenomenological perspective on certain qualitative research methods. *Journal of Phenomenological Psychology, 25*, 190-220. doi: 10.1163/156916294X00034

Giorgi, A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology, 28*(2), 235-260. doi: 10.1163/156916297X00103

Giorgi, A. (2015). The phenomenological psychology of J.H. van den Berg. *Journal of Phenomenological Psychology, 46*, 141-162. doi: 10.1163/15691624-12341292

Giorgi, A., & Giorgi, B. (2003). The descriptive phenomenological psychological method. In P. Camic, J. Rhodes & L. Yardley (Eds.), *Qualitative research in*

psychology: Expanding perspectives in methodology and design (pp. 243-273). Washington, DC: American Psychological Association.

Gladman, J. (2007). Person centred dementia services are feasible, but can they be sustained? *Age and Ageing, 36*, 171-176. doi: 10.1093/ageing/afl161

Goldsmith, M. (1996). *Hearing the voice of people with dementia.* London: Jessica Kingsley Publishers.

Gordon, M. (2014). *Humor, laughter and human flourishing.* USA: Springer.

Greatrex-White, S. (2008). Thinking about the nature of research findings: A hermeneutic phenomenological perspective. *International Journal of Nursing Studies, 45*, 1842-1849. doi: 10.1016/j.ijnurstu.2008.08.011

Green, B. (1993). *Gerontology and the construction of old age.* Hawthorne, NY: Aldine.

Gruenthal, E. (1927). Kleinisch-anatomisch vergleichende. *Z. Ges. Neurol. Psychiatry, 111*, 763. doi: 10.1007/BF02885263

Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation.* Newbury Park, CA: Sage Publications.

Guba, E., & Lincoln, Y. (1994). Competing paradigms in qualitative research. In E. Guba & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). London: Sage.

Gubrium, J. (1986). *Oldtimers and Alzheimer's. The descriptive organisation of senility.* Greenwich, CT: JAI Press.

Gubrium, J. (1992). *Out of control: family therapy and domestic disorder.* Thousand Oaks, CA: Sage.

Hahn, L. (Ed.). (1997). *The philosophy of Hans-Georg Gadamer.* Chicago: Open Court.

Halfon, N., Larson, K., Lu, M., Tullis, E., & Russ, S. (2014). Lifecourse health development: past, present and future. *Maternal and Child Health Journal, 18*(2), 344-365.

Harding, N., & Palfrey, C. (1997). *The social construction of dementia.* London: Jessica Kingsley Publishers.

Hardy, S., Concato, J., & Gill, T. (2002). Stressful life events among community-living older persons. *Journal of General Internal Medicine, 17*, 841-847. doi: 10.1046/j.1525-1497.2002.20105.x

Harman, G., & Clare, L. (2006). Illness representations and lived experience in early-stage dementia. *Qualitative Health Research, 16*, 484-502. doi: 10.1177/1049732306286851

Harris, P., & Keady, J. (2006). Editorial. *Dementia, 5*(1), 5-9. doi: 10.1177/1471301207085364

Harris, P., & Keady, J. (2008). Wisdom, resilience and successful aging: Changing public discourses on living with dementia. *Dementia, 7*(1), 5-8. doi: 10.1177/1471301207085364

Hartshorne, J., & Germine, L. (2015). When does cognitive functioning peak? The asynchronous rise and fall of different cognitive abilities across the life span. *Psychological Science, 26*(4), 433-443. doi: 10.1177/0956797614567339

Heidegger, M. (1962). *Being and time* (J. Robinson, Trans. 7th ed.). New York: Harper and Row.

Heidegger, M. (1982). *The basic problems of phenomenology*. Bloomington: Indiana University Press.

Heidegger, M. (1985). *History of the concept of time*. Bloomington: Indiana University Press.

Heinonen, K. (2015). Van Manen's method and reduction in a phenomenological hermeneutic study. *Nurse Researcher, 22*(4), 35-41. doi: 10.7748/nr.22.4.35.e1326

Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics, 14*(5), 608-619. doi: 10.1177/0969733007080206

Hendricks, J. (2008). Coming of age. *Journal of Aging Studies, 22*. doi: 10.1016/j.jaging.2007.12.015

Hertz, R. (1997). *Reflexivity and voice*. Thousand Oaks, CA: Sage.

Heyman, B., & Henriksen, M. (1998). Values and health risks. In B. Heyman (Ed.), *Risk, health and health care* (pp. 27-64). London: Arnold.

Higgins, I., & van der Riet, P. (2016). A conversation with Max van Manen on phenomenology in its original sense. *Nursing & Health Sciences, 18*, 4-7. doi: 10.1111/nhs.12274

Holstein, J., & Miller, G. (1993). *Reconsidering social constructivism: Debates in social problem theory.* New York: Aldine de Gruyter.

Holstein, M. (1999). Women and productive aging: troubling implications. In M. Minkler & C. Estes (Eds.), *Critical Gerontology* (pp. 359-373). Amityville, NY: Baywood Publishing.

Holstein, M., & Minkler, M. (2003). Self, society and the 'new gerontology'. *The Gerontologist, 43*(6), 787-796. doi: 10.1093/geront/43.6.787

Horlick-Jones, T. (2005). On 'risk work': professional discourse, accountability, and everyday action. *Health, Risk & Society, 7*(3), 293-307. doi: 10.1080/13698570500229820

Hubbard, G., Cook, A., Tester, S., & Downs, M. (2002). Beyond words: older people with dementia using and interpreting nonverbal behaviour. *Journal of Aging Studies, 16*, 155-167. doi: 10.1016/S0890-4065(02)00041-5

Hughes, J. (2010). Ethical issues and decision-making in dementia care. *Living Ethics: Newsletter of the St. James Ethics Centre,* (81), 6.

Hughes, J. (2011). *Thinking through dementia*. Oxford: Oxford University Press.

Hughes, J. (2014). *How we think about dementia.* London: Jessica Kingsley.

Hughes, J., & Baldwin, C. (2006). *Ethical issues in dementia care: Making difficult decisions.* London: Jessica Kingsley Publishers.

Hughes, J., Louw, S., & Sabat, S. (Eds.). (2006). *Dementia: mind, meaning and the person.* Oxford: Oxford University Press.

Hulko, W., & Stern, L. (2009). Cultural safety, decision-making and dementia. In D. O'Connor & B. Purves (Eds.), *Decision-making, personhood and dementia* (pp. 70-88). London: Jessica Kingsley Publishers.

Hunter, R., & Macalpine, I. (1982). *Three hundred years of psychiatry (1535-1860): a history presented in selective English texts.* Hartsdale, New York: Carlisle Publishing.

Hunter, S., & Ritchie, P. (Eds.). (2007). *Co-production and personalisation in social care.* London: Jessica Kingsley Publishers.

Husserl, E. (1900/1970). *Logical investigations* (D. Carr, Trans.). New York: Humanities Press.

Husserl, E. (1907/1990). *The idea of phenomenology* (W. A. G. Nakhnikian, Trans.). Dordrecht: Kluwer Academic Publishers.

Husserl, E. (1913/82). *Ideas pertaining to a pure phenomenology and to a phenomenological philosophy.* The Hague: Martinus Nijhoff.

Husserl, E. (1913/1962). *Ideas: general introduction to pure phenomenology.* New York: Macmillan.

Husserl, E. (1931a). *Ideas 1. Ideas for a pure phenomenology and phenomenological philosophy* (D. Dahlstrom, Trans.).

Husserl, E. (1931b). *Ideas: general introduction to pure phemonenology*. London: George Allen & Unwin.

Husserl, E. (1970). *The crisis of European sciences and transcendental phenomenology*. Evanston, IL: Northwestern University Press.

Hycer, R. (1999). Some guidelines for the phenomenological analysis of interview data. In A. Bryman & R. Burgess (Eds.), *Qualitative research* (pp. 143-164). London: SAge.

Hydén, L.-C. (2008). Broken and vicarious voices in narratives. In L-C. Hydén & J. Brockmeier (Eds.), *Health, culture and illness: broken narratives* (pp. 36-53). New York: Routledge.

Hydén, L.-C. (2013). Bodies, embodiment and stories. In M. Andrews, C. Squire & M. Tamboukou (Eds.), *Narrative research* (pp. 126-141). London: Sage.

Hydén, L.-C. (2013b). Storytelling in dementia: embodiment as a resource. *Dementia, 12*(3), 359-367. doi: 10.1177/1471301213476290

Hydén, L.-C., & Antelius, E. (2011). Communicative disability and stories: toward an embodied conception of narratives. *Health, 15*, 594-609. doi: 10.1177/1363459310364158

Hydén, L.-C., & Orulv, L. (2009). Narrative and identity in Alzheimer's disease: a case study. *Journal of Aging Studies, 23*(4), 205-214. doi: 10.1016/j.jaging.2008.01.001

Ibrahim, J., & Davis, M.-C. (2014). Upholding rights and managing risk while improving quality of care. In R. Nay, S. Garratt & D. Fetherstonhaugh (Eds.), *Older people: Issues and innovations in care* (pp. 147-167). Sydney: Elsevier.

Innes, A. (2009). *Dementia studies: a social science perspective*. Los Angeles: Sage.

Innes, A., Capstick, A., & Surr, C. (2000). Mapping out the framework. *Journal of Dementia Care, 8*(2), 20-21. Retrieved from http://www.careinfo.org/journal-of-dementia-care/

Janssen, B., Regenmortel, T., & Abma, T. (2011). Identifying sources of strength: resilience from the perspective of older people receiving long-term community care. *European Journal of Ageing, 8*(3), 145-156. doi: 10.1007/s10433-011-0190-8

Jokinen, P., Lappalainen, M., Meriläinen, P., & Pelkonen, M. (2002). Ethical issues in ethnographic nursing research with children and elderly people. *Scandinavian Journal of Caring Sciences, 16*(2), 165-170. doi: 10.1046/j.1471-6712.2002.00076.x

Jones, D., & Greene, J. (2016). Is dementia in decline? Historical trends and future trajectories. *New England Journal of Medicine, 374*, 507-509. doi: 10.1056/NEJMp1514434

Kafle, N. (2011). Hermeneutic phenomenological research method simplified. *Bodhi: An Interdisciplinary Journal, 5*(1), 181-200. doi.10.3126/bodhi.v5i1.8053

Karenberg, A., & Förstl, H. (2006). Dementia in the Greco-Roman world. *Journal of the Neurological Sciences, 244*, 5-9. doi: 10.1016/j.jns.2005.12.004

Keady, J. (1996). The experience of dementia: A review of the literature and implications for nursing practice. *Journal of Clinical Nursing, 5*(5), 275-288. Retrieved from http://0-onlinelibrary.wiley.com.library.vu.edu.au/

Keady, J., & Nolan, M. (1994). Younger onset dementia: developing a longitudinal model as the basis for a research agenda and a guide to interventions for sufferers and carers. *Journal of Advanced Nursing, 19*, 659-669. doi: 10.1111/j.1365-2648.1994.tb01136.x

Kelly, F., & Innes, A. (2013). Human rights, citizenship and dementia care nursing *International Journal of Older People Nursing, 8*(1), 61-70. doi: 10.1111/j.1748-3743.2011.00308.x

Kelly, J. (2016). Balancing quality of life and risk. *Australian Ageing Agenda,* (Jan-Feb), 16. Retrieved from http://www.australianageingagenda.com.au/

Killick, J., & Allan, K. (2001). *Communication and the care of people with dementia.* Great Britain: Open University Press.

Kitwood, T. (1990). *Concern for others: a new psychology for conscience and morality.* London: Routledge.

Kitwood, T. (1993). Discover the person, not the disease. *Journal of Dementia Care 1*(1). doi: http://www.cambridge.org/

Kitwood, T. (1995). Exploring the ethics of dementia research. A response to Berghmans and Ter Meulen. A psychosocial perspective. *International Journal of Geriatric Psychiatry, 10*(8), 655-657. Retrieved from http://0-onlinelibrary.wiley.com.library.vu.edu.au/

Kitwood, T. (1997a). Cultures of care, tradition and change. In T. Kitwood & S. Benson (Eds.), *The new culture of dementia care* (pp. 1-11). London: Hawker Publications.

Kitwood, T. (1997b). *Dementia reconsidered. The person comes first.* Buckingham, UK: Open University Press.

Kitwood, T. (1998). Toward a theory of dementia care: ethics and interaction. *Journal of Clinical Ethics, 9*(1), 23-34. Retrieved from http://www.clinicalethics.com/

Kitwood, T. (2013). The concept of personhood and its relevance for a culture of dementia care. In G. Jones & B. Miesen (Eds.), *Care-giving in dementia: Research and applications* (Vol. 2nd., pp. 3-13). London: Routledge.

Kitwood, T., & Benson, S. (Eds.). (1997a). *The new culture of dementia care.* London: Hawker Productions.

Kitwood, T., & Bredin, K. (1992a). A new approach to the evaluation of dementia care. *Journal of Advances in Health and Nursing Care, 1*(5), 41-60.

Kitwood, T., & Bredin, K. (1992b). Towards a theory of dementia care: Personhood and well being. *Ageing and Society, 12*, 269-287. doi: 10.1017/S0144686X0000502X

Kleinman, A. (1988). *The illness narratives: suffering, healing and the human condition.* New York: Basic Books.

Koch, T. (1994). Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing, 19*(5), 976-986. doi: 10.1111/j.1365-2648.2006.03681.x

Koch, T. (1995). Interpretive approaches in nursing research: the influence of Husserl and Heidegger. *Journal of Advanced Nursing, 21*(5), 827- 836. doi: 10.1046/j.1365-2648.1995.21050827.x

Koch, T. (1996). Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation. *Journal of Advanced Nursing, 21*, 827-836. doi: 10.1046/j.1365-2648.1996.17224.x

Koch, T., & Harrington, A. (1998). Reconceptualising rigour: the case for reflexivity. *Journal of Advanced Nursing, 28*(4), 882-890. doi: 10.1046/j.1365-2648.1998.00725.x

Kodner, D. (2003). Consumer-directed services: lessons and implications for integrated systems of care. *International Journal of Integrated Care, 3*(2), 1-6. doi: 10•5334/ijic.80

Kohli, M. (1981). Biography: account, text, method. In D.Bertaux (Ed.), *Biography and society. The life history approach in the social sciences* (pp. 61-76). Beverley Hills, CA: Sage Publications Inc.

Kontos, P. (2003). 'The painterly hand': embodied consciousness and Alzheimer's disease. *Journal of Aging Studies, 17*, 151-170. doi: 10.1016/S0890-4065(03)00006-9

Kontos, P. (2005). Embodied selfhood in Alzheimer's disease. Rethinking person-centred care *Dementia, 4*(4), 553-570. doi: 10.1177/1471301205058311

Kontos, P., & Naglie, G. (2007). Expressions of personhood in Alzheimer's disease: An evaluation of research-based theatre as a pedagogical tool. *Qualitative Health Research, 17*, 799-811. doi: 10.1177/1049732307302838

Kukull, W. (2006). The growing global burden of dementia. *The Lancet Neurology, 5*(3), 199-200. doi: 10.1016/S1474-4422(06)70358-1

Kvale, S. (1996). *InterViews: an introduction to qualitative research interviewing.* Thousand Oaks, CA: Sage.

Langdon, S., Eagle, A., & Warner, J. (2007). Making sense of dementia in the social world: a qualitative study. *Social Science & Medicine, 64*, 989-1000.

Langdridge, D.(2007). *Phenomenological psychology: Theory, research and menthods.* London: Pearson.

Larson, E., Yaffe, K., & Langa, K. (2013). New insights into the dementia epidemic. *New England Journal of Medicine, 369*(24), 2275-2277. doi: 10.1056/NEJMp1311405

Lavretsky, H. (2014). *Resilience and aging: Research and practice.* Baltimore: John Hopkins University Press.

Levenson, R., & Miller, B. (2007). Loss of cells—loss of self: frontotemporal lobar degeneration and human emotion. *Current Directions in Psychological Science, 16*(6), 289-294. doi: 10.1111/j.1467-8721.2007.00523.x

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry.* Beverley Hills, CA: Sage.

Lishman, E., Cheston, R., & Smithson, J. (2016). The paradox of dementia: Changes in assimilation after receiving a diagnosis of dementia. *Dementia, 15*(2), 181-203. doi: 10.1177/1471301214520781

Lupton, D. (1993). Risk as moral danger: the social and political fuctions of risk discourse in public health. *International Journal of Health Services, 23*(3), 425-435. doi: 10.2190/16AY-E2GC-DFLD-51X2

Lupton, D. (1999). *Risk.* London: Routledge.

Lupton, D., & Tulloch, J. (2002). 'Risk is a part of your life': risk epistemologies among a group of Australians. *Sociology, 36*(2), 317-334. doi: 10.1177/0038038502036002005

Lyman, K. (1989). Day care for persons with dementia: the impact of the physical environment on staff stress and quality of care. *The Gerontologist 29*, 557-560. doi: 10.1093/geront/29.4.557

Lyman, K. (2000). Bringing the social back in: A critique of the biomedicalisation of dementia. In J. Gubrium & J. Holstein (Eds.), *Aging and everyday life* (pp. 340-356). Oxford, UK: Blackwell Publishers Inc.

Mace, N., & Rubins, P. (2011). *The 36 hour day: A family guide to caring for people who have dementia.* Baltimore: The John Hopkins University.

MacKinlay, E. (2001). *The spiritual dimension of ageing.* London: Jessica Kingsley Publishers.

MacRae, H. (2008). 'Making the best you can of it': Living with early stage Alzheimer's disease. *Sociology of Health & Illness, 30*(3), 396-412. doi: 10.1111/j.1467-9566.2007.01056.x

Malloy, D., & Hadjistavropoulos, T. (2004). The problem of pain management among persons with dementia, personhood, and the ontology of relationships. *Nursing Philosophy, 5*(2), 147-159. doi: 10.1111/j.1466-769X.2004.00174.x

Manthorpe, J. (2003). Risk and dementia: models for community mental health nursing practice. In J. Keady, C. Clarke & T. Adams (Eds.), *Community mental health nursing and dementia care: practice perspectives* (pp. 63-73). Buckingham: Open University Press/McGraw-Hill Education.

Manthorpe, J. (2004). Risk taking In A. Innes, C. Archibald & C. Murphy (Eds.), *Dementia and social inclusion : marginalised groups and marginalised areas of dementia research, care and practice* (pp. 137-150). London: Jessica Kingsley Publishers.

Manthorpe, J. (2007). Managing risk in social care in the United Kingdom. *Health, Risk & Society, 9*(3), 237-239. doi: 10.1080/13698570701526032

Manthorpe, J., Samsi, K., Campbell, S., Abley, C., Keady, J., Bond, J., et al. (2011). The transformation from cognitive impairment to dementia: older people's experiences. London: NIHR Service Delivery and Organisation programme.

Manthorpe, J., Walsh, M., Alaszewski, A., & Harrison, L. (1997). Issues of risk practice and welfare in learning disability services. *Disability & Society, 12*(1), 69-82. doi: 10.1080/09687599727470

Marshall, M., & Cox, S. (1998). Current and future trends in the development of dementia services. *Mental Health Review, 3*, 16-21. doi: http://dx.doi.org/10.1108/13619322199800004

Martinson, M., & Berridge, C. (2015). Successful aging and its discontents: a sytematic review of the social gerontology literature. *The Gerontologist 55*(1), 58-69. doi: 10.1093/geront/gnu037

Maslow, K. (2013, November 19). Person-centred care for people with dementia: Opportunities and challenges [Web log post]. Retrieved from http://www.asaging.org/blog/person-centered-care-people-dementia-opportunities-and-challenges

Mathews, E. (2006). Dementia and the identity of the person. In J. Hughes, S. Louw & S. Sabat (Eds.), *Dementia: mind, meaning and the person.* London: Oxford University Press.

McAslan, A. (2010). Community resilience. Understanding the concept and its application. Retrieved from https://sustainablecommunitiessa.files.wordpress.com/2011/06/community-resilience-from-torrens-institute.pdf

McGowin, D. (1993). *Living in the labryinth. A personal journey through the maze of Alzheimer's.* San Francisco: Elder Books.

McCormack, B. (2001). *Negotiating partnerships with older people: A person-centred approach.* Aldershot: Ashgate Press.

McCormack, B. (2002). The person of the voice: narrative identities in informed consent. *Nursing Philosophy 3*(2), 114-119. doi: 10.1046/j.1466-769X.2002.00091.x

McCormack, B., Karlsson, B., & Dewing, J. (2010). Exploring person-centredness: a qualitative meta-synthesis of four studies. *Scandinavian Journal of Caring Sciences, 24*(3), 620-634. doi: 10.1111/j.1471-6712.2010.00814.x

McCormack, B., Dewing, J., & McCance, T. (2011). Developing person-centred care: addressing contextual challenges through practice development. *Online Journal of Issues in Nursing, 16*(2), 1-1. Retrieved from http://www.nursingworld.org/ojin/

McGowin, D. (1993). *Living in the labyrinth: a personal journey through the maze of Alzheimer's.* San Francisco: Elder Books.

McMillen, J. (1999). Better for it: How people benefit from adversity. *Social Work, 44*(5), 455-468. doi: 10.1093/sw/44.5.455

Menne, H., Tucke, S., Whitlatch, C., & Feinberg, L. (2008). Decision-making involvement scale for individuals with dementia and family caregivers. *American Journal of Alzheimers Disease and Other Dementias, 23*, 23-29. doi: 10.1177/1533317507308312

Merleau-Ponty, M. (1964). *Phenomenology of perception (C.Smith,Trans.).* London: Routledge Kegan Paul.

Merriam, S. (2009). *Qualitative research: a guide to design and implementation.* San Francisco, CA: Wiley.

Mezuk, B., & Rebok, G. (2008). Social integration and social support among older adults following driving cessation. *Journal of Gerontology: Psychological and Social Sciences, 63*, 298-303. doi: 10.1093/geronb/63.5.S298

Miles, M., Chapman, Y., & Francis, K. (2015). Peeling the onion: understanding others' lived experience. *Contemporary Nurse 50*(2-3), 286-295. doi: 10.1080/10376178.2015.1067571

Milne, A. (2010). The 'D' word: Reflections on the relationship between stigma, discrimination and dementia. *Journal of Mental Health 19*(3), 227-233. doi: 10.3109/09638231003728166

Milte, R., Shulver, W., Killington, M., Bradley, C., Ratcliffe, J., & Crotty, M. (2016). Quality in residential care from the perspective of people living with dementia: The importance of personhood. *Archives of Gerontology and Geriatrics, 63*, 9-17. doi: 10.1016/j.archger.2015.11.007

Minichiello, V., Aroni, R., Timewell, E., & Alexander, L. (1995). *In-depth Interviewing. Principles, techniques, analysis.* Melbourne: Longman Australia Pty Ltd.

Minkler, M., & Holstein, M. (2008). From civil rights ... civic engagement? Concerns of two older critical gerontologists about a "new social movement" and what it portends. *Journal of Aging Studies, 22*, 196-204. doi: 10.1016/j.jaging.2007.12.003

Mitchell, W., & Glendinning, C. (2007). A review of the research evidence surrounding risk perception, risk management strategies and their consequences in adult social care for different groups of service users. Retrieved from https://www.york.ac.uk/inst/spru/pubs/pdf/risk.pdf

Mitchell, W., & Glendinning, C. (2008). Risk and adult social care: identification, management and new policies. What does UK research evidence tell us? *Health, Risk & Society, 10*(3), 297-315. doi: 10.1080/13698570802163677

Mittler, P. (2011). Journey into Alzheimerland. *Dementia, 10*(2), 145-147. doi: 10.1177/1471301211398408

Moniz-Cook, E., & Woods, R. (1997). The role of memory clinics and psychosocial intervention in the early stages of dementia. *International Journal of Geriatric Psychiatry, 12*, 1143-1145. doi: 10.1002/(SICI)10991166(199712)12:12<1143::AID-

Morgan, K. (2009). Risk of living with Alzheimer's disease: A personal view. *Journal of Adult Protection, 11*(3), 26-29. doi: 10.1108/14668203200900019

Morgan, S. (1996). *Helping relationships in mental health*. London: Chapman & Hall.

Morgan, S., & Williamson, T. (2014). How can 'positive risk-taking' help build dementia-friendly communities? Retrieved from https://www.jrf.org.uk/report/how-can-positive-risk-taking-help-build-dementia-friendly-communities

Morris, J. (2004). Independent living and community care: A disempowering framework. *Disability and Society, 19*(5), 427-442. doi: 10.1080/0968759042000235280

Morse, J., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research.

International Journal of Qualitative Methods, 1(2), 1-19. doi: 10.1177/160940690200100202

Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks, CA: Sage.

Munhall, P. (1988). Ethical considerations in qualitative research. *Western Journal of Nursing Research, 10*(2), 150-162. doi: http://wjn.sagepub.com/content/10/2/150.extract

Munhall, P. (1989). Philosophical ponderings on qualitative research methods in nursing. *Nursing Science Quarterly, 2*(1), 20-28. doi: 10.1177/089431848900200109

Munhall, P. (1993). Unknowing: toward another pattern of knowing. *Nursing Outlook, 41*, 125-128. doi: http://europepmc.org/abstract/med/8346052

Munhall, P. (2012). *Nursing research: a qualitative perspective.* Sudbury, MA: Jones & Bartlett.

Munhall, P. (2013). Interpretive phenomenology. In C. Beck (Ed.), *Routledge international handbook of qualitative nursing research* (pp. 405-448). Hoboken: Taylor & Francis.

Murray, S., Kendall, M., & Carduff, E. (2009). Use of serial qualitative interviews to understand patients'evolving experiences and needs. *British Medical Journal 339*, b3702. doi: 10.1136/bmj.b3702

Namazi, K., & Johnson, B. (1992). Pertinent autonomy for residents with dementias: Modification of the physical environment to enhance independence. *American Journal of Alzheimer's Disease & Other Dementias, 7*(1), 16-21. doi: 10.1177/153331759200700105

Napoletan, A. (2016, October 26). Dementia care: What in the world is a dementia village? [Web log post]. Retrieved from http://www.alzheimers.net/2013-08-07/dementia-village/

National Institute for Health and Clinical Excellence. (2007). Dementia: a NICE-SCIE guideline on supporting people with dementia and their carers in health and social care. Retrieved from http://beta.bps.org.uk/

National Institute for Health and Clinical Excellence, & Social Care Institute for Excellence. (2007). Guideline on supporting people with dementia and their carers in health and social care *National Clinical Practice Guideline* (Vol. No.42). Leicester: The British Psychological Society and Gaskill.

Nay, R. (2002). The dignity of risk. *Australian Nursing Journal, 9*(9), 33. doi: http://anmf.org.au/

Netten, A. (1993). *A positive environment? Physical and social influences on people with senile dementia in residential care.* Aldershot, UK: Ashgate.

Nolan, M., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond 'person-centred' care: a new vision for gerontological nursing. *Journal of Clinical Nursing, 13*(3a), 45-53. doi: 10.1111/j.1365-2702.2004.00926.x

Norgaard, B. (2012). Science vs. phenomenology. *Seeking a more enightened world view.* Retrieved from http://enlightenedworldview.com/main-concepts/phenomenology

Norman, A. (1980). *Rights and risk.* London: Centre for Policy on Ageing.

Norman, A. (Ed.). (1988). *Risk.* Chichester: Wiley.

Nuffield Council on Bioethics. (2009). Dementia: Ethical issues Retrieved from http://nuffieldbioethics.org/wp-content/uploads/2014/07/Dementia-report-Oct-09.pdf

Nyström , M., & Dahlberg, K. (2001). Pre-understanding and openness-a relationship without hope? *Scandinavian Journal of Caring Sciences, 15*(11), 339-346. doi: 10.1046/j.1471-6712.2001.00043.x

O'Connor, D., & Nedlund, A.-C. (2016). Editorial introduction: Special issue on citizenship and dementia. *Dementia, 15*(3), 285. doi: 10.1177/1471301216647150

O'Connor, D., Phinney, A., Smith, A., Small, J., Purves, B., Perry, J., et al. (2007). Personhood in dementia care: developing a research agenda for broadening the vision. *Dementia, 6*(1), 121-142. doi: 10.1177/1471301207075648

O'Connor, D., & Purves, B. (2009). Decision-making, personhood and dementia. In D. O'Connor & B. Purves (Eds.), *Decision-making, personhood and dementia* (pp. 11-21). London: Jessica Kingsley.

O'Shea, E. (2007). Implementing policy for dementia care in Ireland. The time for action is now. Retrieved from https://www.alzheimer.ie/Alzheimer/media/SiteMedia/PDF's/Research/Implementing-Dementia-Care-Feb-07.pdf?ext=.pdf

Olsson, A., Engström, M., Skovdahl, K., & Lampic, C. (2012). My, your and our needs for safety and security: relatives' reflections on using information and communication technology in dementia care. *The Scandinavian Journal of Caring Sciences, 26*, 104-112. doi: 10.1111/j.1471-6712.2011.00916.x

Örulv, L. (2010). Placing the place, and placing oneself within it. *Dementia, 9*(1), 21-44. doi: 10.1177/1471301210364449

Osborn, M., & Rodham, K. (2010). Insights into pain: a review of qualitative research. *Reviews in Pain, 4*(1), 2-7. doi: 10.1177/204946371000400102

Österholm, J., & Hydén, L.-C. (2016). Citizenship as practice: Handling communication problems in encounters between persons with dementia and social workers. *Dementia, 15*(6), 1457-1473. doi: 10.1177/1471301214563959

Österholm, J., & Samuelsson, C. (2015). Orally positioning persons with dementia in assessment meetings. *Ageing & Society, 35*(2), 367-388. doi: 10.1017/S0144686X13000755

Overton, R. (1993). Caring for the elderly: a crisis on the horizon. *Iowa Medical 83*(1), 9-10. doi: https://www.ncbi.nlm.nih.gov/pubmed/8420851

Owen, N., Healy, G., Mathews, C., & Dunstan, D. (2012). Too much sitting: the population health science of sedentary behaviour. *Exercise Sport Science Review, 38*(3), 105-113. doi: 10.1097/JES.0b013e3181e373a2

Packer, M., & Addison, R. (1989). *Entering the circle: hermeneutic investigation in psychology*. Albany, NY: SUNY Press.

Page, S., Davies-Abbott, I., & Phillips, M. (2016). Same map, different direction – Exploring new opportunities that dementia care mapping™ can offer to acute mental health admission wards for older people – Innovative practice. Advance online publication. *Dementia*. doi: 10.1177/1471301216675677

Paley, J. (1998). Phenomenology as rhetoric. *Nursing Inquiry, 12*(2), 106-116. doi: 10.1111/j.1440-1800.2005.00263.x

Palmer, R. (1969). *Hermeneutics: Interpretation theory in Schleiermacher, Dilthey, Heidegger, and Gadamer*. Evanston, IL: Northwestern University Press.

Parker, J. (2001). Interrogating person-centred dementia care in social work and social care. *Journal of Social Work, 1*(3), 329-345. doi: 10.1177/146801730100100306

Parse, R. (1992). Human becoming: Parse's theory of nursing. *Nursing Science Quarterly, 5*(1), 35-42. doi: 10.1177/089431849200500109

Parsons, C. (2009, May 2). Dignity of risk: The right to self-governance for people with mental illness [Web log post]. Retrieved from www.openforum.com.au/content/dignity-risk-right-self-governance-people-mental-illness

Pearce, A., Clare, L., & Pistrang, N. (2002). Managing sense of self. *Dementia, 1*(2), 173-192. doi: 10.1177/147130120200100205

Pejlert, A. (2001). Being a parent of an adult son or daughter with severe mental illness receiving professional care: parents' narratives. *Health and Social Care, 9*(4), 194-204. doi: 10.1046/j.0966-0410.2001.00301.x

Penrod, J., Yu, F., Kolanowski, A., Fick, D., Loeb, S., & Hupcey, J. (2007). Reframing person-centred nursing care for persons with dementia. *Res Theory Nurs Pract., 21*(1), 57-72. doi: 10.1891/rtnpij-v21i1a007

Pérès, K. (2011). The epidemiological approach to disability: the specific burden of dementia. *Health & Ageing Newsletter*. Retrieved from https://api.turnitin.com/dv?s=1&o=445518733&u=1030370276&lang=en_us&session-id=1b60ec3bdbfb13717941ec35c8e40fca

Perkins, M., Ball, M., & Whittington, F. (2012). Relational autonomy in assisted living: A focus on diverse care settings for older adults. *Journal of Aging and Health, 26*(2), 214-225. doi:dx.doi.org/10.1016/j.jaging.2012.01.001

Perrow, C. (1984). *Normal accidents: living with high risk technologies*. New York: Basic Books.

Perske, R. (1972). The dignity of risk. In W. Wolfensberger (Ed.), *Normalization: the principle of normalization in human services* (pp. 194-200). Toronto: Leonard Crainford.

Pesonen, H., Remes, A., & Isola, A. (2011). Ethical aspects of researching subjective experiences in early stage dementia. *Nursing Ethics, 18*(5), 651-661. doi: 10.1177/0969733011408046

Pezalla, A., Pettigrew, J., & Miller-Day, M. (2012). Researching the researcher-as-instrument in interviewer self reflexivity. *Qualitative Research, 12*(2), 165-185. doi: 10.1177/1468794111422107

Phinney, A., & Chesla, C. (2003). The lived body in dementia. *Journal of Aging Studies, 17*, 283-299. doi: 10.1016/S0890-4065(03)00029-X

Pierret, J. (2003). The illness experience: state of knowledge and perspectives for research. *Sociology of Health & Illness, 25*, 4-21. doi: 10.1111/1467-9566.t01-1-00337

Pipon-Young, F., Lee, K., Jones, F., & Guss, R. (2012). I'm not all gone, I can still speak: The experiences of younger people with dementia. An action research study. *Dementia, 11*(5), 597-616. doi: 10.1177/1471301211421087

Polkinghorne, D. (1988). *Narrative knowing and the human sciences*. Albany, NY: SUNY Press.

Post, S. (1995). *The moral challenge of Alzheimer disease*. Baltimore, MD: John Hopkins University Press.

Post, S. (1998). The fear of forgetfulness: A grassroots approach to an ethics of Alzheimer's disease. *The Journal of Clinical Ethics, 9*(1), 71-80. doi: http://philpapers.org/rec/POSTFO-3

Powell, J., & Hendricks, J. (2009). The sociological construction of ageing: lessons for theorising. *International Journal of Sociology and Social Policy, 29*(1/2), 84-94. doi: 10.1108/01443330910934745

Prasad, A. (2002). The contest over meaning: hermenutics as an interpretive methodology for understanding texts. *Organisational Research Methods, 5*(1), 12-33. doi: 10.1177/1094428102051003

Prideaux, J. (2015). Age of unreason. Older people. Second childhood. *The Economist, 416*(8946), 10-11.

Primeau, L. (2003). Reflections on self in qualitative research: Stories of family. *American Journal of Occupational Therapy*(57), 9-16. doi: 10.5014/ajot.57.1.9

Pringle, J., Hendry, C., & McLafferty, E. (2011). Phenomenological approaches: Challenges and choices. *Nurse Researcher, 18*(2), 7-18. doi: 10.7748/nr2011.01.18.2.7.c8280

Prior, D., Stewart, J., & Walsh, K. (1995). *Citizenship: rights and community participation*. London: Pitman.

Purves, B. (2010). Exploring positioning in Alzheimer disease through analyses of family talk. *Dementia, 10*(1), 35-58. doi: 10.1177/1471301210392979

Racher, F., & Robinson, S. (2003). Are phenomenology and postpositivism strange bedfellows? *Western Journal of Nursing Research, 25*(5), 464-481. doi: 10.1177/0193945903253909

Ratzan, S. (Ed.). (1993). *AIDS: effective health communication for the 90s*. Abingdon, Oxon: Taylor and Francis Group.

Reeder, H. (1986). *The theory and practice of Husserl's phenomenology*. Lanham, MD: University Press of America.

Rilke, R. (1987). *The notebooks of Malte Laurids Brigge*. Oxford: Oxford University Press.

Roberts, K., & Taylor, B. (2002). *Nursing research processes. An Australian perspective* (2nd. ed.). Southbank, Vic: Thomson Learning

Robertson, A. (1991). The politics of Alzheimer's disease: A case study in apocalyptic demography. In M. Minkler & C. Estes (Eds.), *Critical perspectives on aging* (pp. 135-150). Amityville, New York: Baywood Publishing.

Robinson, L., Hutchings, D., Corner, L., Finch, T., Hughes, J., Brittain, K., et al. (2007). Balancing rights and risks: conflicting perspectives in the management of wandering in dementia. *Health, Risk & Society, 9*(4), 389-406. doi: 10.1080/13698570701612774

Robinson, P., Ekman, S.-L., Meleis, A., Winbald, B., & Wahlund, L.-O. (1997). Suffering in silence: the experience of early memory loss. *Health Care in Later Life, 2*, 107-120.

Rodeheaver, D., & Datan, N. (1988). The challenge of double jeopardy: toward a mental health agenda for aging women. *America Psychologist, 43*(8), 648-654. doi: 10.1037/0003-066X.43.8.648

Rogers, C. (1961). *On becoming a person*. Boston: Houghton Mifflin Co.

Rose, K., & Lopez, R. (2012). Transitions in dementia care: Theoretical support of nursing roles. *The Online Journal of Issues in Nursing, 17*(2), Manuscript 4. doi: 10.3912/OJIN.Vol17No02Man04

Rothschild, D. (1937). Pathologic changes in senile psychoses and their psychological significance. *American Journal of Psychiatry, 93*, 757-784. doi: 0.1176/ajp.93.4.757

Ryff, C., & Singer, B. (2008). Know thyself and become what you are: A eudaimonic approach to psychological well-being. *Journal of Happiness Studies, 9*, 13-39. doi: 10.1007/s10902-006-9019-0

Sabat, S. (1991). Facilitating conversation via indirect repair: A case study of Alzheimer's disease. *Georgetown Journal of Languages and Linguistics, 2*, 284-296.

Sabat, S. (2002). Surviving manifestations of selfhood in Alzheimer's disease - a case study. *Dementia, 1*, 25-36. doi: 10.1177/147130120200100101

Sabat, S. (2010). Prepositioning, malignant positioning, and the disempowering loss of privileges endured by people with Alzheimer's disease. In F. Moghaddam & R. Harré (Eds.), *Words of conflict, words of war: how the language we use in political processes sparks fighting* (pp. 89-104). Oxford: Praeger.

Sabat, S., & Harre, R. (1994). The Alzheimer's Disease sufferer as a semiotic subject. *Philosophy, Psychiatry, and Psychology, 1*, 145-160. doi: https://muse.jhu.edu/article/245016

Sabat, S., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society, 12*, 443-461. doi: 10.1017/S0144686X00005262

Sabat, S., Johnson, A., Swarbrick, C., & Keady, J. (2011). The 'demented other' or simply 'a person'? Extending the philosophical discourse of Naue and Kroll through the situated self. *Nursing Philosophy, 12*(4), 282-292. doi: 10.1111/j.1466-769X.2011.00485.x

Saldaňa, J. (2003). *Longitudinal qualitative research: analyzing change through time.* AltaMira Press, USA.

Sanders, C., Donovan, J., & Pieppe, P. (2002). The significance and consequences of having painful and disabled joints in older age: Co-existing accounts of normal and disrupted biographies. *Sociology of Health & Illness 24*, 227-253. doi: 10.1111/1467-9566.00292

Scheidt, R. (2013). The end of the road. *The Gerontologist, 53*(4), 699-700. doi: http://gerontologist.oxfordjournals.org/content/53/4/699.short

Schoon, I., & Brynner, J. (2003). Risk and resilience in the life course : implications for interventions and social policies. *Journal of Youth Studies, 6*(1), 21-31. doi: 10.1080/1367626032000068145

Schrijvers, E., Verhaaren, B., Koudstaal, P., Hofman, A., Ikram, M., & Breteler, M. (2012). Is dementia incidence declining? Trends in dementia incidence since 1990 in the Rotterdam Study. *Neurology, 78*, 1456-1463. doi: http://dx.doi.org/ 10.1212/WNL.0b013e3182553be6

Schumacher, K., Jones, P., & Meleis, A. (1999). Helping elderly persons in transition: A framework for research and practice. In E. Swanson & T. Tripp-Reimer (Eds.), *Life transitions in the older adult* (pp. 1-26). New York: Springer Publishing Company.

Schwandt, T. (2000). Three epistemological stances for qualitative inquiry: interpretivism, hemeneutics, and social construction. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 189-213). Thousand Oaks, CA: Sage.

Selder, F. (1989). Life transition theory: The resolution of uncertainty. *Nursing and Health Care, 10*(8), 437-451. https://www.ncbi.nlm.nih.gov/pubmed/2797502

Sellevold, G., Egede-Nissen, V., Jakkobsen, R., & Sørlie, V. (2013). Quality care for persons experiencing dementia: The significance of relational ethics. *Nursing Ethics, 20*(3), 263-272. doi: 10.1177/0969733012462050

Sharara, N. (2007). Understanding risk: the potential for both harm and benefit. *Rehabilitation Review, 17*(6), 1-2. doi:

Sharkey, P. (2001). *Phenomenology*. Melbourne: RMIT University Press.

Sherratt, C., Soteriou, T., & Evans, S. (2007). Ethical issues in research involving people with dementia. *Dementia, 6*(4), 463-479. doi: 10.1177/1471301207084365

Silverman, D., & Marvasti, M. (2008). *Doing qualitative research* (2nd. ed.). Los Angeles: Sage.

Slovic, P., Fischhoff, B., & Lichtenstein, S. (2000). Facts and fears: Understanding perceived risk. In P. Slovic (Ed.), *The perception of risk* (pp. 137-153). Sterling,VA: Earthscan.

Smith, L. (2008). How ethical is ethical research? Recruiting marginalised, vulnerable groups into health services research. *Journal of Advanced Nursing, 62*(2), 248-257. doi: 10.1111/j.1365-2648.2007.04567.x

Smith, S. (1997). The phenomenology of educating physically. In D. Vandenberg (Ed.), *Phenomenology and educational discourse* (pp.119-144). Durban: Heinemann.

Sneddon, A. (2013). *Autonomy*. London: Bloomsbury Publishing.

Snelgrove, S., & Liossi, C. (2013). Living with chronic low back pain: a metasynthesis of qualitative research. *Chronic Illness, 9*(4), 283-301. doi: 10.1177/1742395313476901

Snowdon, D. (2001). *Aging with grace. What the Nun Study teaches us about leading longer, healthier, and more meaningful lives*. New York: Bantam Books.

Southwick, S., Bonanno, G., Masten, A., Panter-Brick, C., & Yehuda, R. (2014). Resilience definitions, theory, and challenges: Interdisciplinary perspectives *European Journal of Psychotraumatology, 5*(10), 1-14. doi: http://dx.doi.org/10.3402/ejpt.v5.25338

Spiegelberg, H. (1960). Husserl's phenomenology and existentialism. *Journal of Philosophy, 57*(2), 62-74. doi: 10.2307/2022808

Sroufe, L., & Rutter, M. (1984). The domain of developmental psychopathology. *Child Development, 55*(1), 17-29. doi: 10.2307/1129832

Starfield, B. (2011). Is patient-centred care the same as person-focused care? *Permanente Journal, 15*(2), 63-69. Retrieved from http://www.thepermanentejournal.org/

Stead, C. (1986). *Ocean of Story. Collected Short Stories of Christina Stead*. Melbourne, Australia: Penguin Books.

Steeman, E., Casterle, B., Godderis, J., & Grypdonck, M. (2006). Living with early-stage dementia: a review of qualitative studies. *Journal of Advanced Nursing, 54*(6), 722-738. doi: 0.1111/j.1365-2648.2006.03874.x

Steiner, G. (1978). *Heidegger*. Sussex, UK: The Harvester Press Ltd.

Sterin, G. (2001). Essay on a word. A lived experience of Alzheimer's disease. *Dementia 1*(1), 7-10. doi: 10.1177/147130120200100103

Stewart, D., & Mickunas, A. (1974). *Exploring phenomenology: A guide to the field and its literature* (2nd. ed'n. ed.). USA: Ohio University Press.

Streubert, H., & Carpenter, D. (1999). *Qualitative research in nursing. Advancing the humanistic imperative* (2nd ed.). Philadelphia, PA: Lippincott, Williams & Wilkins.

Swain, J., French, S., & Cameron, C. (2003). *Controversial issues in a disabling society*. Buckingham: Open University Press.

Tate, J. (1998). The hermeneutic circle vs. the Enlightenment. *Telos, 110*, 9. doi: 10.3817/1298110009

Testad, I., & Aarsland, D. (2010). Reducing restraint - the benefits of education and training. In R. Hughes (Ed.), *Rights, risk and restraint free care of older people* (pp. 193-206). London: Jessica Kingsley Publishers.

Teuber, A. (1990). Justifying risk. *Daedalus 119*(4), 235-254. doi: http://www.jstor.org/publisher/mitpress

Thompson, J. (1990). Hermeneutic inquiry. In E. Moody (Ed.), *Advancing nursing science through research* (pp. 223-280). London: Sage.

Thomson, R., & Holland, J. (2003). Hindsight, foresight and insight: The challenges of longitudinal research *International Journal of Social Research Methodology, 6*(3), 233-244. doi: 10.1080/1364557032000091833

Thornton, J. (2002). Myths of ageing or ageist stereotypes. *Educational Gerontology, 28*, 301-312. doi: 10.1080/036012702753590415

Titterton, M. (2005). *Risk and risk taking in health and social welfare*. London: Jessica Kingsley Publishers.

Titterton, M. (2011). Positive risk taking with people at harm. In H. Kemshall & B. Wilkinson (Eds.), *Good practices in assessing risk: current knowledge, issues and approaches* (pp. 30-47). London: Jessica Kingsley Publishers.

Tronto, J. (1993). *Moral boundaries: a political argument for an ethic of care*. New York: Routledge.

Tulloch, J., & Lupton, D. (2003). *Risk and everyday life*. London: Sage Productions.

Ulrich, C., Wallen, G., & Grady, C. (2002). Research vulnerability and patient advocacy: balance-seeking perspectives for the clinical nurse scientist? *Nursing Research, 51*(2), 71. doi: 10.1097/00006199-200203000-00001

Utrecht Summer School. (2013). Phenomenology of practice and the tradition of the Utrecht School. *Summer Schools in Europe*. Retrieved from https://www.utrechtsummerschool.nl/courses/previous/2013

van den Berg, J. (1972). *A different existence*. Pittsburgh, PA: Duquesne Uni. Press.

Van Gorp, B., & Vercuysse, T. (2012). Frames and counter-frames giving meaning to dementia. *Social Science & Medicine, 74*, 1274-1281. doi: 10.1016/j.socscimed.2011.12.045

Van Maanen, J. (1979). Reclaiming qualitative methods of organisational research: A preface. *Administrative Science Quarterly, 24*(4), 520-526. Retrieved from http://online.sagepub.com/

van Manen, M. (1984). Practicing phenomenological writing. *Phenomenology and Pedagogy, 2*(1), 36- 69. Retrieved from https://ejournals.library.ualberta.ca/index.php/pandp/index

van Manen, M. (1990). *Researching lived experience: human science for an action sensitive pedagogy.* Albany, NY: State University of New York.

van Manen, M. (1997). From meaning to method. *Qualitative Health Research, 7*(3), 345-369. doi: 10.1177/104973239700700303

van Manen, M. (2007). Phenomenology of practice. *Phenomenology & Practice, 1*(1), 11-30. Retrieved from https://ejournals.library.ualberta.ca/

van Manen, M. (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing.* Walnut Creek, CA: Left Coast Press.

van Manen, M. (2016). A conversation with Max van Manen on phenomenology in its original sense. *Nursing & Health Sciences, 18*(1), 4-7. doi: 10.1111/nhs.12274

van Manen, M., & Adams, C. (2010). Qualitative research: phenomenology. In E. Baker, P. Peterson & B. McGaw (Eds.), *International Encyclopedia of Education* (Vol. 6, pp. 449-455). Oxford: Elsevier.

van Manen, M., & van Manen, M. (2014). Phenomenology. In D. Phillips (Ed.), *Encylopedia of educational theory & philosophy* (pp. 610-616). Thousand Oaks, CA: Sage Publications.

Van Regenmortel, T. (2002). *Empowerment and tailored care: a strength based psychological approach to poverty.* Leuven: Acco.

Verbeek, H., van Rossum, E., Zwakhalen, S., Kempen, G., & Hamers, J. (2009). Small, homelike environments for older people with dementia: a literature review. *International Psychogeriatrics, 21*(2), 252-264. doi: 10.1017/S104161020800820X

Vernooij-Dassen, M., Derksen, E., Scheltens, P., & Moniz-Cook, E. (2006). Receiving a diagnosis of dementia. The experience over time. *Dementia, 5*(3), 397-410. doi: 10.1177/1471301206067114

Victorian Guardian and Administration Act 1986, 58/1986 Stat. (1986).

Vincent, J. (2008). The cultural construction of old age as a biological phenomenon: Science and anti-ageing technologies. *Journal of Aging Studies, 22*(4), 331-339. doi: 10.1016/j.jaging.2008.05.006

Vittoria, A. (1998). Preserving selves: Identity work and dementia. *Research on Aging, 20*(1), 91-136. doi: 10.1177/0164027598201006

Walker, H., & Paliadelis, P. (2016). Older peoples' experiences of living in a residential aged care facility in Australia. *Australasian Journal on Ageing, 35*(3), E6-E10. doi: 10.1111/ajag.12325

Walker, W. (2011). Hermeneutic inquiry: Insights into the process of interviewing. *Nurse Researcher, 18*(2), 19-27. doi: http://www.nursing-standard.co.uk/

Wall, C., Glenn, S., Mitchinson, S., & Poole, H. (2004). Using a reflexive diary to develop bracketing skills during a phenomenological investigation. *Nurse Researcher, 11*, 22-29. doi: http://www.nursing-standard.co.uk/

Wang, C., & Carr, D. (2004). Older driver safety: A report from the Older Drivers Project. *Journal of the American Geriatrics Society, 52*, 143-149. doi: 10.1111/j.1532-5415.2004.52025.x

Ward-Griffin, C. (2001). Negotiating care of frail elders: relationships between community nurses and family carers. *Canadian Journal of Nursing Research 33*, 63-81. Retrieved from http://online.sagepub.com/

Watzlawick, P. (Ed.)(1984).*The invented reality: How do we know what we believe we know?* London: W.W.Norton & Company.

Welsh, S., Hassiotis, A., O'Mahoney, G., & Deahl, M. (2003). Big brother is watching you—the ethical implications of electronic surveillance measures in the elderly with dementia and in adults with learning difficulties. *Aging & Mental Health, 7*(5), 372-375. doi: 10.1080/1360786031000150658

Wharton, F. (1992). Risk management: basic concepts and general principles. In J. Ansell & F. Wharton (Eds.), *Risk analysis, assessment and management*. Chicester: John Wiley.

Whitehouse, P. (2007). The next 100 years of Alzheimer's—learning to care, not cure. *Dementia, 6*(4), 459-462. doi: 10.1177/1471301207084364

Whitlatch, C., Pilparinen, R., & Feinberg, L. (2009). How well do family caregivers know their relatives' care values and preferences? *Dementia, 8*(2), 223-243. doi: 10.1177/1471301209103259

Whitman, W. (1867). *Leaves of Grass*. New York: W. Chapin.

Wiles, J., Wild, K., Kerse, N., & Allen, R. (2012). Resilience from the point of view of older people: 'There's still life beyond a funny knee'. *Social Science & Medicine, 74*, 416-424. doi: 10.1016/j.socscimed.2011.11.005

Wilkinson, H. (2002). *Including people with dementia in research: methods and motivations.* London: Jessica Kingsley Publishers.

Wilson, A. (1987). A Husserlian phenomenological investigation of the lived experience of an art educator and children. *Iowa Research Online, 6*(1), 3-7. doi: http://ir.uiowa.edu/

Wilson, H., & Hutchison, S. (1991). Triangulation of qualitative methods: Heideggerian hermeneutics and grounded theory. *Qualitative Health Research,1*(2),263-276. doi/ 10.1177/104973239100100206

Wilson, S., Carryer, J., & Brannelly, T. (2016). New risks: the intended and unintended effects of mental health reform. *Nursing Inquiry, 23*(3), 200-210. doi: 10.1111/nin.12130

Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology, 21*(2), 152-169. doi: 10.1017/S0959259810000420

Wolin, R. (2004). *The seduction of unreason.* Princeton: Princeton University Press.

Woods, R. (2001). Discovering the person with Alzheimer's disease: cognitive, emotional and behavioural aspects. *Aging & Mental Health, 5,* S7-S16. doi: 10.1080/713650008

World Health Organisation. (2016a). Dementia. Retrieved from http://www.who.int/mediacentre/factsheets/fs362/en/

World Health Organisation. (2016b). WHO QualityRights Project – addressing a hidden emergency. Retrieved from http://www.who.int/mental_health/policy/quality_rights/en/

World Health Organisation, & Alzheimer's Disease International. (2012). Dementia: a public health policy. Retrieved from https://extranet.who.int/agefriendlyworld/wp-content/uploads/2014/06/WHO-Dementia-English.pdf

Wu, Y., Fratiglioni, L., Mathews, F., Lobo, A., Breteler, M., Skoog, I., et al. (2016). Dementia in Western Europe: epidemiological implications for policy making. *The Lancet Neurology, 15*(1). doi: 10.1016/S1474-4422(15)00092-7

Wynne-Harley, D. (1991). *Living dangerously: Risk taking, safety and older people.* London: Centre for Policy on Ageing.

Wynne, B. (1992). Risk and social learning: reification to engagement. In S. Krimsky & D. Golding (Eds.), *Social theories of risk* (pp. 275-297). Westport, CT: Praeger Publishers.

Zeigler-Graham, K., Brookmeyer, R., Johnson, E., & Arrighi, H. (2008). Worldwide variation in the doubling time of Alzheimer's disease incidence rates. *Alzheimer's Dementia, 4*(5), 316-323. doi: 10.1016/j.jalz.2008.05.2479

Zeilig, H. (2014). Dementia as a cultural metaphor. *The Gerontologist 54*(2), 258-267. doi: 10.1093/geront/gns203

APPENDIX A
INITIAL LETTER TO CDAMS CLINICS

VICTORIA UNIVERSITY
MELBOURNE AUSTRALIA

Faculty of Arts Education & Human Development
City Flinders Campus
PO Box 14428
Melbourne Vic 8001
(Tel) +61 3 9919 1152
(Fax) +61 3 9919 1096

Attention: Director
CDAMS Clinic
.... Health
Melbourne

DATE
Dear Sir,

I am writing for your assistance and support for a proposed research project titled: 'The lived experience of risk for a person with a recent diagnosis of dementia (Alzheimer's type): a longitudinal phenomenological study'. This study will explore risk for people with Alzheimer's disease, where risk is the 'lens' with which to view autonomy. Autonomy is used in this study to understand more about choice and decision-making whenever possible for persons living with dementia. I am seeking to enlist 10 people who have a recent clinical diagnosis of Alzheimer's disease (3-6 months),who have full knowledge of their diagnosis and its implications, who have a proficiency of the English language, who live alone at home, who have an MMSE score between 17 and 25 and who are able and willing to tell a story about risk in their life. It is proposed that I will conduct a series of four open-ended interviews with the participants at approximately 6 monthly intervals- to be completed in 2 years.
Your role in this study would be to:
1. Select clients who fulfil the 6 inclusion criteria above and determine their ability and willingness to take part in this study
2. Provide prospective clients with an Information Sheet about the study prepared by Victoria University
3. Invite those interested clients to complete a Contact information Form, which allows the researcher to make contact by telephone within a week to provide further information and seek formal consent.

This research will be undertaken at Victoria University and Dr. Jocelyn Angus is the Principal Investigator. Dr. Lindsay Morgan is the Associate Investigator. Both supervisors are situated in the Faculty of Arts, Education and Human Development in the City Campus, Flinders Lane, Melbourne.

At this stage, we are asking you to respond with a written **expression of interest** in support of this study, which will be subject to ethics approval at Victoria University. Please find attached a self addressed envelope for your convenience.

If you require further information, I may be contacted on 0401915405 or sally.osborne@live.vu.edu.au.
 I look forward very much to hearing from you,

Yours faithfully,

Sally Osborne	Jocelyn Angus PhD
PhD Candidate	Principal Investigator
Victoria University	Faculty of Arts Education & Human Development Victoria University
	(p) +61 3 99191152 (m) 0411205519

APPENDIX B
BUNDOORA CDAMS LETTER - 17 JANUARY 2012

APPENDIX 2

BUNDOORA
EXTENDED CARE CENTRE

1231 PLENTY ROAD
BUNDOORA, VICTORIA, 3083
Telephone: 9495 3100 Facsimile: 9495 3290

17/01/2012

Sally Osborne
PhD Candidate
Victoria University

Dear Sally,

Further to your request for assistance and support for your proposed research titled; ' The lived experience of risk of a person with early stage dementia; a longitudinal phenomenological study',
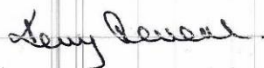
This is to inform you that BECC Cognitive Dementia and Memory Service is expressing an interest in participating in this study.

I have discussed your request with my manager Sue Hull (who is currently on leave) and the Consultants at our clinic and they are supportive of your study. They have requested that;
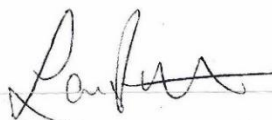
- the project will need to be submitted to The Northern Health Ethics Committee for consideration and approval.

- due to their clinic time limitations they will be unable to recruit clients on your behalf,

- the consultants would encourage you to attend on clinic days (Tues pm and Wed am) to recruit clients for your study.

Please do not hesitate to contact me if you have any queries or wish to discuss this matter further.

Yours sincerely

Kerry Devenish
Clinical Nurse Consultant.
Cognitive, Dementia and Memory Service
Bundoora Extended Care Centre

Laura Penberthy
CTS Clinical Coordinator
Community Therapy Services
Northern Health

cc; Jocelyn Angus PhD, Principal Supervisor, Faculty of Arts and Education & Human Development
Victoria University

MT ELIZA CDAMS LETTER - JANUARY 2012

APPENDIX 2

Dr. Jocelyn Angus
Sally Osborne
Aged Services Management Unit
Victoria University- City Flinders Campus
PO BOX 14428
MELBOURNE VIC 8001

CDAMS

**COGNITIVE
DEMENTIA AND
MEMORY SERVICE**

PO Box 192
Jacksons Road
Mt Eliza
Victoria 3930

Tel: 03 9788 1485
Fax: 03 9788 1486

Dear Sally,

Re your request for an expression of interest for a proposed research project 'The lived experience of risk for a person with early dementia', following discussion with my manager we can provide 'an expression of interest' but with some reservations.

If we are providing personal and clinical information, it is likely we would need to submit the study to Peninsula Health ethics committee for approval.

I understand you will be seeking ethics approval from the university but the health network will also need to give approval.

Kind Regards

Lynn Gray
Manager

APPENDIX C

INFORMATION TO THE ORGANISATION INVOLVED IN RESEARCH

INFORMATION TO THE ORGANISATION INVOLVED IN RESEARCH

VICTORIA UNIVERSITY | **A NEW SCHOOL OF THOUGHT**

You are invited to participate

You are invited to participate in a research project entitled "The lived experience of risk for a person with a recent diagnosis of dementia (Alzheimer's type): a longitudinal phenomenological study".

This project is being conducted by a student researcher Sally Osborne as part of a PhD study at Victoria University under the supervision of Dr Jocelyn Angus and Dr Lindsay Morgan in the School of Arts.

Project explanation

This is a study of the perceptions of risk of people with a recent diagnosis of dementia (Alzheimer's type). Risk is a concept used in dementia research when examining choice and decision-making. It begins with the premise that risk is a part of life for everyone, and the dignity of risk, or the right to failure remains central to growth and the development of resilience. This research may contribute to new knowledge about the lived meanings of risk of persons with a recent diagnosis of dementia (Alzheimer's type).

What will I be asked to do?

We are seeking ten (10) people with a recent clinical diagnosis of dementia (Alzheimer's type) to be potential participants in four (4) interviews over approximately two (2) years. The interviews will relate to the person with dementia's lived experiences of risk. The informal interviews will be conducted at approximately 6 monthly intervals, and may be terminated at any time at the request of the participant. Other inclusion criteria for participation include having a full disclosure of the diagnosis and its implications, living alone at home, being proficient in the English language, having an MMSE score of between 17 and 25 and being able to tell a story about risk.

We are asking your staff to make initial assessments for potential selection in this research, and to brief suitable clients about the project in a general sense. If they are interested, we are asking the staff member to give them an *Information To Participants Involved In Research* form. Clients who wish to pursue the study further will be asked to fill in a *Contact Information For Potential Participation in Research* form. At the request and direction of the CDAMS staff, the student researcher may be required to provide information to potential participants. This form provides the researcher with minimal contact details for the purpose of following up within a week and arranging a meeting. This completes the selection phase of the study.

What will I gain from participating?

It is anticipated that your participation in this study has the potential to inform policy makers and to improve care practices and priorities for people with dementia.

How will the information I give be used?

Information collected from the organisation will be used by the student researcher to supplement and increase knowledge about the participants in this research.

What are the potential risks of participating in this project?

For the person with dementia, a potential risk in this study is that they may experience negative emotions. In the event of an 'upset' or an incident, the research will cease immediately, and with the consent of the participant the student researcher will contact the Dementia Behaviour Management Advisory Services (DBAMS) or a GP on their behalf for counselling and support.

In the event of upset from participating in the study, the student researcher in consultation with the participant will contact Ms Anne Graham , clinical psychologist. Anne is registered with the Psychologists Registration Board of Victoria, and is available to assist the participant with counselling. Her address is Victoria University , PO Box 14428, Melbourne, VIC, 8001 and she may be contacted on 99192159 .

How will this project be conducted?

The project will be conducted by informal interviews between the researcher and the participant only. There will be four (4) interviews over approximately two (2) years, and they will be conducted in a place of choice and at a time of the participant's choosing.

This research consists of 2 distinct phases:
Phase 1

Your organisation will be asked to assess and invite clients to the study, provide some basic information and then provide each interested client with an *InformationTo Participants Involved In Research* form (Appendix 4.5). At the request of the CDAMS clinic, the student researcher may assume these duties. If the client is interested in participation, he/she will be given a *Contact Information For Potential Participation In Research* form (Appendix 4.6). When filled out, this form will provide minimal personal contact details, and the student researcher will follow up within a week to seek confirmation of the client's intention to participate in the research. A meeting will be arranged, and at that meeting further study details may be shared, any questions answered and the *Consent for Participant Involved in Research* form (Appendix 4.7) requires the signature of the potential participant. Then a 'person responsible' may be nominated in the event of change or an emergency. This information will be contained in the *Participant Consent to Share Information* form (Appendix 4.8) and should be signed by the potential participant and co-signed by the student researcher. This is a choice of the participant, not a condition of participation in the study. The research can then commence.

Phase 2

Interviews will be conducted with ten (10) participants who have signed a "*Consent Form'* and are willing to participate in four (4) consecutive interviews over approximately two(2)years. These interviews will be conducted face-to-face at home or in a location of the participant's choosing, and only the researcher and the participant will be present. The initial interview will be longer due to its 'setting the scene' of the participant's life experiences of risk and may take an hour and a half. Subsequent interviews will require a shorter period of time. The questions asked will be open-ended, and they will be about risk, allowing the participant to generalise and explore their perceptions of risk. The aim here is to hear the voice of the person with dementia. Research data will be analysed using the methodology of Max van Manen and hermeneutic phenomenology.

The research student is responsible for the recording of all the data. It will be collected on-site of the interviews with an audio-digital tape recorder and transcribed onto a protected computer for ongoing and final analysis .Other data may be collected in field notes, and in a reflective journal kept by the researcher. Only the researchers will have access to the data, which will be stored in a locked cabinet. On completion of the study, all the computer files, documents and any hard copy data will be securely stored at Victoria University for five (5) years.

Who is conducting the study?

Principal Researcher – Mrs Sally Osborne
Phone 95109758
Mobile 0401915405
sally.osborne@live.vu.edu.au

Principal Supervisor- Dr Jocelyn Angus
Phone 9919 1152
Mobile 0411205519
Email – Jocelyn.Angus@vu.edu.au

Associate Supervisor- Dr. Lindsay Morgan
Phone 99191323
Mobile 0420558755
Email Lindsay.Morgan@vu.edu.au

Any queries about your participation in this project may be directed to the Principal Researcher listed above.
If you have any queries or complaints about the way you have been treated, you may contact the Ethics and Biosafety Coordinator, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4148.

<div align="center">

APPENDIX D

INFORMATION TO PARTICIPANTS INVOLVED IN RESEARCH

</div>

INFORMATION TO PARTICIPANTS INVOLVED IN RESEARCH

You are invited to participate

You are invited to participate in a research project entitled "The lived experience of risk for a person with a recent diagnosis of dementia (Alzheimer's type): a longitudinal phenomenological study"

This project is being conducted by a student researcher Sally Osborne as part of a PhD study at Victoria University under the supervision of Dr Jocelyn Angus and Dr Lindsay Morgan in the Faculty of Arts.

Project explanation

This is a study of the perceptions of risk of people with a recent diagnosis of dementia (Alzheimer's type). It begins with the premise that risk is a part of life for everyone, and the dignity of risk, or the right to failure remains central to the ways in which we live our lives.

This research has important implications for dementia care and practice. Its findings may increase awareness of the rights of people with dementia and this will encourage a more active role in future decision-making that may affect your life. It may also assist in a better understanding of your preferences and future planning, based on your previous experiences. This understanding will assist in developing supportive and proactive care practices that meet the individual needs of people with dementia, which may enable them to continue to live full and productive lives.

What will I be asked to do?

You will be asked to participate in four (4) informal interviews at approximately six(6) monthly intervals. This will take place over approximately two (2) years. The interviews will relate to your stories about your life experiences of risk. It is anticipated that the conversations may take approximately 60-90 minutes of your time. The conversations may be terminated at any time at your request.

What will I gain from participating?

There is no payment available for your participation. However your direct input into the findings has the potential to inform policy makers and to improve care practices and priorities for people with dementia. Being a partner in the research process is an opportunity to talk about, and make sense of your experiences, and it also allows you to have a more active role in future decision-making that directly affects your life- both now and into the future.

How will the information I give be used?

Your interviews will be combined with other interviews and analysed together anonymously. There will be no identifiable details evident in the findings of this study. Information collected in this research will be used by the Student Researcher to form the basis of a thesis to be submitted for assessment for admission to the degree of PhD.

What are the potential risks of participating in this project?

As a result of your participation in the conversations, you may feel a range of emotions in recounting your experiences. A referral to an appropriate provider (General Practitioner and/or the Dementia Behaviour Management Advisory Services) can be made on your behalf, if you experience negative consequences as a result of an interview. The DBMAS is a specialised support service established to support carers or people with dementia who experience behaviours of concern that may impact on their care. It is available twenty four hours a day. Ms Anne Graham is a registered clinical psychologist with the Psychologists Registration Board of Victoria, Victoria University , PO Box 14428, Melbourne VIC 8001 Australia TEL + 61 3 99192159 who may also be contacted by the participant for consultation.

How will this project be conducted?

These interviews will be conducted face-to-face at home or in a location of your own choosing, and only the researcher and the participant will be present. They will initially take an hour to an hour and a half, and then a shorter period of time. The initial interview will be longer due to its 'setting the scene' of your life experiences of risk. It will be informal, allowing you to generalise and explore risk.

Who is conducting the study?

Victoria University

Principal Researcher – Dr Jocelyn Angus
Phone 9919 1152
Mobile 0411205519
Email – Jocelyn.Angus@vu.edu.au

Second Researcher- Dr. Lindsay Morgan
Phone 99191323
Mobile 0420558755
Email Lindsay.Morgan@vu.edu.au

Student Researcher – Mrs Sally Osborne
Phone 95109758
Mobile 0401915405
Sally.Osborne@live.vu.edu.au

Any queries about your participation in this project may be directed to the Principal Researcher listed above.
If you have any queries or complaints about the way you have been treated, you may contact the Ethics and Biosafety Coordinator, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4148.

APPENDIX E

CONTACT INFORMATION FOR POTENTIAL PARTICIPATION IN RESEARCH

CONTACT INFORMATION FOR POTENTIAL PARTICIPATION IN RESEARCH

VICTORIA UNIVERSITY | **A NEW SCHOOL OF THOUGHT**

You are invited to participate

You are invited to participate in a research project entitled "The lived experience of risk for a person with early stage dementia (Alzheimer's type): a longitudinal phenomenological study"

This project is being conducted by a student researcher Sally Osborne as part of a PhD study at Victoria University under the supervision of Dr Jocelyn Angus and Dr Lindsay Morgan in the School of Social Sciences and Psychology.

Project explanation

This is a study of the perceptions of risk of people with early stage Alzheimer's disease. The idea of risk used in this study is based on the view that risk is a part of life for everyone, and that it is central to continued growth and the development of resilience throughout life.

What will I be asked to do?

You will be asked to participate in four (4) informal interviews at approximately six (6) monthly intervals. These informal interviews will be conducted face-to-face at home or in a location of your own choosing at a time that suits you. It is anticipated that the first interview will take approximately 90-120 minutes, setting up your life story relating to risk. Subsequent visits will be shorter. You will also be asked to nominate a 'person responsible' who the student researcher may contact in an emergency. Participation may be terminated at any time at your request.

What do I need to do now?

If you wish to learn more, there is a space below for your **first name** and a **contact phone number**. The researcher whose name is Sally will contact you on that number within a week and answer any further questions that you may have. If you wish to participate in the study, a meeting will be arranged to talk more about the study and your involvement.

First name_____

Contact phone number_____

CONSENT FOR PARTICIPANT INVOLVED IN RESEARCH

VICTORIA UNIVERSITY | **A NEW SCHOOL OF THOUGHT**

INFORMATION TO PARTICIPANTS:

We would like to invite you to be a part of a study titled "The lived experience of risk for a person with a recent diagnosis of dementia (Alzheimer's type): a longitudinal phenomenological study". This research will be looking at your life experiences of risk. It will contribute to new knowledge about the lived meanings of risk of persons with a recent diagnosis of Alzheimer's disease. This understanding will assist in developing supportive and proactive care practices that meet individual needs of people with dementia, which may enable them to continue to live full and productive lives.

CERTIFICATION BY PARTICIPANT

I,

_____

of

_____

certify that I am at least 18 years old* and that I am voluntarily giving my consent to participate in the study "The lived experience of risk for a person with a recent diagnosis of dementia (Alzheimer's type): a longitudinal phenomenological study" being conducted at Victoria University by student researcher Sally Osborne under the supervision of Dr Jocelyn Angus and Dr. Lindsay Morgan.

I certify that the objectives of the study, together with any risks and safeguards associated with the procedures listed hereunder to be carried out in the research, have been fully explained to me by Sally Osborne and that I freely consent to participation involving the below mentioned procedures:

- Four interviews with Sally Osborne lasting approximately 90-120 minutes initially and then 30-60 minutes subsequently, responding to a number of questions relating to my lived experience of risk within a recent diagnosis of dementia (Alzheimer's disease).

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed: _____

Date: _____

Any queries about your participation in this project may be directed to the student researcher Sally Osborne on 9510 9758. If you have any queries or complaints about the way you have been treated, you may contact the Ethics & Biosafety Coordinator, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4148.

APPENDIX G
PARTICIPANT CONSENT TO SHARE INFORMATION

PARTICIPANT CONSENT TO SHARE INFORMATION

VICTORIA UNIVERSITY | **A NEW SCHOOL OF THOUGHT**

INFORMATION TO THE 'NEXT-OF-KIN/GUARDIAN'

I, _____ will participate in a study titled "*The lived experience of risk for a person with early stage dementia (Alzheimer's type): a longitudinal phenomenological study*". This research will be looking at my life experiences of risk, and will contribute to new knowledge about the lived meanings of risk of persons with early stage Alzheimer's disease.

I am willing to nominate my Next-of-Kin / Guardian to play a role in this study. Their consent is required at the initial interview, and for all further participation by me. The role of the Next-of-Kin/Guardian is outlined in the *Guardianship and Administration Act Section 28(2)*. This form will be signed by me and the contact details of the Next-of-Kin /Guardian is below.

CERTIFICATION

I, _____ have _____

as my "Next-of-Kin/Guardian.

They may be contacted on _____

Signed: _____

Date: _____

Any queries about your participation in this project may be directed to the student researcher Sally Osborne on 9510 9758. If you have any queries or complaints about the way you have been treated, you may contact the Ethics & Biosafety Coordinator, Victoria University Human Research Ethics Committee, Victoria University, P.O. Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4148.

APPENDIX H

INITIAL CONSENT SUPPORTING PARTICIPATION IN RESEARCH

INITIAL CONSENT SUPPORTING PARTICIPATION IN RESEARCH

VICTORIA UNIVERSITY | **A NEW SCHOOL OF THOUGHT**

INFORMATION TO NEXT OF KIN/ LEGAL GUARDIAN:

We are seeking your support for the participation of _____ in a study titled "The lived experience of risk for a person with early stage dementia (Alzheimer's type): a longitudinal phenomenological study". This research will be looking at the life experiences of risk for _____. It will contribute to new knowledge about the lived meanings of risk of persons with early stage Alzheimer's disease. This understanding will assist in developing supportive and proactive care practices that meet individual needs of people with dementia, which may enable them to continue to live full and productive lives.

CERTIFICATION BY NEXT OF KIN/LEGAL GUARDIAN

I, _____

certify that I am the legal guardian ☐

      the next of kin ☐

and that I am voluntarily giving my consent for _____ to participate in the study "The lived experience of risk for a person with early stage dementia (Alzheimer'stype): a longitudinal phenomenological study" being conducted at Victoria University by student researcher Sally Osborne under the supervision of Dr Jocelyn Angus and Dr. Lindsay Morgan.

I certify that the objectives of the study, together with any risks and safeguards associated with the procedures listed hereunder to be carried out in the research, have been fully explained to me by Sally Osborne and that I freely consent to the participation of _____ in the below mentioned procedures:

- Four interviews with Sally Osborne lasting approximately 90-120 minutes initially and then 30-60 minutes subsequently, responding to a number of questions relating to my lived experience of risk within a diagnosis of early stage Alzheimer's disease.

I certify that I have had the opportunity to have any questions answered and that I understand that I withdraw my support for _____ to participate if I consider that it is no longer appropriate. This would be done after consultation with the student researcher Sally Osborne. I have been informed that the information I provide will be kept confidential.

I understand that this form may be sent to me in a self-addressed envelope, it may be scanned and emailed or it may be signed in person in order for my signature of consent.

Signed: _____

Date: _____

Any queries about your participation in this project may be directed to the student researcher Sally Osborne on 9510 9758. If you have any queries or complaints about the way you have been treated, you may contact the Ethics & Biosafety Coordinator, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4148.

APPENDIX I

ONGOING CONSENT SUPPORTING PARTICIPATION IN RESEARCH

ONGOING CONSENT SUPPORTING PARTICIPATION IN RESEARCH

VICTORIA UNIVERSITY | **A NEW SCHOOL OF THOUGHT**

INFORMATION TO PARTICIPANTS:

We would like to invite you back to a study titled "The lived experience of risk for a person with a recent diagnosis of dementia (Alzheimer's type) a longitudinal phenomenological study". This research will be looking at your life experiences of risk. It will contribute to new knowledge about the lived meanings of risk of persons with a recent diagnosis of Alzheimer's disease. This understanding will assist in developing supportive and proactive care practices that meet individual needs of people with dementia, which may enable them to continue to live full and productive lives.

CERTIFICATION BY SUBJECT

I,

_____

___

of

_____

__

certify that I am at least 18 years old* and that I am voluntarily giving my consent to again participate in the study: "The lived experience of risk for a person with a recent diagnosis of dementia (Alzheimer's type): a longitudinal phenomenological study" being conducted at Victoria University by student researcher Sally Osborne under the supervision of Dr Jocelyn Angus and Dr. Lindsay Morgan.

I certify that the objectives of the study, together with any risks and safeguards associated with the procedures listed hereunder to be carried out in the research, have been fully explained to me by Sally Osborne and that I freely consent to participation involving the below mentioned procedures:

- Four interviews with Sally Osborne lasting approximately 90-120 minutes initially and then 30-60 minutes subsequently, responding to a number of questions relating to my lived experience of risk within a diagnosis of early stage Alzheimer's disease.

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed: _____

Date: _____

Any queries about your participation in this project may be directed to the student researcher Sally Osborne on 9510 9758. If you have any queries or complaints about the way you have been treated, you may contact the Ethics & Biosafety Coordinator, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4148.

APPENDIX J
VERBAL OR WRITTEN CONSENT FOR CONTINUED PARTICIPATION IN RESEARCH

VERBAL OR WRITTEN CONSENT FOR CONTINUED PARTICIPATION IN RESEARCH

VICTORIA UNIVERSITY | **A NEW SCHOOL OF THOUGHT**

CERTIFICATION

As the nominated Next of Kin of _____,
I, _____ give my verbal permission for _____ to continue participation in the research: "The lived experience of risk for a person with a recent diagnosis of dementia (Alzheimer's type): a longitudinal phenomenological study".

Interview 1_____**Date**_____

Interview 2_____**Date**_____

Interview 3_____**Date**_____

Interview 4_____**Date**_____

I understand that this may be signed by the principal researcher on my behalf. In the event of the participant not having the capacity to consent, my signature will be required. This will be at the discretion of both the researcher and myself.

Any queries about your participation in this project may be directed to the student researcher Sally Osborne on 9510 9758. If you have any queries or complaints about the way you have been treated, you may contact the Ethics & Biosafety Coordinator, Victoria University Human Research Ethics Committee, Victoria University, P.O. Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4148.