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How perceived societal understandings and expectations impact adult childrens' risk narratives for their parents with dementia

by

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ABSTRACT

FACULTY OF ENVIRONMENTAL AND LIFE SCIENCES

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HOW PERCEIVED SOCIETAL UNDERSTANDINGS AND EXPECTATIONS IMPACT ADULT CHILDRENS' RISK NARRATIVES FOR THEIR PARENTS WITH DEMENTIA

Amelia Charlotte Abbott

The UK government has prioritised maintaining people with dementia in the community setting to reduce costs to society (DH 2009) and there is an increasing societal pressure on family members (especially adult children) to take responsibility for dementia care (Pickard et al. 2007). Ineffective management of risk may be one reason people with dementia may require hospital or residential care. Another reason may be due to burdens associated with maintaining safety for a family member with dementia. Each group of dementia care stakeholders may be considered a culture with differing knowledge, values and responsibilities which in turn shape how they manage risk for the person with dementia. However, each of these cultures will also be impacted upon by societal norms and expectations. This project aimed to understand how adult children may be impacted by cultural norms and societal expectations when managing risks for their parents with dementia. Twelve adult children as case studies produced both written and interview narratives where they constructed and reconstructed risk accounts for their parents with dementia. These were analysed through narrative inquiry which focussed on how the adult children structured their narratives, utilised characterisation and rhetoric, positioned themselves and how they positioned their audience (society). The participants positioned themselves at differing levels of responsibility which impacted on how and why they constructed risks and justified management strategies. They also required less 'narrative effort' (use of more or less narrative elements in constructing their accounts) for health/safety risks when compared with non-safety risks. This implies that society, as the narrated to audience, may better understand, and perhaps assign more importance to, health/safety risks as opposed to non-safety risks. The thesis concludes that burden may not only be associated with (in)effective risk management for parents with dementia, but also from perceived societal expectations and pressures to ensure safety for a parent above all else. The findings have implications for greater societal education with respect to dementia care and better support for adult children as caregivers.

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DECLARATION OF AUTHORSHIP

I, Amelia Abbott

declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

How perceived societal understandings and expectations impact adult childrens' risk narratives for their parents with dementia

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signed: ....

Date: ....

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Definitions and Abbreviations

Adult children – sons and daughters over the age of 18 years old

AS – Alzheimer's Society

BNF – British National Formulary

BRC – Better Regulation Commission

CPN – Community Psychiatric Nurse

CSCI – Commission for Social Care Inspection

DH – Department of Health

DVLA – Driver and Vehicle Licensing Agency

GP – General Practitioner

HCP – Healthcare Professionals – throughout the document HCPs refers to health and social care professionals who have undertaken training and qualifications for their roles, this excludes healthcare assistants, support workers and professional caregivers

NICE – The National Institute for Health and Care Excellence

OED – Oxford English Dictionary

ONS – Office for National Statistics

POA – Power Of Attorney

QOF – Quality and Outcomes Framework

UK – United Kingdom

UN – United Nations

USA – United States of America

Chapter 1: Introduction and research questions

Dementia refers to a set of symptoms produced by diseases of the brain (Jacques 1992). With the ageing population, the global prevalence of dementia is increasing (UN 2015). It is estimated that 46.8million people are living with dementia worldwide and that this figure is set to double every 20 years (Prince et al. 2015); in the UK (United Kingdom) estimates were 850,000 people with dementia in 2015 (AS 2014b). The cost of dementia to the UK was estimated at £26billion a year (Prince et al. 2014) and the UK government therefore prioritised the importance of dementia since the first *National Dementia Strategy* (DH 2009) and David Cameron's *Challenge on Dementia* (DH 2012, 2015).

Of the £26billion yearly cost of dementia, £11.6billion is paid for by people with dementia and their family caregivers (AS 2014b). This demonstrates the importance of family caregivers for the UK economy. Therefore one of the key aims of the national strategy is the support of dementia caregivers to enable them to care for their family members in the community for longer (DH 2009). According to the UK Census 2011, the number of people providing unpaid care in England and Wales was 5.8million (ONS 2011). The number of unpaid caregivers for people with dementia in the UK is roughly 670,000 (Newbronner et al. 2013; AS 2014a). These numbers may not cover all people with dementia and their caregivers; there are still some people living with dementia that is undiagnosed and some unpaid caregivers do not associate themselves with the term caregiver. Therefore, the numbers of caregivers of people with dementia are likely to be greater than these figures indicate.

Although policy focus is on ageing-in-place, many people with dementia may consider a move to residential care. One reason may be because the risks associated with remaining in the community and caregiver burden in managing these risks may become too high. Risk, defined as "the possibility of loss, injury, or other adverse or unwelcome circumstance" (OED 2019), is present for everyone across everyday situations. Due to the nature of dementia, where symptoms can include a variety of problems in function and cognition, risk can increase (Clarke et al. 2010; Bailey et al. 2013).

Risk can be approached objectively to consider the probabilities of negative consequences due to a particular action (Lupton 2003). However, people do not often comply with such objective approaches to risks, they often rely on intuition and past experience (Zinn 2008), therefore risk can be highly subjective. Such subjective meaning-making in risk must therefore be socially and culturally grounded (Mythen 2004). There are three key sociocultural approaches to theorising about risk: the Foucauldian concept of governmentality (Foucault 1980), Risk Society theory (Beck

2013) and Cultural Theory (Douglas 1994, 2004). Governmentality asserts that risk is a construct of a governing body to gain and maintain control over a given population through regulation and social surveillance. However, governmentality relies on people being ultimately manipulable, yet some continue to take risks despite a governing body's advice (such as continued smoking). Risk Society theory considers that society is preoccupied with the negative consequences of risk-taking and therefore accepts a safety-first approach to risk. However, Risk Society theory fails to address individuality in the face of risk, for example, some people choose to bungee jump despite known risks. Cultural Theory aims to understand individuality through the cultures people align themselves to. Members then a have a responsibility to adhere to their cultures' values, norms and expectations, and those who do not are considered a threat to the culture. In the context of risk, an individual must act upon a risk according to their culture's expectations, if they do not they may face blame should negative consequences occur. However, cultures exist within society and therefore must be, in part, effected by societal norms. Although each theory approaches risk differently, all are necessary to understand how an individual may address risk. That is, the individual must comply with their cultures' expectations, but will also be influenced by wider societal expectations and regulation from governing bodies which may be enforced through social surveillance.

In the context of dementia care, negotiating risk can become more of a challenge. Due to the nature of dementia, capacity to make decisions regarding risk can be questionable. There will therefore likely be input regarding risk from the person with dementia, their family caregivers and their healthcare professionals (HCPs[1]). Each of these stakeholders has a responsibility for the person with dementia and the literature has consistently demonstrated how the stakeholders understand and act upon risk differently (Clarke 2000; Gilmour et al. 2003; Beattie et al. 2004; Clarke et al. 2009; Dickins et al. 2018) which often leads to challenges in collaboration. In viewing these stakeholders as different cultures, it is possible to recognise how their different knowledge bases, values, experiences and norms may differ in the face of risk. As an example, there are policies to guide HCPs in supporting people with dementia in taking and managing their own risks such as *Nothing Ventured, Nothing Gained* (DH 2010). This policy guides HCPs to support people with dementia to do what they can for as long as they can (risk enablement) instead of reducing or removing risks entirely (risk aversion). However, the target audience of such policies is HCPs, not family caregivers. Family caregivers often rely on their previous relationship with the person

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[1] Healthcare Professionals refers to members of the person with dementia's health and social care team throughout the remainder of this document. This excludes healthcare assistants and support workers because they are unlikely to have undertaken the same extensive training and qualifications as health and social care professionals.

with dementia when considering risks (Clarke 2000; Stevenson and Taylor 2016). Their expertise stem from experience and prior knowledge of the person. Family caregivers are not governed by the same explicit rules as HCPs. Further, the notion of risk enablement is complex. There is a need to maintain the person with dementia's health and safety whilst also maintaining a good quality of life and the person's independence and autonomy.

Within these dementia care stakeholder cultures, it is possible for sub-cultures to emerge; there may be differences in approaches between nurses and physiotherapists, for example, who are trained differently and have different expertise. Similarly, there may be differences between different types of family caregivers, thus the different types of family caregivers may need to be acknowledged as their own separate sub-culture. Family caregivers include spouses, adult children[2] and other family members or close friends. Often adult child caregivers differ from other types of family caregivers in why and how they provide care to a person with dementia (Kjällman-Alm et al. 2013). They typically have to balance their own lives (both work and social), the lives of their children, potential grandchildren and support their parents (Victor 2005). This can often lead to adult children experiencing higher burden than spouse caregivers (Yeager et al. 2010; Chappell et al. 2014; Kahn et al. 2016).

Figures from Pickard et al. (2007) suggest that there is roughly a 50/50 split between spouses and adult children as primary caregivers for people with dementia, with a small percentage for other types of family caregivers. Typically where the person with dementia has a living spouse, the spouse would be named as primary caregiver. However, they often have adult children who provide support to both parents. There may be, therefore, a much larger number of adult children as caregivers than spouses - a consideration that is often overlooked by statistics and the literature. Pickard et al. (2007) discuss a societal need for more adult children to take on the role of caregiving for their parents with dementia as the prevalence of dementia is predicted to increase. This need arises from the financial implications for the UK economy in providing care for people with dementia, therefore the government and policies are prioritising maintaining people with dementia in the community and maintaining their family caregivers. Society also expects adult children to provide care to their parents, however there is less certainty about what types of care and how that care should be provided (Finch and Mason 1990, 1993).

In order to support adult children, as the higher proportion of family caregivers, to maintain their parents with dementia in the community for longer, there is a need to provide better support and

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[2] Adult child caregivers are defined as anyone aged 18 years or older who provides support to a parent with dementia

resources surrounding risk to adult children. It is therefore important to explore the culture of adult children as caregivers in the face of risk in order to recognise the types of support they may require. Adult children may be impacted upon by their own cultural norms, but also societal expectations and pressures. These expectations may not only impact the adult childrens' reasons to provide care to their parents with dementia, but also *how* they provide such care. There is therefore a need to explore societal expectations and impacts in adult childrens' care practice. The aim of this study is to understand how adult children may be impacted by cultural norms and societal expectations when managing risks for their parents with dementia.

In order to understand how adult children may be impacted upon by societal expectations, it is first important to recognise the cultural boundaries of adult children as caregivers. Douglas (2004)'s Cultural Theory and Bernstein (2003)'s Theory of Language Coding demonstrate how it may be possible to recognise these cultural boundaries. Bernstein (2003) identified two language codes: restricted and elaborative. Restricted language may be used when two people have a shared understanding (or culture), whereas elaborative language may be required when there is no shared understanding. It is therefore through narratives that it may be possible to recognise where these two codes are required. Narrative inquiry recognises that all narratives are produced with an aim in mind, and for an audience. Therefore through interpreting constructions of narratives through structures and required narrative elements (such as plots, characterisations and rhetoric), it is possible to understand how and why an argument is formed for a particular audience. In positioning the audience as society, it is then possible to recognise that which adult children consider to be a shared understanding and that which is not shared. These perceptions of shared or not shared understandings allow for an exploration of societal understandings and expectations in how they impact upon adult childrens' narratives of risk.

The research questions therefore are:

1. How do adult children of parents with dementia construct risk narratives?
2. What are the implications of these constructions for understanding societal expectations of risk in dementia care?

These questions are answered through exploratory, narrative inquiry of twelve adult children as case studies. The participants were invited to write about their experiences of risks for their parents with dementia and then discuss them further at interview. The combination of written and verbal accounts produced risk narratives. The narratives were then analysed for: content (Riessman 2000), structure (Labov and Waletzky 1997) and narrative elements (Baldwin 2013). In order to recognise the wider implications for societal understandings, a close understanding of how the adult children positioned themselves and their audiences within their narratives was required.

The following thesis addresses risk, risk in dementia care and adult children as caregivers. As such, the following three chapters form literature reviews of these topics (see appendix A for literature search strategy). Chapter 2 addresses the concepts associated with risk and introduces the three sociocultural approaches to theorising about risk: governmentality (Foucault), Risk Society Theory (Beck) and Cultural Theory (Douglas). Chapter 3 explores the literature pertaining to risk in dementia care and highlights differences between the dementia care stakeholders as separate cultures. Chapter 4 explores the literature regarding adult children as caregivers and draws upon differences between adult children and spousal caregivers. Following the literature review chapters, chapter 5 presents and justifies the methodological assumptions and methods of data collection and analysis. Chapters 6, 7 and 8 present the analysis methods in practice and the findings. Chapter 6 is a relatively short description of some of the explicit references the adult children made to impacts from society and culture. Interestingly, the adult children not only narrated risk, but also responsibility. Chapter 7 explores how the adult children position themselves or others as responsible and the impacts of these positionings upon their constructions of risks. Chapter 8 focusses on how the adult children construct risk through different structures and plots, characterisations and use of rhetoric devices. The discussion chapter (chapter 9) positions the findings (chapters 6-8) within the literature and sociocultural theories of risks (chapters 2-4). The thesis concludes with chapter 10 which highlights the main conclusions of the study, limitations, future directions for research and implications for practice.

Chapter 2: Risk: Concepts and theories

Life is risky; risk is present for everyone in everyday situations. However, the word risk can have multiple meanings which may impact upon how it is managed. This initial chapter discusses conceptualisations of risk and introduces key sociocultural theories of risks which are drawn upon throughout the thesis.

2.1 Risk concepts

“Risk has multiple meanings for multiple people in multiple situations” (Clarke et al. 2011b, pp. 11)

The search for a perfect, succinct definition of risk feels impossible in the face of multiple concept-laden aspects across varying disciplines and risk authors. The word has also changed in definition over the centuries, and with it, the nature of risk also (Lupton 2003). Risk is too complex and conceptual to be afforded a single, simple definition. The online Oxford English Dictionary (OED 2019) provides at least 14 (sub-)definitions of risk including as a noun or verb but also an adjective, for example, in considering something as risky. In their paper titled *Defining risk*, Fischoff et al. (1984, pp. 124) conclude “no definition is advanced as the correct one, because there is no one definition that is suitable for all problems”. Instead of attending to a single definition of risk, the following section explores the changes in what and how it has been possible to know about risk which will later be drawn upon to understand differences in risk understandings and management in dementia care (chapter 3).

Firstly, language use and risk synonyms add to the complexity of finding a risk definition. In present day vernacular risk is synonymous with words like: hazard, harm, danger and threat (Lupton 2003). Typically such definitions focus only on negative repercussions of risk (Lupton 2003), however to take a risk, one would always have a positive aim in mind, otherwise one would not consider to take said risk. There are always, therefore, both positive and negative outcomes. The word risk may also be used synonomously with the words gamble or bet, however, risk typically goes further to acknowledge a level of probability – a calculable and predictive element unlike with bet or gamble (Lupton 2003). Risk involves deciding whether or not to take an action based on the potential consequences of that action. However, the word risk can be used to describe the action, the potential consequence and the weighing up of the decision. The use of the word risk should therefore be considered in the context within which both the word and the concept of risk are constructed.

Secondly, there are also challenges in defining risk due to multiple approaches to researching and theorising about risk. Lupton (2003) discusses the shifts and changes in approaches to risk research, initially approaches from such disciplines as statistics, engineering and psychology focussed on the probabilities and hazards associated with taking a risk. These approaches attempt to understand more about risk through controlled environments and standardised assessments with limited applicability to real-life scenarios and experiences (Mythen 2004). These reductionist and objective views are appropriate to considering risk through probabilities, however, Zinn (2008) suggests that people typically do not comply with objective measurable constructs of risk; with little time or knowledge people may instead rely on intuition (or reflex) and previous experiences instead of likelihoods.Meaning-making in relation to risks must be socially- and culturally-grounded (Mythen 2004). Sociocultural perspectives move away from such objective approaches and instead consider the social and cultural contexts within which risks are constructed (Lupton 2003).

2.2 Sociocultural theories – an introduction

This thesis draws on three sociocultural theories and concepts that can be applied to risk. These are: governmentality (Foucault 1980), Beck's Risk Society theory (Beck 2013) and Douglas' Cultural Theory (Douglas 1994, 2004). Between them, they provide ways of understanding the impacts of society and culture on perceptions of risks and approaches to risk management. Initially this sub-section provides an introduction to the three sociocultural theories which are drawn upon throughout the remainder of the thesis.

2.2.1 Governmentality

Foucauldian governmentality is a concept that combines government (a body that regulates action and behaviours) and mentality (the, often implicit, thought processes causing behaviour) (O'Malley 2008). Government can be described as the 'conduct of conduct' – which plays on two meanings to the word conduct: the first is leadership or guidance; the second is self-direction in terms of actions and behaviours (Dean 2010). Therefore government is the guidance of people's self-direction. Governmentality, as a discourse, not only pertains to power and control but also impacts upon individuals in terms of self and identity (Dean 2010). According to governmentality, risk is a construct which can be used to gain or maintain power or control through regulation and surveillance of a given population (Foucault 1980). In order to ensure governmentality, surveillance may be used to enforce consequence should an individual not conform. Surveillance is not limited to the governing body (Foucault 1980; Dean 2010). Although a government may use measures to enforce a particular mentality, for example, broken laws may be punishable through imprisonment (depending on the crime), surveillance is also the responsibility of society. For example, if one sees a crime committed, one has a duty to report it to the appropriate authorities. This example may be extreme, but surveillance continues into other aspects of societal norms and expectations. For example, the government may release guidance on not smoking due to health implications. It is not a broken law if one chooses to smoke, however through governmentality, society may see the act of smoking as immoral. Surveillance then moves further to the individual through self-surveillance and self-regulation, the requirement not only from a government but also society to act within the guidance provided. An individual then may choose to stop smoking for their own health or due to societal expectation to conform to government-regulated guidance. Of course it may be possible for an individual to not conform to government guidance or societal pressures (some people continue to smoke) but in doing so they may face consequences of judgement from their government or society. The idea of facing consequences is later returned to in section 2.2.3 with a discussion about the ability to assign blame.

A criticism of governmentality is that it relies heavily on the assumption that all people are ultimately manipulable. However, it is important to remember that governmentality is a process through which how one conducts oneself is guided by a governing body. Therefore, it is important to recognise self-regulation is a key aspect of governmentality. Another criticism of governmentality is the reliance on applying collective governance to individuals, that is the assumption that all people should be subject to the same regulation and surveillance. This is especially apparent in governmental approaches to psychiatry where individuals were categorised by their diagnosis, treated as having the same level or type of risk and ultimately managed in the same way (Lupton 2003; Rose 2009). In the past this led to all individuals with mental health diagnoses being considered as dangerous and requiring higher levels of surveillance through institutionalisation to maintain the safety of the wider society (Rose 2009; Dean 2010). Although, mental health care has progressed and moved towards a more person-centred, case-management approach in the community as opposed to institutions, aspects of this mentally may still remain (discussed later in chapter 3).

The two key aspects of governmentality are regulation (whether over-regulation, under-regulation or self-regualtion) and surveillance (whether by governing bodies, society or individuals) and will be returned to later within the context of this thesis.

2.2.2 Risk Society Theory

Until the 1980s, risk was considered to be an inevitable part of life that was out of society's control, such as natural disasters. However through the course of modernity (increases in technological and industrial advances), risk became a man-made concept (such as pollution) that should be managed, mitigated or eradicated (Beck 2013). Where it has been possible to calculate and mostly, at least in western society, eradicate natural risks such as famine and drought, risk has changed focus towards manmade risks which likewise should be eradicated (Mythen 2004). According to Beck (2013) risk is a social construction and no longer a natural part of life. Individuals have become increasingly responsible for managing risks (both to themselves and their dependents' health and safety). Beck argues that society is on the brink of self-destruction and continuously positions risk as a wholly negative concept. However, some people do still take risks and gain pleasure in engaging with risky activities despite the potential negative consequences (Lupton and Tulloch 2002; Mythen 2004).

Further Beck (2013) argues that in risk society, everyone is equally at risk and risk is no longer distributed according to class or status as had previously been the case. However, Mythen (2004) argues that this is not the case, for example in considering pollution as a risk which can be higher or lower in particular geographies, wealth becomes a factor in where people can afford to live. Therefore, risk is not equal across the entire population. Furthermore, through individualisation of experience, how a given person acts in relation to risk will likely differ from another (Mythen 2004). Thus Risk Society theory fails to address cultural impacts.

2.2.3 Cultural Theory

Through her anthropological work, Douglas' Cultural Theory considers risk from a cultural perspective. She describes different cultures in the form of grid/group categories where grid refers to the level of authority that culture holds and group refers to the volume of people within that culture. These four levels range from high grid/high group (a large collection with high authority - hierarchical) to low grid/low group (a small group or individual with little authority - individualistic) with high grid/low group and low grid/high group in between (as seen in figure 1). However, it should also be noted that people may move between different cultures (or grid/group) depending on the situation or context they are presented with. For example, an individual could belong to a family unit which may be considered low grid/low group – that is there are few people within that family unit and they have low authority (when compared to the rest of society). That individual may go to work for a large, leading company (high grid/high group) where there are multiple colleagues who share the same values, knowledge and understanding with a high level of authority on the company's expertise. Thus, culture is context-specific.

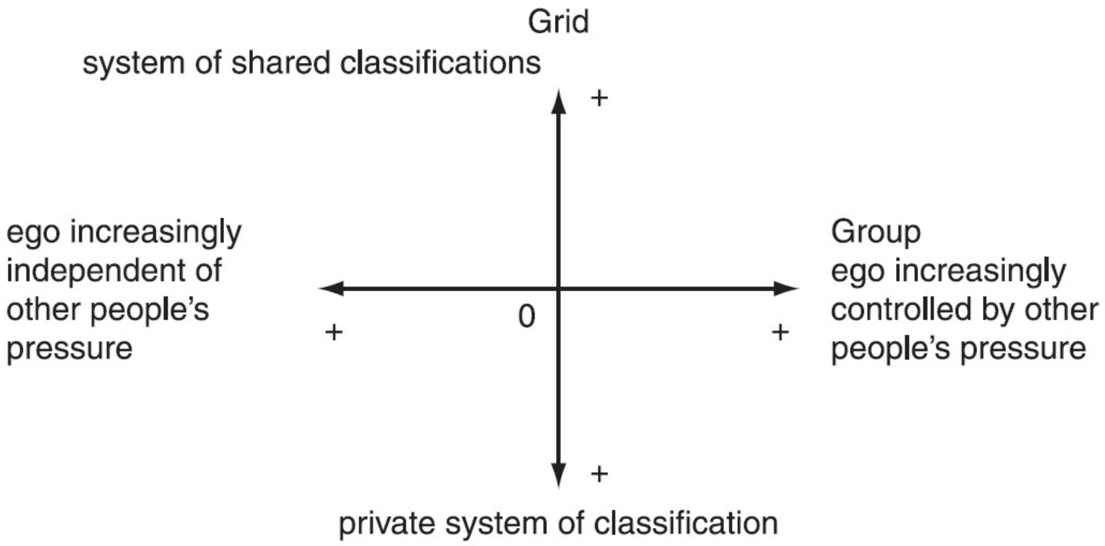

Figure 1 Gird and group - *Natural Symbols* (Douglas 2004)

Cultural Theory also considers that where risk is involved, there is always a level of cultural responsibility and blame can be placed on those 'others' who threaten the culture. For example, environmentalists may position governments and industries as responsible for high-level pollution that is to blame for global warming (Lupton 2003). Members of a culture have a responsibility to adhere to the expectations of their culture; those that do not adhere are blamed for threatening that culture (Douglas 1994). This then means that an amount of pressure is being placed on an individual to maintain and reinforce that culture - the higher the grid and group, the higher the pressure (Douglas 2004). This may then also impact upon other cultures, those with higher authority and more people may exhibit higher pressure and control over weaker cultures (Douglas 2004).

The only way to be rid of such pressure and control is to be perfectly isolated from society and cultures, however this is rare which suggests that individuals will always be impacted upon by pressures from cultures and indeed society as a whole (Douglas 2004). When an individual or culture is pressured to comply to the specifics of another culture, there will be tension (Douglas 2004) – on a societal level this could be evidenced through war, on the individual level it could be as extreme as suicide. It is possible to reduce external pressures through private thought (Douglas 2004). This does not mean that private thought is exempt from societal or cultural pressures, but instead allows for the process of self-reflexivity. That is, an awareness of societal pressures and how they may be applying pressure and therefore an avoidance of the potential temptation to comply.

In relation to risk, an individual may be influenced by their culture's expectations of risk and may also experience pressure from other cultures and society in how to respond to risk. If the two competing expectations do not align, the individual may experience a tension in deciding how to act on said risk which may result in uncertainty. Alternatively, they may, through self-reflexivity, actively avoid pressures from culture or society and rely on their private thoughts to determine how to proceed. This will also likely result in the potential for blame or uncertainty.

Drawing on one comprehensive model of decision-making in risk, it may be possible to recognise how individuals in different cultures may form different understandings of and decisions about risks. Chicken and Posner (1998) discuss in depth the philosophy of risk and highlight 11 factors associated with making a decision about risks. These are: knowledge (all relevant information), judgement (ability to assess information), trust (reliability of information), regulation (legal/official frameworks), bias (disposition that affects the significance of the information), nature of risk (likelihood of unacceptable outcome), funding (financial constraints), political belief (compatibility of risk with political beliefs), aims (and objectives of decision), demand (need for decision/risk) and supply (availability of resources). With 11 factors that can affect risk decision-making, it is possible to understand how different cultures may weight these factors differently. With different weightings assigned, different cultures will likely act differently on any given risk.

2.2.4 Section summary: Risk theories

Here initially outlines an introduction to three key sociocultural theories or concepts that are frequently applied to understanding risk. All three address risk very differently: as a tool for governmentality (Foucault), a societal shift towards negative aspects of risks as a manmade construct and the expectation that risks should be managed and minimised (Beck) or addressing cultural variance in the face of risk, pressures and blame (Douglas). The following sub-sections draw on these three approaches to theorising about risk and discuss the key concepts and debates surrounding risk. It is important to note that although such sociocultural theories are more appropriate to exploring the topic of this thesis than more objective approaches, risk can be viewed in many different ways including both objectively and subjectively. It may be possible to objectively pursue risk probabilities and likelihoods, however how or whether these affect individual decision-making in the face of risk is a matter of subjectivity.

2.3 Reality of risk or risk perceptions

Risks can be real, observed or perceived (Thompson 1986). Thompson (1986) defines real risks as the probability of a negative consequence that exists in the real world, observed risk as the measure of real risk and perceived risk as the rough estimate of that risk made by an ‘untrained person’. He argues that perceived risks are often ‘sensationalised’ and that this is typically how the general public view or make decisions regarding risks whereas trained professionals would focus on real or observed risks.

Governmentality holds that risk is not necessarily real, but as a construct that is shaped through governmentality in how it is viewed or acted upon (O'Malley 2008). Governments may guide the population through a rational approach to risk, but how an individual within that population chooses to act may be very different. Foucauldian writers focus on relevant risk factors, for example people with a certain diagnosis will likely exhibit similar symptoms, which may be considered a rational approach (Dean 2010). But given that the hazards of a risk can never be actualised until the risk has occurred (Castel 1991), the regulatory guidance of risk management may be limited and too restrictive for its intended purposes. This discussion is returned to later in considering over- and under-regulation (section 2.4).

Through Risk Society theory, it may be possible to consider that risks are increasing, more specifically, in line with modernity, manmade risks are increasing (Beck 2013). However, this may not be the case, instead it is the fixation on risk that is increasing, not the risks themselves. Alongside this debate over reality, it is necessary to consider the severity and likelihood of a given risk. Beck (2013) argues that society is increasingly preoccupied with risk as a wholly negative concept and risks such as nuclear catastrophe are at the forefront of society’s concerns. However Mythen (2004) argues that the more severe risks are not the most focussed upon, for example one may recognise nuclear catastrophe as a more severe risk than losing one’s job, however one is more likely to be concerned with losing said job over nuclear catastrophe. Likewise, “the fact that a particular risk may not directly impact on an individual who fears it does not invalidate its status as a risk” (Mythen 2004, pp. 111). Perhaps the reality of a risk should not necessarily be the predominant focus in understanding risk, instead it is the perception of risks that is important in order to regulate (or self-regulate) risk.

Perceptions of risk can be divided into “either rational and based upon empirically proven knowledge or irrational, being based on hope, faith or beliefs that are not justified by experience or scientific knowledge” (Zinn 2008, pp. 440). A rational risk is considered to be based on evidence, however lacks the importance of subjectivity; whereas an ‘irrational’ risk is based on subjectivity such as beliefs, and is considered to reject expert knowledge or facts. The word ‘irrational’ here does not reject the importance of that perspective; instead it considers that perspective to be less evidence-based than rational risks. Thus the argument is not which perception is right but instead demonstrates further complexities of risks and varying approaches to risks. Perhaps more appropriately, Mythen (2004) discusses multiple rationalities: scientific rationality (based on knowledge and facts) and social rationality (based on subjectivity, social knowledge and beliefs).

According to Foucauldian writers, risk governmentality is a systematic calculation and employment of knowledge as rational (Dean 2010). That is a government may objectively consider risk through a rational approach, whereas the public may be more inclined to consider risk through an irrational approach. In the face of uncertainty within Risk Society, it may be possible to argue further that the public may irrationally view risk as something to be avoided whilst focussing solely on the negative repurcussions of taking a risk. However, as Cultural Theory demonstrates, cultures may have differing knowledges and experiences of risk on which they base their decisions. Thus, the public perception of risks may not be entirely as irrational as could be assumed based on Risk Society theory.

2.4 Responsibility

Within the governmentality notion that governments should be held responsible for regulation of the population, there must always be a balance between over-regulating and under-regulating the population. If a government over-regulates, the population may feel restricted and individualisation is removed. In under-regulation, there is surely the chance for anarchy and increased uncertainty. Likewise, Beck (2013) argues that society no longer trusts experts and governments through the example of the Chernobyl Disaster, which led to a decrease in trust in the expert-led research into the use of nuclear power. Giddens (1991) discusses this shift from expert information in terms of reflexivity, where people are more aware of themselves within society and can therefore choose to accept or reject ‘expert opinion’ and form their own knowledge regarding risk. An important aspect born out of Risk Society theory is that individuals are viewed as responsible for risks and are becoming increasingly self-reliant in understanding and managing them (Lupton 2006).

Historically, institutions (including governments, science experts and legal professionals) led risk knowledge in calculations and management, however Beck (2013) argues that through faltering and repeatedly failing to protect the populations these insitutions aimed to serve, the institutions have been left open to public doubt. This shift towards individualisation and self-reflexivity, and through Cultural Theory, the ability to assign blame to ‘others’ who threaten one’s culture may further perpetuate distrust in experts or institutions. This may be further exacerbated through the mass media which actively encourages chastisement of institutions that fail the population (Mythen 2004) (this is returned to later in section 2.5).

In turn this shift towards self-reflexivity may mean that people are looking for alternative sources of information (Taylor-Gooby and Zinn 2005). This can be seen in the current UK 'Brexit' debate and politician, Michael Gove's comment that "people in this country have had enough of experts" (Mance 2016) and also in the USA election of Donald Trump for president as US citizens search for an alternative from the "political system that wants to serve itself" (Fishwick 2016). Again, this notion of alternative sources of information is returned to later in section 2.5.

As described earlier, there are differences between scientific rationality and social rationality in the face of risk. Therefore the distrust in experts as argued by Beck (2013) may be more of a difference of opinions. That is that institutions approaching risk through scientific rationality may ignore social rationality whilst the public employing social rationality may not understand scientific rationality (Mythen 2004). Furthermore, a criticism of Risk Society theory is that this notion of distrust is not generalisable to all public as the term 'public' refers to an unfathomable range of different individuals and cultures (Mythen 2004). Both Foucauldian governmentality and Beck (2013)'s Risk Society may be criticised for not acknowledging the impact of cultures. Cultures develop their own knowledges and understandings of risks as alternative experts (Mythen 2004).

Risk society and governmentality both rely on a passive public, but cultural theory draws on active agency for meaning-making in the face of risk. However, members of a culture can also sub-consciously accept beliefs and practices of that culture although the source of information may vary. Instead of relying on institution-led expertise, individuals may instead rely on family, friends, colleagues and others as a source of information (Mythen 2004). In Cultural Theory, individuals may align themselves with certain cultures who share their experiences and values. This could be argued as not too dissimilar from governmentality categorising, however, one's alignment with a certain culture allows for flexibility to move between cultures depending upon the situation and context. Through Cultural Theory then it is possible to understand how differences between expert and public rationalities may form through differing knowledge, beliefs and values.

2.5 Movement and communication

Movement is a key aspect of society today, with the ability to move geographically whether for residence or holiday, it is more possible for an individual to encounter social interactions and cultural diversities than ever before (Mythen 2004). Exposure to diversity of knowledge should not be limited only to face-to-face encounters; as has already been noted in section 2.4, the emergence of mass media has, in Beck's eyes, encouraged Risk Society. However, as Mythen (2004) criticises, Beck fails to recognise the importance of economy within structures of mass media. That is, mass media serves to benefit the elite few who own it financially and could therefore be considered as a tool for governmentality as opposed to a society-serving tool for disseminating and communicating facts and news. However, with the invention of the internet, one's ability to consume a range of diverse media has increased. Indeed anyone can choose to create media, and in turn anyone can choose which media they consume. Culturally speaking, one can now align oneself not only to a certain culture, but also engage with different cultures within media.

The media is a source of information and evidence in risk identification and management strategies, therefore Beck (2013) considers it a tool serving to communicate between scientific and social rationalities (as discussed above in section 2.4). However, Beck fails to grasp ownership of power within media, for example media can be selective in what and how it reports, often embroiled with inaccurate information. There are then a number of different mediums through which an individual may be influenced (whether actively or passively) and through self-reflexivity may impact upon how they understand or act upon risks.

2.6 Summary: Risk concepts and theories

Risk is concept-laden and a challenge to define. There are numerous theoretical approaches to risk; of most importance to the present thesis are sociocultural theories as they do not overly objectify risk in a reductionist manner. Instead they consider the impacts of society and cultural diversity in the face of risk. Governmentality considers risk to be a construct of governments (or institutions) to regulate a given population. Risk Society theory considers that society is preoccupied with negative aspects of risks and that risks should be mitigated or erradicated. Cultural Theory, in constrast to the other two theories recognises the importance of cultural diversity in the face of risk. Individuals can align themselves to certain cultures and in turn must act appropriately within those cultural boundaries but will also likely be impacted by overarching societal norms and expectations and be subjected to governing regulation and surveillance.

Risk can be viewed objectively or subjectively, it can be approached rationally or irrationally, and can be real or perceived. Within this thesis, not one of these polarities is highlighted as the most appropriate form of understanding a risk, instead it is assumed (and demonstrated above) that individuals may comply with each. Therefore, the question is not of whether a risk should be objective/subjective, approached rationally/irrationally or considered to be real/perceived. Instead it is acknowledged that all of these approaches and considerations should be understood before considering how an individual may understand risk. There are therefore different ways of recognising, understanding and managing risk.

Much of the debates in the risk literature compare these differences between institutions with scientific rationality and the public with social rationality (therefore inclusive of all perceptions of risk as acceptable and grounded within some form of evidence). However, the danger of such debates is in viewing the lay, public, population as a whole without recognising the impact of culture – that is how one person interacts with risk may be different from another. Having said that, an individual may not only be impacted upon by their own culture, but also by societal norms and impacts from institutional practices. Again, the purpose of this literature was not to afford one theoretical position as more or less correct than the others, but instead attempt to make sense of the literature surrounding risk in dementia care in terms of cultural and social theories of risks.

Each theory with its own merits and pitfalls have shaped the current thesis both in relation to understanding the literature and findings of the present study but also the methodological assumptions that have shaped this study (discussed later in chapter 5). Moving forward, the following chapter (chapter 3) pertains to risk in dementia care literature and draws upon discussions within this chapter to position understanding of risk in dementia care, within wider cultural and societal norms.

Chapter 3: Risk and dementia

Dementia refers to a variety of diseases of the brain; symptoms can include difficulties in cognition and functioning to varying degrees based on the disease. Due to the nature of dementia, everyday risk can increase, and equally, due to the various diseases dementia encompasses, the risks will be different depending on the individual and their diagnosis. Risk can take many forms and the literature demonstrates that there are health/safety risks and other risks associated with quality of life (QOL), wellbeing and other psychological constructs (non-safety). The latter, Clarke and Mantle (2016) eloquently describe as 'silent harms', that is harms that are not as visible or obvious as the physical, health and safety risks.

This chapter aims to discuss key aspects of risk in dementia care and literature that demonstrates different understandings of risk between the dementia care stakeholders (person with dementia, family caregivers and practitioners). The chapter builds on the previous discussions of theoretical approaches to risk – the premise of which is that each dementia care stakeholder could be considered a culture in their own right (that is assigning different weightings to different experiences, values and knowledge). Therefore, their understandings and decisions regarding risk for the person with dementia will likely differ. Equally, these stakeholders may also be impacted upon differently by governmental and societal expectations in light of risk. Initially, the chapter focusses on capacity and policies as the context for dementia care in the UK. Following which is a discussion of key papers and models pertaining to understandings and management of risk in dementia care for each of the three stakeholders. The final section then discusses the differences between the stakeholders and reasons why they may approach risk differently.

3.1 Context: capacity and policies

Dementia affects cognition and memory, this therefore brings into question the person with dementia's capacity to be able to make decisions regarding risk. To summarise the key principles in the Mental Capacity Act 2005 (DH 2005): capacity must be assumed unless established otherwise, all practicable steps must be taken to aid the person to make a decision, an unwise decision is still a valid decision, decisions made on a person's behalf must be in their best interests and decisions must be the least restrictive to the person's rights. It should also be noted that much like the symptoms of dementia, capacity is fluid, it changes moment to moment, therefore one should never consistently hold the label of 'lacking capacity' without a new assessment or check for each decision they face. It should therefore hold that a person with dementia has the right to regular capacity checks for each risk or decision they face and just because someone has the diagnosis of dementia, ‘a lack of capacity’ should never be assumed. Equally just because a person with dementia makes a seemingly ‘poor decision’, as long as they have understood and weighed up the benefits and consequences of that decision, their decision should stand.

The responsibility of assessing capacity is held by HCPs who have a duty of care to their patients and must abide by laws and policies when providing care to patients with dementia. They undertake extensive training (including laws such as the Mental Capacity Act 2005) to become experts in their field. Historically, risk was viewed negatively and protecting people with mental illness (particularly, but not necessarily exclusively, those lacking capacity) was the accepted approach and often this protection was sought through institutionalisation (Mitchell and Glendinning 2008).

The current approach to health and social care for people with mental illness (including those with dementia) is care in the community and such policies as *Nothing Ventured Nothing Gained* (DH 2010) aim at promoting positive risk-taking or risk enablement for people with dementia. Risk enablement is supporting the person with dementia to do what they can for as long as they can. This is directly opposing the concept of risk aversion which aims to reduce or eliminate risks altogether. Risk enablement encourages a balance of risk outcomes and considering both safety and non-safety aspects of risk. This therefore recognises a policy-driven attempt to counteract the potential negative associations of risks as born out of Risk Society theory. The challenge is in recognising which risks are appropriate for enablement and which risks should be reduced.

Family members do not undertake such training upon becoming a caregiver and must rely on HCPs to make capacity assessments. However through policies and guidance, patients and family caregivers are being afforded more choice and rights to make their own decisions which represents a shift in responsibility (Mitchell and Glendinning 2008) – or responsibilisation. For example, *Risk, Responsibility and Regulation – Whose risk is it anyway?* (BRC 2006) argues that managing risk is typically assumed to be the government’s responsibility to maintain the safety of the public and that the public should move away from this reliance on the government in managing risks. The policy *Independence, choice and risk* (DH 2007) describes a consultation with the public who requested more choice in their healthcare. In response the policy provides key principles to guide people in making choices. The *Making choices: taking risks* (CSCI 2006) policy for social care for older people argues for supporting people to make their own *informed* choices regarding risk and thus affording them their independence. However, aiming for a societal shift away from expert-led risk management and toward healthcare service users taking responsibility for their own decisions is not without challenges – these challenges are drawn upon throughout the remaining chapter. One of the biggest challenges in dementia care is in how the different stakeholders collaborate to ensure the best care for the person with dementia in the face of risk.

3.2 Different understandings of risk in dementia care: key studies and models

The literature surrounding risk and dementia consistently demonstrates differences in risk understandings and decisions between the person with dementia, their family caregivers and health and social care practitioners (Clarke 2000; Gilmour et al. 2003; Beattie et al. 2004; Dickins et al. 2018). The following section draws upon these key studies and others to highlight what is currently known about such differences between the various stakeholders. The initial sub-section outlines the above four key studies in risk in dementia care. Following which are several sub-sections pertaining to the differences between stakeholders in dementia care.

3.2.1 Key studies in risk in dementia care

Here outlines four key studies of risk in dementia care, which particularly highlight the differences between the dementia care stakeholders.

Clarke (2000) explored meanings of caring for a person with dementia from family caregivers and and social care staff in North-East England. The study was designed in three phases. The first involved 14 caregivers and developed concepts about the meaning of caregiving. The second was a questionnaire for 60 care staff (health, social and voluntary) to explore issues of working with people with dementia and their families. The third clarified emerging theory through case studies of 9 family caregivers and 25 practitioners. Through grounded theory, the study identified different knowledge bases used by family caregivers and care staff. Care staff typically relied on technical knowledge of dementia and often focussed on health and safety risks. Family caregivers relied more on interpersonal aspects of their relationship and may feel threatened by care from outside the home environment. The study concludes that there is a need for both parties (care staff and family caregivers) to recognise, understand and respect the differences in knowledge bases upon which they understand risks in order to work in partnership for the person with dementia.

Although Beattie et al. (2004) did not specifically focus on risk, they discovered how risk was a key factor in the experiences of 14 people with young-onset dementia in England. They applied principles of grounded theory to data collection (qualitative interviews) and analysis. Although the aim of the study was to demonstrate how people with young-onset dementia can be interviewed and the overall conclusion was that young people with dementia are “articulate and insightful about their experiences and needs” (Beattie et al. 2004, pp. 364), four themes about the experience of living with young-onset dementia were found. These were: “(1) the general experience of living with dementia; (2) issues around dementia diagnosis; (3) concerns about age-appropriate services; and (4) risk and danger issues.” (Beattie et al. 2004, pp. 362). It is interesting that through asking questions about the participants’ experiences of dementia, the services they used and their needs, risk was identified as a theme. This perhaps demonstrates how important the concept of risk is in the lives of people with dementia and dementia care. The study demonstrated that professionals and carers often held different perceptions of risks and dangers than did the people with dementia who above all desired independence. This would often create tensions in the management of care for the person with dementia. The example given is that one person with dementia’s train pass was taken by the statutory authorities as it was deemed a risk. The authors argue the possibility that professionals may conduct ‘overly narrow’ risk assessments which in turn may remove independence from the person with dementia too early. However, the authors only interviewed the person with dementia and did not explore the position of the statutory authorities in the matter who may well have had reasons for removing the train pass that the person with dementia may not have understood, known or remembered. In dementia care there is often the issue of insight (or lack thereof) which may well impact on the appropriateness of drawing conclusions from only the person with dementia. Insight is returned to later in this chapter (section 3.3.3).

Gilmour et al. (2003) employed a case study approach to concepts and contexts of risk for people with dementia living alone in rural areas in Northern Ireland. Ten people with moderate to severe dementia were interviewed, the authors also interviewed: twelve family members, nine care staff, six GPs, four district nurses and six social workers who provided care to the ten people with dementia. The authors used a template approach to analyse the interviews; this approach is used to code and organise themes which are then applied to the entire dataset. The different members of the care team used different knowledge bases to inform their assessment of risk, for example district nurses focussed on risks that were most relevant to their role such as falling, for which the district nurses would then be involved in the follow-up care. Through multiple examples of how the different participants (and their roles) affected their judgement of risk, Gilmour et al. (2003) demonstrated possible differences of opinions and areas of tension between the stakeholders. For example, responsibility for risk was often coupled with blame; one son described being blamed if his mother were to fall because he ignored the advice from social services to move his mother to residential care. Another interesting finding was that no major incidents of harm were reported, instead the participants focussed on potential risks. This led the authors to question “should risk assessment be based on the actuality of an adverse event or on the assessment of professionals and family carers of the likelihood of an event?” (Gilmour et al. 2003, pp. 416). This question is returned to later in section 3.3.

Dickins et al. (2018) explored conceptualisations of risk for people with dementia across five groups: 7 people with dementia, 22 carers, 20 older people with no experience of dementia, 8 community nurses and 23 staff from a nursing organisation (including senior nurses, social workers and management). Data were collected through semi-structured interviews and focus groups which were analysed through thematic analysis. Through themes of risk identification, management, ramifications, conceptions of dementia and risk enablement, that authors found that each group held different perceptions. People with dementia emphasised risks pertaining to loss of independence, carers wanted to balance maintaining safety and happiness, and nurses and staff focussed more on health risks. The interesting inclusion of the older people group enabled a consideration of social stereotypes and these participants focussed on harmful risks (cooking and financial abuse) but also caregivers’ stress. Although this study was conducted in Australia, there are sufficient similarities in social context and the context of health and social care in dementia to include this study within this literature review.

I have outlined several key papers that demonstrate that there are differences in understanding and managing risks between the person with dementia, family caregivers and HCPs. The following sub-section focusses on models of understanding risk and decision-making.

3.2.2 Models of decision-making

In chapter 2 (section 2.2.3) I summarised Chicken and Posner (1998)’s 11 factors for decision-making in the face of risk. The reasons different dementia care stakeholders’ perceptions and understandings of risks may vary because the weightings they assign to those 11 factors may differ. In this sense it may be possible to consider each stakeholder as having their own culture. With separate cultures, assigning different weightings to values, experiences and knowledges, there is no wonder differences in understanding and managing risk would occur. While Chicken & Posner’s model was not specific to dementia care, it still provides a valuable starting point to address the differences between stakeholders. This sub-section addresses models of risk understanding and decision-making in risk assessments for older people and then more specifcally dementia care.

In their study in Canada exploring twelve practitioners’ risk assessments for older people, MacLeod and Stadnyk (2015) discovered that practitioners used four elements to define ‘living at risk’: ‘impairment, environment, events and outcomes or consequences’ (MacLeod and Stadnyk

2015, pp. 50). Impairment including cognitive impairment and physical impairment would suggest causality (impairment caused the risk) or contributory (impairment increased the risk). Environment typically included physical environment within the person’s home (such as scatter rugs that could present a fall risk), but in some cases considered social and economic factors (such as social support networks and finances). Events such as fires and falls would be considered in terms of frequency as evidence of a risk, for example, increased weight loss evidenced malnourishment as a risk. Consequences or outcomes typically focussed on negatives (such as negative impacts on health). However, the participants may continue to support their clients to live with risks if the potential outcomes were limited only to the client. If a potential outcome may impact or cause harm to others then the participants considered it their duty to manage the risk even if this meant going against their client’s preferences.

A definition of ‘living at risk’ that MacLeod and Stadnyk (2015) formed across their 12 participants was: “a judgement about a client’s impairment within an environment that can cause an event that has the increased potential for a negative consequence” (MacLeod and Stadnyk 2015, pp. 53). Although participants were able to identify several risks from practice, they were unable to form a clear single definition of risk. The definition formed above demonstrates that risk is multidimensional, but focuses on the negative outcomes with limited consideration of positive aspects of risk-taking. The practitioners identified seven factors that influenced their risk assessments (although not all used all seven), these were ‘capacity, occurrence, severity, imminence, frequency, support and complexity’ (MacLeod and Stadnyk 2015, pp. 55). The participants recognised that risk was a continuum (MacLeod and Stadnyk 2015) and therefore fluid and subject to change. Some of the participants discussed risks through ‘traffic lights’ with green as low risk, yellow as medium and red as high risk. Some also used ‘flags’ to demonstrate how they identified risks, with yellow flags as potential risks and red flags as situations of high risk and requiring immediate attention. This suggests that risks should be assessed frequently to ensure that risks are appropriately monitored and new risks identified.

Stevenson and Taylor (2016) explored concepts and experiences of risk from 22 family caregivers in Northern Ireland through focus groups. Grounded theory principles were applied and several themes emerged. These included: perceived risk factors (such as: activity, impairment and environment), context (such as: personal history, dementia progression), anticipated consequences (such as: harm to person with dementia or others), communication (such as: with health and social care professionals or person with dementia), management strategies (such as: aversive, accepting or enabling) and potential outcomes (such as: benefits and harms). Unlike the previous model for practitioners (MacLeod and Stadnyk 2015), this model for family caregivers emphasises the history of the person with dementia. It also focusses predominantly on consequences and potential outcomes as opposed to frequency of risk occurance which was noted by practitioners in the study by MacLeod and Stadnyk (2015).

For caregivers, upon perceiving or recognising a risk, there is then a decision to be made about how best to manage said risk. Jacques (1992, pp. 247) describes three conditions when making a decision about risks for someone with dementia: “a) to leave her in charge and accept the risk, b) to persuade her to accept help to lessen risk, or c) to take control out of her hands by compulsory means”. This decision is influenced by an assessment of that person with dementia’s capacity to make decisions themselves but said assessment is not necessarily conducted by experts with understanding of the Mental Capacity Act.

In their study of 15 family caregivers of people with dementia (12 adult children and 3 spouses) in the United States (US), Berry et al. (2015) conducted interviews over the course of two years to explore the risks and risk management surrounding functional decline. They describe three stages which are not too dissimilar from Jacques (1992). Initially a collaborative stage where the person with dementia had insight into their condition and welcomed support. There then follows a transition stage where the person with dementia may have, as their participants described, ‘spotty awareness’ of their condition and family members may monitor certain activities more carefully (Berry et al. 2015, pp. 7). Finally a unilateral support stage whereby the person with dementia no longer had insight and the family member would increase supervision, assistance and attempt to restrict certain risky activities (Berry et al. 2015). In this sense family caregivers appear to perform their own capacity assessments to determine whether the person with dementia is able to make decisions surrounding risks. The family caregivers also discussed that they may be unable to recognise risks because their family members with dementia would conceal the mistakes they made during the transition stage (Berry et al. 2015). Often in the unilateral support stage, family caregivers engage with deceptive strategies to maintain a balance between autonomy and safety whilst minimising distress (Berry et al. 2015).

In their study of caregivers for people with Mild Cognitive Impairment (MCI) – a condition that shares similarities with some symptoms of dementia - Cott and Tierney (2013) explored how 20 family caregivers in Canada recognised risks. They discuss four states of risk that were constantly negotiated and renegotiated. First, acceptable risks were everyday risks as part of living alone, the authors comment that as cognition and function declined, those previously acceptable risks would be renegotiated because the risks may have increased. Second, ‘red flags’ were signs that risks had changed and may not be as acceptable. These were gradually recognised and suggested that an action must be taken. Third, unacceptable risks were either dramatic or gradual red flags that would dictate action was necessary. Once this third state was reached, the caregivers engaged with risk-balancing strategies in attempt to return the risk to an acceptable state. Should a management strategy fail, the caregivers would try a new course of action. Once the risk returned to a state of acceptable, the process started again. The final state was continued unacceptable risk which often resulted in change of accommodation (i.e. sheltered accommodation or residential care).

Each of the above models demonstrate how risk may be understood and managed for older people, people with MCI and in dementia care. Practitioners tended to focus on health/safety risks and potential causes of harm to others. Family caregivers focussed more on their previous history with the person with dementia, attempts to maintain the person with dementia's independence and minimising distress. However, each model addresses different stakeholders separately and does not provide a model of shared responsibility and decision-making between all stakeholders. Furthermore there is no attention to the person with dementia's perspective on risk. These studies (or models) together with the literature from the previous sub-section (3.2.1), provide an overview of the differences between the stakeholders in how they perceive and manage risks.

3.2.3 Section summary: Key papers and models

The literature has consistently demonstrated that HCPs are more likely to focus on health and safety risks (Clarke 2000; Gilmour et al. 2003; Dickins et al. 2018), family caregivers aim to find a balance between both health/safety and non-safety (Clarke 2000; Gilmour et al. 2003; Dickins et al. 2018), and people with dementia tend to focus more on non-safety, typically reduced independence (Gilmour et al. 2003; Dickins et al. 2018). Further differences demonstrated within the literature are that family caregivers may focus more on the consequences or outcomes of a risk (Stevenson and Taylor 2016), whereas HCPs may focus more attention on the frequency of a risk occurring (MacLeod and Stadnyk 2015). As discussed in Clarke (2000) differences may occur due to a reliance on different knowledge bases, where HCPs may rely on technical knowledge of dementia and family caregivers focus on interpersonal knowledge of the person with dementia. Both HCPs and family caregivers may negotiate risks through similar systems of risk recognition, such as red and yellow flags (Cott and Tierney 2013; MacLeod and Stadnyk 2015), however the risks they identify and their management strategies may still differ.

Building on the literature discussed here, and theories (discussed in chapter 2), the following section highlights further differences between the dementia care stakeholders and considers how and why these differences may occur when considering the stakeholders as independent cultures.

3.3 Further differences between care cultures

Building on the previous two sections pertaining to UK dementia care context and key studies and models in risk decision-making, this section considers further differences between dementia care cultures. Furthermore, it draws upon the theories introduced in chapter 2, to understand how and why these differences may occur.

3.3.1 The label of dementia

A sticking point in dementia is judgement, or lack thereof, therefore capacity checks are crucial in recognising whether a person with dementia has the ability to make decisions for themselves (see section 3.1). People with dementia often appear to be excluded from the risk assessment process (Beattie et al. 2004); this could be due to the label of 'dementia' which can lead to the assumption of lacking capacity (Dickins et al. 2018). Indeed through governmentality, it is possible to consider that all people with dementia could be categorised as lacking capacity due to their diagnosis and are also subject to higher levels of surveillance and regulation. This in turn leads to unnecessary forced cessation of particular activities through over-regulation. It can also lead to potentially increasing or creating new risks. In their study of electronic tracking devices to aid in managing the risks associated with walking about independently, Robinson et al. (2007) noted that although caregivers considered such devices to provide 'peace of mind', a person with dementia identified that risk of vulnerability and becoming a target of theft would increase.

Clarke and Mantle (2016) argue away from viewing the person with dementia as vulnerable and instead consider the contexts or situations within which someone may become vulnerable. This shift in perception may enable HCPs to address risk from a more person-centred perspective. This should not then become a governmentality of every risky situation making every person with dementia vulnerable, instead the context and background to that patient must determine which situations may make them vulnerable or place them at risk. This one-size-fits-all approach does not work in terms of personalisation and thinking of the person as an individual; nor does it consider the complexity of their dementia diagnosis and symptoms (Kales et al. 2015). Risk assessments need to be more frequent, not a one-off assessment (Clarke et al. 2011a), much like with capacity assessments. This would then avoid the over-regulation associated with governmentality approaches to risk management in dementia care and lead towards a more person-centred approach. This is returned to in section 3.3.4.

For family caregivers, some situations that prior to diagnosis would not have been seen as a risk, suddenly become risky with the dementia diagnosis (such as living alone) (Dickins et al. 2018). This is not too dissimilar to the above comment where HCPs may assume a lack of capacity due to the diagnosis of dementia, family caregivers may also hold some assumptions of dementia which could impact on their understanding of risk.

In some cases the person with dementia may not have insight into their condition and the risks surrounding it (Gilmour et al. 2003; Steeman et al. 2007). Due to decline in cognition they may lack insight into their condition. They may also not understand their condition or may have denial about their diagnosis (Steeman et al. 2007). This is often due to lack of societal awareness and understanding of dementia and the social stigmas attached to dementia. The stigma that is associated with dementia remains prevalent, despite the efforts of such charities and groups as the Alzheimer’s Society to raise awareness and understanding of dementia within the UK (such as the Dementia Friends campaign (AS 2017)). It is therefore challenging to discern the person with dementia’s understanding of associated risks.

3.3.2 Expertise

Health and social care professionals have undertaken extensive training to become experts in their field. They therefore could be considered an authority on dementia and the risks associated. Their knowledge of dementia through past experiences of patients or through clinical knowledge of dementia progression is how they are likely to form an understanding of the risks associated with living with dementia (Clarke 2000). However, family caregivers and people with dementia should be considered experts in the knowledge of the person with dementia. Both expertise (medical/social care knowledge and knowledge of the person) are important in providing gold-standard person-centred care and tailored support around risk.

In considering the professionals as an expert in dementia care and risk, family caregivers may require advice on risks, have risks pointed out to them (Clarke et al. 2011a) and have information resources provided to them (Peterson et al. 2016). Interestingly, in Tudor Car et al. (2017)’s study of clinicians’ experiences of safety in the care of people with dementia, a challenge highlighted was that family caregivers required more education in identifying the risks and knowing when to approach professionals for help and advice – perhaps demonstrating the shift of responsibility towards family caregivers instead of professionals (section 3.1). With this shift, family caregivers may not know that they can still involve professionals.

The literature surrounding risk and living with dementia is relatively lacking in including the perspectives of people with dementia. Often such literature is reliant on family caregivers and how they perceive and manage risk in the best interests of their family member with dementia. Although this may be appropriate to a certain extent, Miller et al. (2018) argued that although 75% of their sample of 228 caregiving dyads (person with dementia and family caregiver) exhibited a shared understanding of the person with dementia's values, 25% of caregivers underestimated these values and within the 75% there were discrepancies between the members of the dyads. This was especially apparent in recognising the importance people with dementia placed on autonomy; if the caregiver underestimated this importance they would be more likely to initiate support that could lead to dependence. Equally, the importance people with dementia placed on 'not being a burden' was underestimated by caregivers, again leading to their providing more care/support than the person with dementia required or wanted. This could be a demonstration of governmentality over-regulation through increased surveillance.

Some caregivers report that their family members with dementia reduce or stop certain activities themselves (Berry et al. 2015). This potentially suggests that they recognise the activities are becoming more risky (Clarke et al. 2010; Berry et al. 2015) through self-regulation and self-reflexivity. Often they discontinue an activity because they lack the insight to continue a necessary task or because they lose confidence in their abilities (Berry et al. 2015). Dickins et al. (2018) note that people with dementia aimed for independence and often modified their ongoing activities to ensure safety. This reduction of activity can be a 'mixed blessing' for family caregivers who may recognise that the person with dementia reduces risks by reducing certain activities but alternatively, some activities are crucial to maintaining one's health (such as cooking).

3.3.3 Enablement and aversion

HCPs often focus on health and safety issues due to their extensive training and knowledge but this may not extend to other aspects of the person with dementia's life. As alluded to earlier, this may be due to a reliance on the governmental approach. However, person-centred care is considered the gold-standard (DH 2018) which should take into account these other aspects through individual assessments. Traditionally the aim of the HCP was to protect, and through expert knowledge provide care to their service users, however with more recent policies such as *Nothing Ventured, Nothing Gained* (DH 2010), the focus has moved towards providing patients with more choice and support to take risks (Bailey et al. 2013). The ethical complexity of risks requires balancing duty of care whilst encouraging autonomy (Marsh and Kelly 2018) and may therefore be a challenge in practice. Again, this balance can be understood further through governmentality and the need to strike the balance between surveillance, regulation and individual choice.

A safety-first approach prioritising health and safety risks in turn may increase other 'silent harms' that are equally important but less recognisable (Clarke et al. 2011a; Clarke and Mantle 2016). The management of safety risks are also easier to recognise and manage; when a risk can be seen and easily demonstrated, it is easier to decide upon a management strategy (Clarke et al. 2011a). Likewise, negative associations with risk eliminate the opportunity to take risk and reap benefits of risk-taking (Marsh and Kelly 2018) as can be recgonised through Risk Society and the increasing preoccupation with negative outcomes of risks. There needs to be a balance between benefits and harms (Taylor 2006).

Family caregivers tend to balance health and safety concerns with silent harms. For family caregivers, maintaining the person with dementia in the community was often seen as preferable in order to protect personhood and avoid distress (Clarke 2000; Cott and Tierney 2013). Similarly, management strategies used must also avoid distress (Dickins et al. 2018). Closer monitoring and increased supervision is often a method used by family caregivers to support their family members with dementia (Gilmour et al. 2003; Clarke et al. 2010; Dickins et al. 2018) which may be seen as a form of governance through surveillance. Dickins et al. (2018) takes this further by stating that family caregivers felt some activities were too important for the person with dementia to stop and therefore used closer surveillance to allow the person to continue. In some cases, it is necessary for the family caregiver to simply accept the risks. However, a challenge of accepting risk is uncertainty (Clarke et al. 2011a) which can lead to an increase in controlling behaviours in order to alleviate uncertainty for example, increased supervision (Buri and Dawson 2000) – or over-regulation through surveillance.

Family caregivers often face a difficult balancing act between maintaining safety but also encouraging independence and autonomy (Robinson et al. 2007; Cott and Tierney 2013). Stevenson and Taylor (2016) found that their participants (family caregivers) would discuss more health/safety concerns as risks, and discussed other concepts (silent harms) separately from risk. In comparison to HCPs, family caregivers tend to appear more risk-enabling, or at least accepting of risks, instead of attempting to eliminate them (Stevenson and Taylor 2016). This is because they have a history with the person they care for, they have a past relationship and understanding of their family member prior to dementia and therefore are more likely to take this into account when managing risks (Clarke 2000; Stevenson and Taylor 2016).

This prior relationship with the person with dementia may frequently impact upon their decision-making in the face of risk. Maintaining this past relationship is often important to the family caregiver, and risk management strategies that compromised this relationship were viewed as the most difficult decisions (such as causing distress) (Clarke 2000). In these cases, the family caregivers often sought permission from others to manage the risks in order to share responsibility and accountability for that decision (Clarke 2000). Thus even through increased choice,self-regulation or self-reflexivity, the family caregivers are still looking for external governance by way of advice or supporting the decisions they make. The impact of becoming a caregiver for a family member is not limited to starting to make decisions for that family member and may also be considered a form of biographical disruption (Bury 2001). Following a diagnosis of dementia for their family member, the family caregivers often focussed on reconstructing their relationship and their own identity by way of normalisation (Buri and Dawson 2000). These challenges associated with biographical disruption must also be supported by HCPs.

People with dementia place importance on autonomy and 'not being a burden' (Steeman et al. 2007; Miller et al. 2018) and may demonstrate a lack of appreciation for care, help and support and may resent the notion that help is necessary (Gilmour et al. 2003). Furthermore, people with dementia have been reported to engage with covert risk-taking behaviours (that is secretly continuing activities that their HCPs or family caregivers have advised against) (Mitchell and Glendinning 2008; Clarke et al. 2010). This could promote the idea that people with dementia would prefer to remain independent, therefore their aims are to manage silent harms instead of safety risks. This idea of covert risk-taking may be the person with dementia considering their HCPs and family caregivers' actions as a threat to their way of life, their choices and their culture. However, as discussed above, their judgement may be impaired and they may lack insight into the safety risks associated with their conditions.

3.3.4 Narrow risk assessments

Professionals are bound by policies and procedures from their organisation's approach (a higher form of governance), most of which reduce risk assessments to a 'tick-box exercise' – a list of aspects to consider in assessing a risk (Sykes 2005). It can be argued that by attempting to provide a 'one-size-fits-all' tick-box approach to risk management, person-centred care cannot be afforded, and professional judgement is removed (Sykes 2005). Each professional is different with varying degrees of knowledge, judgement and experience, which in turn affects their approach to risk (Mitchell and Glendinning 2008; Clarke et al. 2011a). These types of assessments also avoid the true complexity of risk assessment; comprehensive risk assessments would need to be much longer (Clarke et al. 2011a). Tick-box approaches, rules and guidelines may lead to automatic processes of recording each potential risk instead of considering the risks that are present (Clarke et al. 2011a). This returns to the previously discussed debate of real versus perceived risk; it could be assumed that through knowledge and expertise professionals would be more likely than, for example, family caregivers to focus on 'real risks'. However, evidence from discussions surrounding the tick-box approach suggests that professionals are discouraged from using professional opinion (Sykes 2005) and instead address every risk for each patient, whether present or potential. This is one of the main criticisms Rose (2009) indentifies of governmentality -

through such checklists experts are removed of professional judgement. This in turn leads to perceived risks that have may never come to fruition for that patient (Clarke et al. 2011a) through over-regulation.

3.3.5 Contradictory policies

It would be easy to consider through governmentality that HCPs are to blame for not providing appropriate risk assessments to the service. However, HCPs are bound by policies and duty of care to their service users as a higher form of governance. With so many policies and guidelines, coupled with laws, legislation and duty of care (over-regulation), there are increasingly contradictions and complexities around how best to provide care (Bailey et al. 2013). Maslow et al. (2002) explored guidelines and policies in the USA prior to 2002 and discovered 17/23 policies made reference to risk and/or safety concerns for people with dementia. Although these may make mention to balancing safety and autonomy, the advice given surrounded three very specific risks (falling, wandering and driving) and promoted risk-aversive management strategies (for example using door locks that people with dementia may not be able to open in order to manage ‘wandering’). Although, policies and guidance may have moved forward since these policies were regarded the gold-standard, the messages within them may still be engrained within the culture of care provision. This paper relates to US policies in risk and dementia care, however, Taylor (2006) in the following discussion explored healthcare practices within the UK and found further challenges in risk management practice in dementia care.

Taylor (2006) discovered six key paradigms for risk management for older people within the UK. Each were consistent within themselves in that a single paradigm would not contradict itself, but when considered collectively, all six consistently contradicted each other. For example, in one paradigm the professionals talked of meeting the needs of their service users, but another paradigm was more financially-driven to prioritise accounting for resources. This created a tension between wanting to provide resources to those service users who needed or requested them, whilst reducing costs to the organisation. Additionally, with the growing prevalence of dementia, resources are becoming increasingly scarce to match the need within health and social care (Adams 2001; Gilmour et al. 2003; Beattie et al. 2005; Taylor 2006; Tudor Car et al. 2017). Alongside the need for family caregivers to reduce this financial burden there is also a requirement for HCPs to reduce resource demands to those with higher priority and in line with their organisation’s approach.

Through considering Taylor (2006) paradigms within which the professionals practiced risk management, there was a strong theme of defensible decision-making and less about doing what was right for the service user. With so many policies and duties to service users, the employment of professional judgement is reduced, which in turn leads to shifting managing risk away from the service user to the service itself (Taylor 2006). This is discussed further in the following section 3.3.6. Although this paper discussed risk management for older people, not specifically people with dementia, within the NHS the mental health services are divided into ‘adult’ and ‘older people’ mental health (OPMH) services. Therefore the policies and practices that govern HCPs in OPMH services cover both those older people with and without dementia.

Using interviews with caregivers and HCPs, Behrman et al. (2017) demonstrate that HCPs recognise their need to act within policies and guidelines but that these may not align with family caregivers’ approaches. Interestingly, the family caregivers also recognised that HCPs could only act within policies and organisation’s approach to practice (Behrman et al. 2017) perhaps demonstrating that there is a shared understanding of what each member’s responsibilities are.

It should also be noted that HCPs not only have a duty of care to the person with dementia, but also to family caregivers (Clarke 2000; Clarke et al. 2011a; Tudor Car et al. 2017) (see: NICE (2018)). This is in line with recent policies that aim to support caregivers in order to maintain people with dementia in the community for longer (one of the government’s key aims). This duty of care extends further to the public also in recognising the risks people with dementia may present to the public (Taylor 2006; Mitchell and Glendinning 2008) – for example continued driving. Thus the complexity of the decisions HCPs make regarding risk increases. One huge challenge for HCPs is in recognising and meeting multiple needs and expectations of their service users, caregivers and the public (Taylor 2006; Gridley et al. 2014).

As Beck states “if three scientists come together, fifteen opinions clash” (Beck 2013, pp. 167), the same can be seen within policy-making. With numerous contradictions across policies (for example risk enablement versus duty of care), it can easily be understood that professionals may not always be able to fulfil the expected standards of each individual policy. Instead, policies should be redressed and considered always in comparison to each other to provide a succinct set of guidelines for professionals to work within.

3.3.6 Blame

As discussed earlier, a key aspect of Cultural Theory is that inherent within the notion of responsibility is accountability and blame. Family caregivers may typically recognise the expertise of their HCPs, and may attempt to seek out HCP advice (Buri and Dawson 2000). They may however, ignore such advice if it does not align with their own experiences or values as a family (such as not moving the family member with dementia to residential care) (Gilmour et al. 2003).

This demonstrates that family caregivers may consider HCP regulation as a threat to their values as a part of their family culture. If they ignore expert advice they may feel blamed by HCPs should anything go wrong (Gilmour et al. 2003). In considering HCPs as the authority on dementia care, family caregivers may fear questioning HCP advice or become silenced altogether in the care process (Womack et al. 2017). Seemingly a lack of shared responsibility and decision-making leads to further complications when working together for the care of the person with dementia (Womack et al. 2017). This also impacts on the family caregivers' ability to make decisions for the person with dementia.

Fear of litigation was commonly reported as an underlying concern by HCPs when managing risks for clients with dementia, especially in attempting to balance duty of care and taking a risk-enablement approach (Gilmour et al. 2003; Clarke et al. 2011a). Mitchell and Glendinning (2008) discuss this fear of litigation in relation to the change over time towards openness and an increase in public scrutiny and readily available information on claims of malpractice. This in turn can lead to service users and caregivers to doubt their HCPs which feeds the distrust of HCPs as experts as a product of Risk Society. Acting within practices through which governmentality operates (policies and maintaining duty of care and safety for person with dementia) means HCPs need to be accountable for their practice to avoid litigation (Adams 2001; Taylor et al. 2018). This in turn could be a reason for HCPs to be more likely to follow narrow risk assessments instead of professional judgement.

The fear of litigation associated with HCP practice may also prevent person-centred care (Clarke et al. 2011a). The policies and organisation's approach that HCPs are bound by may be risk-aversive, therefore HCPs are expected to adopt the organisation's standpoint despite their professional opinion for fear of litigation (Clarke et al. 2011a). Although the majority of the literature considers that HCPs are likely to aim to reduce risks (for example Taylor (2006)'s 'minimising situational hazards'), there is evidence of risk-tolerance or risk-acceptance in aiming to support the person with dementia to maintain independence (Clarke et al. 2011a). This may not be entirely risk-enabling, but is certainly a step away from aversion.

3.4 Summary: Differences between care cultures

In considering the dementia care stakeholders as having their own separate cultures from one another, it is easy to recognise how their different cultural understandings, experiences and values may cause challenges in collaboration. However, rigidly viewing the differences between the stakeholders as simply due to them being different cultures does not demonstrate the full picture of how these different understandings are formed. Each stakeholder also belongs to society. Through governmentality and the notion that society may engage with surveillance and regulation, societal expectations may too have an impact upon how different stakeholders make decisions regarding risks. If a stakeholder does not adhere to societal expectations they may be subject to consequences, including blame, for their actions.

HCPs typically focus on health/safety rather than non-safety risks. This may be in part due to the visible nature of health/safety risks without knowing the person with dementia prior to their diagnosis. It may also be in part due to governmentality that people with dementia are all assigned risks due to the the dementia diagnosis. This may not always be an explicit application of governmentality from policy-makers on risk assessment checklists, but through the use of such assessments, the recognition of these risks may be subtly engrained within their cultures. Likewise such checklists reduce and often remove professional judgement. This removal or reduction of professional judgement may be further enflamed through Risk Society's distrust of experts and movement towards self-reflexivity. Furthermore through contradictory policies and guidance, even if the HCP felt they could use professional judgement the conflicting governance of their practice may make it near impossible to do so.

Historically all persons with mental health conditions required protection but also themselves were considered dangerous to society. In considering Cultural Theory, it is possible that the traditional methods of mental healthcare could have in part been due to the threat people with mental health posed to the rest of society. In considering mental health in this way, they should be removed from society as they pose a risk. Through Risk Society's fear of the unknown and preoccupation with negative consequences of taking risks and governmentality's approach to categorising, regulation and surveillance, it is easy to understand how then every person with dementia could be viewed as requiring protection, lacking capacity and as dangerous to society. Since the days of institutionalisation however, care has moved to the community and viewing the person with dementia as an individual and not as a threat to society. However, such a change does not necessarily eradicate knowledge that is engrained within a culture. It is still possible that despite the HCP and policy-makers' best efforts, culturally-engrained historical understandings may still impact upon assessments and decisions. It is through such culturally-engrained understandings and the impact of Risk Society and governmenatlity that a safety-first approach may still remain.

Family caregivers typically aim to find a balance between health/safety and non-safety risks. They are often found to promote risk-taking for their family members with dementia, however not always. Partially a lack of risk enablement may be due to a similar governmentality to that perhaps seen amongst HCPs and considering a person with dementia as lacking capacity to make informed decisions. Or from a wider societal perspective of the person with dementia as a risk. Further through social surveillance, there is a societal expectation that they are responsible for the safety of the person with dementia. However, often family caregivers build their understandings of risk more from their knowledge of the person with dementia prior to diagnosis. In this sense they have access to privileged information that could aid a more person-centred approach to risk assessment. In current practice, this information is often sought by HCPs through the diagnosis and management phases of dementia. However, with limited resources and the movement towards choice, the relationship with HCPs reduces and surveillance falls to family caregivers.

With this shift in responsibility there is an interesting dilemma for family caregivers. Through Risk Society they may distrust HCPs and through over-regulation (often resulting from past governmentalities), family caregivers now must take on more responsibility and accountability than before. They often struggle to find the advice and support they were once reliant on HCPs to provide and instead must (or choose to) find alternative sources of information. Their aim is to typically maintain their family member in the community as long as possible and in order to do so must take on the new role not just of caregiving but of surveillance and regulation.

In accepting responsibility, family caregivers too accept with it accountability. They are not immune to blame through having more choice in the care of their family members. Instead quite the opposite, leading to them potentially attempting to seek ways of managing accountability and achieving justifiable risk management practices.

It is important to recognise that the family caregivers themselves experience vastly new challenges as a result of their family member’s diagnosis. This is a biographical disruption in the face of becoming a caregiver which requires another type of support which should be readily available from HCPs but often is not.

People with dementia’s views on risk are often not present within the literature. Perhaps this in itself is an example of governmental assumptions of lacking capacity/insight. Typically people with dementia aim to maintain their independence. They may engage in self-regulation by reducing risky activities in light of their new diagnosis. They may resent the help that is offered to them, perhaps as a result of over-regulation, by HCPs and family caregivers. They may also engage in covert risk-taking, which could be because they perceive a threat from HCPs and family caregivers to their way of life and right to make their own choices. Alternatively, they may lack insight and be unable to make informed decisions about ongoing risky activities.

In considering the stakeholders as separate cultures with different weightings assigned to such factors as knowledge and values, it is understandable that there are then differences in understandings and therefore risk management. These cultures are then impacted upon in different ways by societal expectations and understandings some of which have been addressed here through sociocultural theories. However, the literature has not explored the impacts of these societal expectations and understandings on how the different stakeholders understand and manage risk for people with dementia. The challenge of such a project is in recognising that there are many factors that impact upon care and risk management. Further still there may be different sub-cultures amongst the stakeholders, for example, the role a nurse has in comparison to an occupational therapist may differ in dementia care and therefore affect their understandings of and management of risks further still. Likewise spousal caregivers may be very different from adult children as caregivers.

Therefore, in order to address societal understandings and impacts upon risk decisions in dementia care, one must address a single culture, or further still a sub-culture. This would aid in recognising where potential societal understandings differ in how they impact on a given stakeholder. The literature has focussed considerably more on HCPs' practice in managing risk for their patients with dementia than family caregivers or people with dementia. It could also be argued that where policies are shifting responsibility for care management towards family caregivers and away from HCPs, it is important to embrace this change within research in order to understand how risk is understood and managed by those who are predominantly more involved in the care of people with dementia. Also, current policies (as discussed earlier in section 3.1) focus on providing care to the caregivers of people with dementia. It is therefore important to build an evidence base from which to start addressing how HCPs and third sector organisations may provide such care to family caregivers.

The family caregiving literature has provided a starting point in recognising understandings and management strategies of risk for people with dementia. However, the literature rarely delineates the differences between adult children and spouses as sub-cultures of family caregivers. The following chapter discusses comparisons that can be drawn between adult children and spousal caregivers within the available literature.

Chapter 4: Adult children as caregivers

It is estimated that 540,000 people provide care to people with dementia in England (AS 2014a; DH 2015). Roughly half of the people cared for in the community receive care from their spouses, and the other half from their adult children as primary caregivers (Pickard et al. 2007) with a small percentage receiving care from other types of family caregivers, friends and some receiving no informal care. The phrase 'adult children' refers to anyone over the age of 18 years old who provides care or support to a parent (Victor 2005). It can be argued that even when a named primary caregiver is a spouse, there will likely be input in terms of care or support from adult children (if the couple have children). Furthermore, Hou et al. (2015) explored the experiences of adult children who had a parent that provided care to a family member with dementia. The study showed that despite not being a primary caregiver, the adult children still experience stress and also a willingness to take primary responsibility of caregiving in the future.

In their report Facts About Carers, CarersUK (2014) discuss the NHS Information Centre survey which demonstrated that 40% of informal caregivers cared for their parents or parents-in-law, with 26% providing care to spouses/partners. Although these figures are not specific to dementia care, they demonstrate that there may be more adult children as caregivers for parents with dementia than spouses than originally thought. There is also an argument that with the increased prevalence of dementia over the coming years, spousal caregiving will likely increase but that filial caregiving will need to increase also (Pickard et al. 2007). There is therefore a societal need for adult children to take on caregiving roles. This could lead to expectation and increase adult children's expected responsibility for their parents with dementia.

This study focusses exclusively on adult children to understand why and how society may impact upon the care they provide. The following section draws upon the literature in demonstrating differences between spouses and adult children as caregivers and some of the societal expectations and impacts upon adult children that are already recognised, demonstrated and understood within the family caregiving literature. The purpose of this chapter is to explore the literature to asscertain what is known about adult children and how they differ from other family caregivers.

4.1 Burden

Burden is a frequently discussed topic in the dementia caregiver literature. Some researchers demonstrate that burden is higher for adult children than for other types of family caregivers

(Yeager et al. 2010; Chappell et al. 2014; Kahn et al. 2016). Kahn et al. (2014) argue that the increase in burden adult children feel is in part related to their experience of stigma despite the inability to draw causal conclusions from their dataset. They do however conclude that burden and stigma are both higher in adult children (particularly daughters) which they suggest should lead to more strategies to reduce stigma in family caregiving in order to reduce burden (the concept of stigma is returned to later in section 4.4). Yeager et al. (2010) found that of those caregivers who provided care to people with dementia who had psychotic symptoms and impaired activities of daily living, burden increased and this was more so in females and adult children. They suggest that being a female adult child increases the risk of poor coping strategies in the care of a parent with dementia. This quantitative study however was again unable to produce a causal link as to why burden increased for adult children. The authors recommend further research to understand differences between sub-types of family caregivers in order to produce effective, tailored education and support to reduce burden.

Chappell et al. (2014) discovered how adult child caregivers experience a higher level of burden than did spousal caregivers, however, adult child caregiver’s subjective burden decreased over time, while spouses’ did not. The study followed adult child and spousal caregivers at six months after the care recipient received their first treatment (cholinesterase inhibitors) and a year later (when the care recipient had been treated for 18months) (Chappell et al. 2014). The decrease in levels of burden over time may demonstrate how the initial period after the parent receives their diagnosis of dementia is experienced as a biographical disruption to the adult child caregiver. With time, this new state of caregiving for a parent with dementia may become the norm. However, this does not take into account the increasing severity of the parent’s dementia and the necessity to provide more support or care as shown by Reed et al. (2014). They found adult child caregivers had higher burden than spousal caregivers but that burden across both spouses and adult child caregivers increased similarly when the care recipient’s dementia was more severe (based on MMSE score).

Chappell et al. (2014) used a large sample of adult child caregivers and spouses (n=878), however this was heavily weighted towards more spousal caregivers (613 spouses; 265 adult children). They also made note of the reasons for those who chose not to participate in the first instance or subsequently withdrew at the second time point. These reasons included: too busy, that the care recipient was too ill or the caregiver was too ill; perhaps these caregivers would have demonstrated higher burden at follow up. Reed et al. (2014) used a large sample (n=1390), but again, this sample was weighted towards more spousal caregivers (985 spouses; 405 adult children). The study included equal numbers of mild, moderate and severe stages of dementia, however, the study was cross-sectional and, therefore, did not demonstrate how caregiver burden changed over the course of the care recipient's disease progression (for example changes over time from mild severity to severe severity of dementia).

Savundranayagam et al. (2011) suggest that there is *no difference* in levels of burden between spouses and adult children, but instead there are differences in the types of burden experienced. They looked at different dimensions of burden across participants (280 spouses/partners and 243 adult children) and discovered that adult child caregivers experienced higher relationship burden. This included changes in relationship with their parent, the parent increasingly exhibiting overly demanding bahviours and the adult child feeling that they were being manipulated or taken advantage of as caregivers. Whereas spousal caregivers experienced higher stress burden which included aspects of anxiety and depression. The authors argue that the differences between relationship burden and stress burden were due to the initial relationship with the person with dementia and the way in which the family caregivers 'assume responsibility' and respond to the experience of providing care (Savundranayagam et al. 2011, pp. 329). This discussion of assuming responsibility is discussed further throughout the remainder of this chapter (especially section 4.3).

Although there were differing types of burden, both were typically found to increase the caregiver's intention to move their family member with dementia to residential care (Savundranayagam et al. 2011). The differences in burden found between adult child caregivers and spouses in the afore mentioned studies may be due to the burden scales used; perhaps multi-dimensional burden scales would reveal different results (as with Savundranayagam et al. (2011)). However the argument drawn out is not one of arguing for or against the different caregivers having higher or lower levels of burden, instead Savundranayagam et al. (2011) argues that attention needs to be paid to the different needs of each type of caregiver both in research and in care practice (including guidance and support from HCPs).

There is evidence in the literature of differences in burden between adult children and spouses as caregivers. Some demonstrate that burden is higher in adult children due to increased feelings of stigma, changes in their relationships with their parents with dementia, the demands of providing care (potentially associated with biographical disruption – discussed next) and due to the way they assume responsibility for their parents (discussed later in section 4.3). One study demonstrated here argues that there is no need to consider who is at higher or lower risk of burden, but to instead consider that burden has multiple aspects. Therefore, with a goal of supporting family members to provide care to a family member with dementia, the argument is for understanding the sub-types of family caregivers and their individual needs in order to provide better tailored guidance and support.

4.2 Duty or disruption

Spouses often view caring for their spouse with dementia as a part of their ‘marital duty’, but adult child caregivers may view it as a ‘biographical disruption’ (Conde-Sala et al. 2010). Biographical disruption as defined by Bury (1982, pp. 169) is “that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted”. His original paper was discussing patients with rheumatoid arthritis as a chronic illness, yet biographical disruption can be seen across patients with various chronic illnesses. Biographical disruption can not only experienced by patients but also by their family caregivers. Zimmermann (2013) discusses biographical disruption for adult children of people with dementia; for the two cases, she describes disruption to the adult child’s personality and identity. They also have to combine aspects of caring for their parent with dementia and their own social, family and working lives as another level of biographical disruption (Conde-Sala et al. 2009).

Adult child caregivers typically have to manage a variety of demands as a form of ‘balancing act’ (Davies et al. 2000; Kjällman-Alm et al. 2013; Vreugdenhil 2014; Johannessen et al. 2015). This refers to the need to balance their own lives, both social and working, their own children and their parent(s) (Victor 2005). Indeed, many adult children face reducing their hours of work or giving up work altogether (CarersUK 2014), which has clear financial implications, in order to provide care to their parent with dementia.

Continuing care in the community could often be a product of adult children’s beliefs that their care would preserve their parents’ and family relationships (Hwang et al. 2017). Often maintaining a parent in the community outweighed other responsibilities such as employment, leading to adult children taking early retirement to provide care (Hwang et al. 2017). The identity of a caregiver to a parent with dementia is heavily cited within the literature. It is possible that expectations of identity may be a result of societal expectations that the term ‘person living with dementia’ refers not only to the person with the diagnosis but also their family caregivers.

The new role of providing care to a parent with dementia could be considered a form of biographical disruption unlike spouses who accept the role as part of their marital obligations. However, accepting the role despite disruption, may also be due to societal expectations of how adult children should behave with respect to caring for their parents with dementia.

4.3 Expectations

Obligation or expectation are heavily cited as the reason adult children care for their parents with dementia. One study explored expectations of providing care to a parent in the future (Franks et al. 2003). Of their sample of 206 participants, 93.7% expected that they would be involved in care for their parents. Of these, 53.9% expected to be primarily responsible, 39.8% expected involvement in a secondary caregiver role. The 13 participants who the authors referred to as having no expectation of care in the future were not included. They also explored correlations between situational characteristics of the adult children or parents with expected responsibility. The key characteristic the authors found to affect adult child responsibility for parent care was number of sisters, that is those with more sisters were less likely to expect primary caregiving responsibility than those with fewer sisters. Similarly better health of the adult child increased likelihood of primary responsibility. They did not find any significant correlations between age, gender, race, education, employment, marital status, children, parents' health, parents' marital status, distance from parent or number of brothers.

Although this study was not specific to dementia care, and was conducted in the USA, there is likely to be some overlap with the culture of adult child caregivers for parents with dementia and, being a developed country there are likely to be similarities to the UK (and other developed countries in western populations). However, the study only included participants who were aged between 35 and 75 thus excluding a part of the potential adult child caregiver population, and the study only included participants who had not provided care in the previous year. The questions they used to elicit responses for their research aims could be considered to be leading for example "If your parent(s) were to require care or assistance due to being frail, disabled, or having a chronic illness in the future, would you provide such assistance" (Franks et al. 2003 pp. 108). Asking this question holds with it a sense of obligation to respond in the way that would be most socially acceptable. The authors also interpreted loosely that 'respondents who did not affirm this item were categorised as having no expected involvement' (Franks et al. 2003, pp. 108) without examining more qualitative the reasons why the adult children responded in this way. The results do however draw upon societal expectations of adult children providing care to parents in the future and examine some of the characteristics that may be associated with such expectation. The findings also demonstrate two levels of responsibility: primary and secondary, and start to consider the reasons why expectations of responsibility may be at one of these two levels.

In her study based on an Australian sample, Cahill (1999) concluded that HCPs needed to be more aware of decision-making processes involved in taking on a caregiving role. They conducted interviews with 39 female caregivers of people with Alzheimer's Disease (24 wives; 12 daughters; 3 daughters-in-law), and found that the main motivations for providing care to a parent with Alzheimer's were: concern, love, duty, obligation and guilt. More predominant for wives was obligation due to marriage, whereas for daughters and daughters-in-law these was more moral obligation due to social concepts of love and family ties. Cahill (1999) argues that the processes of motivation to care are more complex for daughters and daughters-in-law than for spouses and that the adult children drew on situational characteristics (much like with Franks et al. 2003 above). These included: gender, work, siblings, and other family care responsibilities. Although these preliminary findings are restricted to 39 family caregivers, the strength of the study is in the narrative approach Cahill used in order to allow her participants the opportunity to discuss important aspects of decision-making for caregiver role than closed questions as with Franks et al (2003). This study as with the above (Franks et al. 2003) demonstrates the multi-faceted process of deciding to provide care and take responsibility for a parent (with or without dementia) which often draws on situational characteristics.

Additionally, more recently, Hwang et al. (2017), in Canada, found that adult children may resign themselves to providing care to their parents with dementia when other family members were unable to. This is a similar theme in Tatangelo et al. (2018), in Australia, where family expectations may lead to a lack of choice in providing care. Expectations were often of the daughter to provide care and not the son (Hwang et al. 2017), despite political movements surrounding feminism and equality. To balance, there is also evidence that sons as adult child caregivers may experience more barriers than daughters in accessing appropriate support and resources. This may sometimes be through ambivalence and sometimes through lack of relevant information about services from HCPs (Greenwood and Smith 2015).

In the UK, Egdell (2013) used thematic coding (based on Ground Theory principles) to explore qualitative interviews of 13 family caregivers about changes in obligation and responsibility for a family member with dementia. The adult children within their sample (4/13) drew upon geography (distance to parent) and gender as default reasons to provide care. They also noted that they provided care if there was no one else available to do so. Egdell (2013) argues that caregiving obligations and responsibilities are not only a product of individual or family circumstances but also of social and cultural norms and expectations. That is that there is an expectation from society that adult children should provide care to their parents with dementia in the community, a finding that is also highlighted in Pickard et al. (2007).

Although focussed upon adult children of older parents as opposed to those with dementia, Finch and Mason (1990) explored both societal expectations of responsibility, obligations and how negotiating responsibilities worked in practice. The study was conducted in England and addressed societal expectations of obligations through a survey of 978 adults of all ages and how obligation worked in practice through interviews with 88 individuals. Of the 88 individuals interviewed, case studies were selected to highlight their findings, predominantly a case study of seven interviews with six members of one family. In addressing the question of societal norms in obligations, the survey data from responses to vignettes was used. They found that there was a societal expectation that adult children should ‘do something’ for their ageing parents who required care, but the question of what that ‘something’ was changed by scenario. Interestingly, whether son or daughter did not differ in terms of level of responsibility, but the responsibility roles that survey respondents assigned to sons and daughters did. For example, expectations were that sons would provide financial support, whereas expectations of personal care typically fell to daughters. They concluded that societal expectations are that adult children should do something but society demonstrated less certainty about what, how and who depending on circumstances. Based on this conclusion, the authors consider two consequences: 1. Adult children must work out what to do to care for their parents and 2. Get society to accept their actions as fulfilment of their obligations. The authors go further to question whether these consequences are consecutive - that is the former followed by the latter - or parallel - the actions society are willing to accept impacts upon the actions they take.

Through their second set of data (qualitative interviews) and one case studyin particular , Finch and Mason (1990) address the process of how responsibility and obligation works in practice. Their case study of six adult children providing care to an ill father with an estranged wife (their mother) demonstrated that there may be more expectation of care from one sibling in comparison to another. That is that some adult children held ‘legitamate reasons’ as to why they could not provide care (for example: distance to parent or having children themselves). Similarly, the case demonstrated differing roles of responsibility amongst the six adult children (for example, a son would bath dad, but this was not expected of the daughters). These roles and responsibilities also changed over time and as new situations presented themselves (for example, the father moved in with one adult child and their partner, then in with another adult child and their partner, then to his own home where another child was living). Overall the findings demonstrate that there is a societal expectation that adult children should provide care to their parents, but are less certain of how, to what extent and who. In practice the assignment of responsibilities are also not clear-cut, are open to negotiation and are not rigid; instead flexible depending on situations and time. Although this study was not dementia specific, it has paved the way for recognising how the reasons adult children may provide care to a parent is not independent to the individual but bound by societal expectations of obligation.

Despite one family member often being named by HCPs as primary caregiver, there is a need for family members to work together to provide care. However this can often lead to conflict where different family members hold different values and expectations of their family member’s care (Hwang et al. 2017; Tatangelo et al. 2018). Similarly disagreements may emerge over disproportionate care responsibilities, that is some siblings providing more care than others (Hwang et al. 2017).

Through the literature, motivations to care typically revolve around obligation. However, the above studies demonstrate how obligation to provide care is multi-faceted, that is there are a number of situational characteristics that increase or decrease expectation to care and obligation. Obligation is socially-constructed through understandings of such situational characteristics and societal expectations may in turn affect an adult child's decision to provide care to their parent. This is not without challenges for family cohesion, where one sibling may expect more responsibility, there may be increased conflict. Societal expectations however go further than expected care responsibilities and may impact on *how* adult children provide care.

4.4 Societal impacts

Societal impacts upon caregiving are rife amongst the caregiving literature but rarely discussed in light of social theories. In a note from her autoethnographic work, Bromley (2012, pp. 210) acknowledges the impact from society by stating "the social pressure to embrace the mantra ''I can do it all'' is strong". Furthermore, peer support, especially those peers who appear similar, is considered increasingly important to adult children (Wasilewski et al. 2018). That is, perhaps adult children as caregivers may choose peer support options for advice and information over and above HCPs.

Social expectations have a role in how adult children (and indeed other stakeholders) provide care to parents with dementia. One such attitude is that of stigma which is born out of societal understandings of dementia. As discussed earlier in chapter 3, historically the approach to dementia and other mental health conditions was that of institutionalisation – separating those people with such diagnoses from the rest of society. This stigma remains prevelant and, it is argued, can directly affect a caregiver's ability to live well under the circumstances of providing care to a family member with dementia (Cecchin 2001). Similarly, Kahn et al. (2014) notes that adult children (particularly daughters) experience higher levels of stigma which is associated with increased burden (as discussed earlier in section 4.1). However, the study by Kahn et al. (2016) was unable to shed light on why this may be the case, nor the types of stima the participants experienced. This was perhaps due to the rigidity of quantitative data that did not allow for understanding the reasons behind the effects of stigma on burden, however the study did find a significant correlation between the two. The danger of these societal understandings of dementia and their impact of adult children's care to their parents with dementia is highlighted in Clayton et al. (2017). The authors found that their participants' beliefs about their parents abilities impacted on conflict between daughter and parent and therefore increased caregiver burden. Stigma surrounding dementia may also increase social exclusion of both the person with dementia and also the family caregiver (Greenwood et al. 2018).

Adult children may also choose to care for their parents in in the community, whereby the parent remains in their own home or moves into their adult children's homes as a preferred option over residential care (Clarke 2000; Hwang et al. 2017). There is often a distrust in healthcare systems and indeed residential care options built from evidence of accelerated health decline (both physical and mental) and assumptions of social isolation in residential care (Hwang et al. 2017). These assumptions of residential care are often exacerbated by media exposure of abuse in care homes and negative cases of care in residential settings (Hwang et al. 2017). This demonstrates societal understandings of residential care and their impact on family caregivers and adult children specifically to maintain their family members with dementia in the community setting, which in turn can increase burden.

Over recent years, attempts to break the stigma surrounding dementia are increasing with multiple autobiographies by family caregivers, for example: Calmer Waters (Cohn 2016), and people with dementia, for example, Somebody I Used to Know (Mitchell 2018), even a graphic novel, Wij Twee Samen (Ephameron 2015) and fictional works such as Still Alice (Genova 2015) which was also made into a film. Likewise, such initiatives as the Dementia Friends campaign (AS 2017) aim to raise awareness and understanding of dementia amongst the public. It is perhaps too soon to notice changes in societal understandings of dementia, but there is a growing wealth of attempts to change the way society views dementia and caregiving.

In their work exploring social representations of dementia caregiving, Toepfer et al. (2013) conducted interviews with wives and daughters as caregivers and explored representations of caregiving within newspaper articles. They found three key representations of family caregivers for people with dementia that they deemed directly comparable to the care of children, these were: the care recipient as a 'clinging child' (the person with dementia is similar to a child in terms of attachment and dependency), the caregiver as an 'ever-present mother' (much like with childcare, societal expectations are that caregiving should take precedence over all other responsibilities), and the caregiver as having 'a natural aptitude for caring' (again, similarly to parenting, a wife or daughter as caregiver senses through intuition what is required for their family member with dementia) (Toepfer et al. 2013, pp. 240). These societal expectations and comparisons to mothering may enforce gender roles within caregiving, but also increase pressures of what is expected of the caregiver.

There are a number of ways in which societal expectations may directly impact on how adult children provide care to a parent with dementia. These include social stigma attached to dementia, impacts of the media in exacerbating negative residential care cases and media representations of adult children as caregivers. Each of these impact on the decisions and ways in which adult children can provide care to their parents with dementia.

4.5 Risk management

Family caregivers are bound by social and cultural contexts when making decisions regarding risks in dementia care whereas HCPs are typically bound to policies. One conclusion from Bailey et al. (2013) is that policies should be produced within the wider contexts they aim to serve. Likewise Alaszewski (2013) comments that HCPs may be experts but their advice is often disregarded by family caregivers because they may not take into account the social contexts within which their patients are bound. Policies were traditionally produced in the context of the government or healthcare practice, increasingly they are incorporating the voice of family caregivers and indeed people with dementia. However, this may still be too narrow, instead the social and cultural contexts within which these policies are formed should also be considered. For example, in recognising differences between adult children and spouses as caregivers, there should be different guidelines in how to best support these different caregivers.

Clarke (2000) also notes that expectations of others impact on the reasons family caregivers provide care, and also how the care they provide can by influenced by or justified by societal ‘others’. Furthermore, Berry et al. (2015) discuss how their results demonstrate that functional decline is situationally constructed and separate from cognitive decline. They consider that dementia symptoms “do not have a pure form that exists outside of social context” Berry et al. (2015, pp. 13). Instead social context only allows family caregivers to perceive dementia, and therefore the risks associated, in a certain way. The example Berry et al. (2015) draw upon is how functional decline is not alone in demonstrating a risk or how to manage said risk, but socially impacted upon by the person with dementia’s awareness of their own defecits. That is, it is more challenging to provide support around a given risk if the person at risk is unaware that they are.

A further insight from Berry et al (2015) is in how family caregivers may manage risk through deception or using their family member’s memory deficits to their advantage. For example, by promising to return to a risky activity, the family member with dementia would forget and the risky activity would not be returned to. Russell (2018) takes this further to explain why ‘white lies’ and deception may be necessary in the care of a parent with dementia to protect them from the complexities associated with their conditions and reduce risk of distress. An example she provides is when her mum with dementia asks where her dad is, dad had passed away two years previously and she considers how repeatedly informing her that dad has passed away causes more distress than is necessary. Instead she now explains that dad ‘is not here right now’ (Russell 2018 pp. 136). Although in her paper, she accepts the social controversy of employing such tactics, she argues that the distress the truth causes mum far outweighs the social expectation of honesty in this circumstance. This paper was written as a commentary but addresses a key issue that many family caregivers face in finding a balance in managing not only health and safety but also non-safety risks.

There is limited evidence of delineating differences between different family caregivers in terms of risk recognition and management. Typically the literature draws upon family caregivers as a general population. However, some studies note that their samples of caregivers include spouses, adult children and others and therefore demonstrate some differences between.

In their study of 89 caregivers exploring risk for people with dementia, Walker et al. (2006) were able to compare risks and management strategies between differing family caregivers including 45 spouses, 34 adult children, 6 other relations and 4 friends. They discovered that spousal caregivers were less likely to use management strategies for risks in comparison to the other types of caregivers. The authors suggest that despite their original thought that this was due to spousal caregivers spending more time supervising the person with dementia, analysis did not demonstrate a significant correlation between time spent supervising and number of management strategies employed. Because the study was quantitative by nature, there was no scope to explore what management strategies were used by the different caregivers and why these may differ.

Another study that provided opportunity to recognise differences between spouses and adult children was that of Berry et al. (2015). They explored risk management by family caregivers surrounding the challenges of functional decline in their family members with dementia. Their main findings were that family caregivers move through three phases of support: collaborative, transition and unilateral, discussed earlier in chapter 3 (section 3.2.2). In their study of 15 family caregivers, 12 were adult children and 3 were spousal caregivers. The authors identified this as a limitation of their study, that their sample was predominantly adult children because they considered that adult children are likely to experience transitions associated with functional decline differently from spouses as caregivers. They argue that this may be because adult children are required to negotiate these transitions with siblings or other family members. They also argue that differences may occur because spousal caregivers spend more time in closer proximity to the family member with dementia and therefore may identify more subtle changes in functional decline. However, these identified factors are speculation and not backed by evidence within their study.

Although limited there are some studies that allude to differences between different types of family caregivers in how they understand, address and manage risks. However, the two studies discussed here are limited to considerations based on speculation and do not necessarily demonstrate important aspects associated with how and why these differences may occur.

4.6 Summary: Adult children as caregivers

Although adult children are just one type of family caregiver, they were chosen as the subject of interest for this study because it can be argued that there are more adult children providing care to a parent with dementia than there are spouses providing care to their spouse. Likewise, from a societal perspective, the prevalence of dementia is increasing and with it the need for an increase in adult children providing care to parents with dementia. In comparison to spousal caregivers, adult children typically experience biographical disruption and a need to balance multiple responsibilities in their lives alongside their new role of providing care to a parent with dementia. Occasionally, the responsibility for providing care to a parent is considered to be more important than these other responsibilities (such as employment).

Alongside this societal expectation for an increase in adult child caregivers, there are a number of expectations in terms of levels of responsibility that the adult child has for their parents with dementia. These levels are primary or secondary caregiver, both of which are important to maintaining the parent with dementia in the community. The level of responsibility is often impacted on by a number of situational characteristics. Examples within this literature review include: gender differences and number of siblings. Within the literature pertaining to family dynamics there is evidence of different family members (the parent without dementia and siblings) holding different values and expectations of the parent with dementia’s care which in turn impacts on family cohesion. When considering societal expectations for care and responsibility, there are also a number of ways societal expectations can impact upon the care an adult child provides. For example, through stigma, the media and societal expectations regarding what constitutes ‘good care’. Also, societal impacts can occur through social surveillance whether by friends, family, HCPs or others.

In addition to previous discussions of family caregivers’ understandings of risk and management strategies they use, there is a discussion surrounding some of the societal impacts upon family caregivers employing risk management strategies. A limited number of studies provide insights into differences in risk management strategies between adult children and spousal caregivers.

There are also a number of considerations for risk management and dementia care that are discussed as adult child specific and how these relate to previous concepts of risk.

This chapter discussed what is already known about adult children as caregivers to parents with dementia in the context of risk and impacts of societal expectations independently of each other. There is a need to undertand how societal expectations impact more specifically on risk understandings and management in order to provide better tailored support and guidance to adult children as caregivers.

The literature review (chapters 2-4) has demonstrated that there are different cultures of care amongst stakeholders who aim to support the person with dementia. These can be understood through the different weightings each stakeholder assigns to knowledge and values, and through application of sociocultural theories it is possible to recognise societal impacts upon dementia care and risk management. Furthermore the literature, to a certain extent, demonstrates differences within these cultures in the form of sub-cultures for example adult children as different from spousal caregivers. One such difference between the two sub-cultures is that spousal caregivers are less likely to use management strategies but spend more time supervising their spouse with dementia. In order to understand more about societal impacts upon dementia care practice and risks management, it is necessary to explore the experiences of a single sub-culture. Therefore this study focusses exclusively on adult children as caregivers and interprets societal expectations and impacts through how the adult children construct their experiences surrounding risk for their parents with dementia.

In order to address the individual experiences of adult children, a case study approach is used to delineate the boundaries between the case and the context within which it is situated. This therefore allows for individual differences between adult children whilst attending to the wider purpose of understanding societal impacts upon them. In order to recognise how societal understandings and expectations impact upon adult children’s constructions of risk, narrative inquiry is used. Upon understanding how society influences these constructions of risks, it is then possible to consider how to better support and guide adult children as caregivers for their parents.

Chapter 5: Methodology: Narrative inquiry

This project aims to explore how adult children may be impacted by cultural norms and societal expectations when managing risk for their parents with dementia. The study therefore employs narrative inquiry which recognises that narratives are always produced with both an argument and audience in mind. It is then in how the adult children construct their narratives to argue for their audience (society) that a risk is a risk and the appropriate management strategy was employed, that it is possible to understand the potential impacts from society. This chapter provides justification for the methodology and methods employed within this study. The first sections discussion the methodological assumptions, drawing on: constructivism, Cultural Theory, case study approach and narrative inquiry. Following which is a description of the sample and recruitment methods. The chapter then focusses on the data collection methods (both written and interview narratives) and finally outlines the narrative analysis methods. Analysis includes: thematic analysis (Riessman 2000), structural analysis (Labov and Waletzky 1997) and attention to seven narrative elements (Baldwin 2013).

5.1 Methodological assumptions

Following on from the earlier introduction to Cultural Theory (chapter 2), this project draws on assumptions that people are impacted upon by their own cultural norms and the expectations of society. To understand the societal impacts, it is therefore important to distinguish the individual’s cultural boundaries, some of which were highlighted earlier in chapter 4 and returned to later in section 5.2. In her earlier work surrounding Cultural Theory, Douglas drew upon Bernstein’s theory of language coding (Bernstein 2003; Douglas 2004). Bernstein theorised that there are two language codes: restricted and elaborative. Restricted language is used when two people share knowledge and understanding, they then require less language to communicate (Bernstein 2003). Ellaborative language is required when a shared understanding is not apparant and therefore requires more communication to convey the same message (Bernstein 2003). Bernstein’s work focussed on education and the differences in children’s language use when from different social classes in the early 1970s. He considered how as children are learning language, they are simultaneously learning social structures and expectations of these structures and norms (Bernstein 2003). Douglas considered that these language codes may enable an understanding of cultures, that is, with shared knowledge, values and understanding as within a particular culture, restricted language may be used (Douglas 2004). Whereas if two people do not share the same culture, language needs to be more elaborative (Douglas 2004). It is through language then that it may be possible to recognise cultural norms and societal expectations in constructions of risk narratives.

Constructivism focuses on “intra-individual process” (Vall Castelló 2016, pp. 130) that is how people construct and reconstruct knowledge. However, as Charmaz (2006, p. 129) suggests “we do not exist in a social vacuum”. Therefore, the constructivist approach is concerned with how people construct and reconstruct their own knowledge, but also how it is shaped by social and cultural norms. This project treats each participant as a case study in its own right where detail on context is important to understanding their differing situations and circumstances that have shaped their experiences and therefore constructions of risk. Through sociocultural theories, such as Cultural Theory, it is then possible to interpret how these constructions of risk may be shaped by social and cultural norms.

5.1.1 Case studies

Case studies are particularly useful where too little is known about a given phenomenon to be able to create a deductive design (Payne et al. 2007), as is the situation for adult children caregivers managing risk for their parents with dementia. Case studies are used to explore a phenomena of interest holistically (Yin 1994; Mason 2002), instead of focussing on one particular aspect of a phenomena, it is possible to recognise multiple aspects - both internal (within the case) and external (between cases). The case study approach allows the researcher to recognise the boundaries between the individual case and the societal impacts it is bound to (Ridder 2017). Within this project it would therefore be possible to understand the adult children as having independent characteristics as an individual case and explore how societal understandings and expectations impact upon that case.

Through multiple case studies it is possible to explore similarities and differences between the individual cases and also patterns across the collection (Ridder 2017). This leads to some positivist case study researchers (such as Yin (1994)) to consider that case studies can be generalisable. However the constructivist researcher does not aim to find ‘facts’ or produce generalisable results from a positivist stance, instead the interest is in the process of ‘meaning-making’ as an activity that is spatially and temporally constructed (Ridder 2017). That is, the constructivist researcher recognises that the findings produced are bound by the context within which they are constructed. It is then not the content of the data that is the focus for generalisability, instead it is the processes through which meaning is constructed that inform theory that may be applicable more generally. That is through multiple case studies, it is possible to find patterns in how the adult children construct their narratives. These patterns will allow for interpretations of societal impacts.

The case study approach however is not without its limitations. In recognising that the data collected is bound by the context within which it is constructed, it is important to acknowledge the researcher as embedded within the processes of data collection and analysis. Reflexivity therefore must be engaged with throughout the research process; throughout this thesis I comment on my own impact within the project. Likewise, defining the case is crucial to recognise the individual aspects of the case and to recognise the external impacts upon that case (Crowe et al. 2011). The cases for this project are outlined in section 5.2.1 when discussing sampling. It should also be noted that the criteria for assessing quality in case studies is different to other types of research designs because they often employ multiple data collection and analysis methods (Yin 1994). Therefore, these aspects of case study quality are addressed later in the chapter alongside the corresponding discussions of each method.

The case study approach is used within this study to explore the meaning-making processes of adult children as caregivers for their parents with dementia. This approach allows for a holistic understanding not only of the processes through which the adult children construct risks, but also how they are impacted upon by society. In order to gain access to these processes of constructing risks, the study employs narrative inquiry.

5.1.2 Narrative inquiry

To access lived experiences, narrative inquiry can be appropriate. One definition of a narrative is:

> *"a meaning structure that organises events and human actions into a whole, thereby attributing significance to individual actions and events according to their effect on the whole" (Polkinghorne 1988, pp. 18).*

This definition was chosen (from many) because it describes the importance of both the whole narrative and how its parts relate to each other in order to inform the whole. The focus then, of narrative inquiry, is not only on *what* is being said but also *how* and *why* the narrative is constructed to achieve its purpose. This is described as a step away from the fragmenting of data by coding and categorising (Coffey and Atkinson 1996) as seen in grounded theory for example; instead the aim is to understand different elements that are constructed to inform the whole. By considering the narrative as a whole, it is possible to position the accounts within the context of that participant, but also the context of social and cultural norms.

A narrative is a way of not only communicating, but also understanding and constructing one's experiences. Narratives are often considered to be temporal accounts of events, where the narrator conveys the sequence of events and connections between those events can be inferred (Polkinghorne 1988; Sandelowski 1991; Bryman 2012). For example ‘the cat sat on the mat and the dog barked at the cat’ – it can be inferred that first the cat sat on the mat and afterwards the dog barked at the same cat. Narratives are not only used as a tool for communication, Sandelowski (1991) suggests that narratives are used as a constant ‘never ending monologue’ that can be used to make sense of one’s own life or to relate to others. Further, Douglas (2004, pp. 25) argues that language is used to “express the social structure, embellish and reinforce it”. This is key to gaining insight into the ‘intra-individual processes’ of adult children’s constructions of risk narratives whilst recognising the impacts from societal expectations.

Narrative inquiry has been used across a range of different disciplines including Psychology, Anthropology, Linguistics, History and Literature; not only in research, but it is also heavily relied upon by therapies and counselling due to the nature of understanding how and why a narrative is constructed. Within the study of health and medicine, there have been several ‘shifts’ in the importance of patients’ narratives. Bury (2001) discusses how traditionally, prior to the mid-19th century, doctors relied on full patient histories and getting to know their patients to find the most appropriate treatments. He suggests how with improvements in science, hospitals and laboratories in the mid to late 19th century, the patient and their illness became increasingly separate and the patient’s narrative became less important as the focus was on treating the condition, as opposed to the person (Bury 2001). He argues that now there is a return to narrative which stems from the ageing population and increase in chronic illnesses for which cures and treatments are limited. Thus the focus turns towards illness management and care, and the illness narrative as a tool for gaining insight into living with chronic conditions. This is especially important in diseases, such as dementia, where there are no cures and treatment options are limited, yet the prevalence of the disease is increasing.

The challenge of considering narratives as important to accessing lived experiences is that there is potential to over-empathise with the participants. All narratives are created from the individual’s point of view and with an audience in mind (this is discussed further later in section 5.4.3). As discussed earlier, the researcher is embedded within the data collection and analysis processes and it is easy to consider that qualitative research allows the researcher to delve beneath the surface of people’s voices and actions and access internal processes (Bryman 2012). However, researchers only have access to the construction that is presented to them. This construction offers *insight* into the perceptions, cognitions and understandings of participants, but the construction is bound by context. For example, the way the participant constructs their narrative may be responsive to the research setting which includes the location (at an office or within that participant’s home), the relationship that develops between the researcher and participant, and the questions the researcher asks. Context is especially important in narrative inquiry where the researcher may fall short of analysing the data they are presented with and instead retell the stories of their participants (Atkinson 1997). It is therefore important to not only reflect on the experience of researching lived experiences but also conduct the analysis in a systematic way to ensure the integrity of the data (Rosenberg and Yates 2007; Hyett et al. 2014).

Another consideration in qualitative research is the concept of 'truth'. In studying how people construct their own meanings the focus is on multiple truths and the processes by which people construct and reconstruct their own truths, realities and meanings. In narrative inquiry, the focus is not only on what is said but also how and why. Science is concerned with finding truth; narrative is concerned with understanding experience and applying meaning (Bleakley 2005). As discussed above, the challenge with narrative inquiry is that often it is considered a route to understanding the personal and private experiences as privileged information; however, narrative is a tool for constructing truth(s) and should therefore be approached as such and in context (Atkinson 1997). The use of narrative inquiry within this study is not to understand the truth within the adult children's narratives, instead the focus is on how and for what purposes those truths were constructed.

Narratives are always produced with an audience in mind, therefore interview and written narratives may be constructed differently. For example written narratives may be afforded more time and consideration in their creations (Bartlett and Milligan 2015), whereas interviews may be considered more organic and a result of social interactions (Polkinghorne 1988). In constructing and reconstructing a narrative, the structure and meaning may change between the two methods. Instead of using multiple methods of data collection for the purpose of triangulation or corroboration of facts, multiple constructions of a narrative may be used to explore multiple truths.

For the purposes of this study, it is important to recognise the adult children as independent cases. Using narrative inquiry will aid in gaining insights into the intra-individual processes through which the adult children construct risks and management strategies. In recognising the narratives as both the whole and the sum of its parts it is possible to determine how different aspects of their narratives relate to each other. This could be in terms of content (i.e. how different aspects of a situation may present as a risk), the characteristics of the adult child, or the structural elements used to construct a risk, relate to each other. Upon recognising the boundaries of the case in this way, it will then be possible to interpret how and why societal expectations and understandings impact upon the constructions of risks.

5.2 Sampling and recruitment

The purpose of sampling within case studies is not that of sampling logic which aims for statistical generalisations, but instead replication logic should be applied (Yin 1994). Replicablity in the present study is in recognising that the meaning-making processes within one adult child's case can occur in the next case and the next. This replicability could be reached within several adult children's narratives but also within one adult child's narrative as they discussed multiple accounts of risk. Through Yin's guidance it could have been possible to justify a smaller sample, however through twelve cases this replication was reached and therefore *theoretical* generalisation could be gained. Twelve cases also allowed opportunity to consider comparisons of similarities and differences in contexts.

As discussed earlier (section 5.1.1), defining the cases prior to conducting a case study approach is important in order to recognise the boundaries of a case compared to the wider social context within which that case is constructed. Adult child caregivers are defined as anyone aged 18 years or older who provides care or support to a parent. The lower age limit is set at 18 years old to ensure that the sample is *adult* child caregivers as opposed to minors. This is because minors would potentially have a different set of challenges that may affect their experiences and constructions of narratives. The parent with dementia must have been living in their own home or in the home of their child or another family member at the time of interview (i.e. not residential care, sheltered accommodation, nursing home or hospital). This is because the focus was on how adult child caregivers support their parents and manage risk, a responsibility that may be alleviated when their parent moves to a residential care setting. Although some participants may employ paid caregivers to support their parent(s) in their own homes, the adult child would still play an important role in supporting that parent. Therefore, those who employed paid carers were not excluded from the sample.

Since the original ethical approval, an amendment was approved to allow one daughter whose mum[3] had recently (within three months of the interview) moved to residential care. The decision to amend the protocol inclusion criteria was due to recruitment and finding that many adult children wanted to participate despite their parent moving to residential care. A challenge within recruitment was that due to the nature of adult children as having to balance several responsibilities, it was difficult for the adult children who were interested to find time to participate. The amendment was chosen to broaden the scope of the sample further.

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[3] The use of the words 'mum' or 'dad' were chosen purposely, to actively engage with the personal aspects of the adult children's narratives. They are the words used by the participants.

Interestingly, this did not affect the replicability of the findings, in fact I believe, strengthened it – this will be discussed further in chapter 9.

Purposive sampling is often the favoured technique for case studies (Yin 1994), however, a criticism of such an approach is that the researcher chooses the cases and therefore they may not be representative of the population of interest and may serve only to add to the researcher's pre-formed argument. Therefore, in order to reduce such a potential bias, I advertised my study and included participants who responded to the advert and fit the inclusion criteria. However, this too holds limitations because the sample is then self-selecting (this is discussed further later in chapter 9). The inclusion was also kept purposely broad in order to explore the application of sociocultural theories upon the narratives of different adult children with different situational characteristics. A demonstration of the characteristics as collected through the use of an initial 'demographics form' (see appendix B) discussed next in section 5.2.1.

Participants were recruited via a recruitment poster (appendix C). The poster was advertised locally in dementia services across Hampshire, including: Alzheimer's Society, Andover Mind, Carers Together, the Admiral Nurses, Dementia Friendly Hampshire, Dementia Action Groups and circulated electronically to mailing lists. The poster was also promoted on social media (Facebook and Twitter), dementia forums and websites (for example, the Alzheimer's Society featured the study on their 'Studies seeking participants' page). Four participants were recruited via Facebook groups, three by Twitter, two by word of mouth, one via a local memory café and two made contact from the Alzheimer's Society website.

The selection of cases in case study research need not comply with typical sampling logic which is representative of the general population, however for the purpose of informing future research direction, the limits of the sample should be acknowledged. Firstly, due to the nature of the study, participants must be comfortable (to a certain extent) in writing in English. The writing part was important to the data collection process, but participants were informed that they may write as much or as little as they would prefer and that spelling and grammar would not be judged as part of the process. Indeed some participants limited themselves to writing bullet points which, although perhaps not structurally defined as a narrative, still provided a base for discussions at interview. However potential participants may have excluded themselves should they not feel comfortable with writing.

Also where the participants were partially recruited through social media, they may be very comfortable with communication in a written format. However, where seven were recruited through social media platforms and five were recruited through other forms of advertisement, the split between was roughly half and therefore did not limit the sample to only those comfortable with writing. Likewise all participants were asked to complete both written and oral narratives (which are discussed later, section 5.3) which would reduce any bias for either. Although the study was promoted UK-wide[4], the final cases were from England only (one interested adult child was from Scotland but did not meet the inclusion criteria). In recruiting through social media and with the use of Skype technology to complete interviews, it was possible to include participants from across England and not only those local to Hampshire. However, the use of Skype to complete interviews may have led potential participants to self-exclude on the basis of not being comfortable in using such technology.

Twelve adult children were recruited as case studies in two stages. Initially, eight participants were recruited in relatively quick succession. At this point there was a break in active promotion of the study in order to start preliminary analysis. During this preliminary analysis across the eight participants, I considered that further participants may be necessary and therefore a further four participants were recruited. The processes through which I collected and analysed data remained consistent with the first eight. Initially the addition of four participants was because I felt more data were required, in hindsight the same use of structures and narrative elements were consistent across all twelve participants. Therefore the final four participants served as a confirmatory group that add the strength of replicability across multiple cases. A potential weakness of such an approach was that by starting analysis on the first eight, I may have formed preconceptions of the use of narrative structures and elements which I then sought to affirm in the final four. However, through consistently adhering to the same systematic process of data collection and analysis (addressed later in this chapter), the risk of preconceived ideas was mitigated.

5.2.1 The participants

This sub-section introduces the twelve cases to provide context for the chapters that follow with detail regarding the participant's similarities and differences in terms of demographic information. Appendix D demonstrates key contextual information regarding the participants' demographic information and appendix E provides short case studies for each participants. From these overviews, it is possible to compare similarities and differences across the sample of twelve cases and recognise the contexts of each participant to draw upon within the data analysis and findings.

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[4] In fact the study was promoted world-wide through the use of social media as a recruitment tool. Interestingly two adult children from America contacted me wishing to participate but were unable to participate due to restrictions in ethical approvals but demonstrate the potential impact a larger study could have globally.

All participants described their and their parent's ethnicity as: white, Caucasian, or British (or a combination of these words) apart from one participant, Patricia, who described herself as white Irish/British and her mother as white Irish. The majority of participants described their, and their parent's religions as a form of Christianity (including: Church of England, Roman Catholic, Methodist, Quaker). Four participants stated that they had no religion and one of these, Kate, stated that their parent also had no religion. Only one of the twelve participants' parent lives in residential care, Jodie, whose mother had moved to residential care within two months of participating in the project.

The demographics demonstrate the modest variety amongst the participants. Although there was limited variety in ethnicity and religion, there are some demographic differences that could be considered relatively demonstrative of the general population. For example, three participants were male and nine were female; which reflects the general population where the majority of family caregivers for people with dementia are female (ARUK 2015). Four parents had been diagnosed with young-onset dementia thus including both adult children of those parents with young- or late-onset dementias. The sample also covers the four possible parent-child relationships: seven daughter-mother, two daughter-father, two son-mother, one son-father. The focus of the project was regarding sons' and daughters' experiences of their parents' dementia, it was therefore acceptable to include the one daughter-in-law, Mary[5], as she perceived herself to be appropriate for the study.

A positive reflection regarding the limited variation between adult children participants is that with limited variability in terms of ethnicity and religion, there would be less cultural variation between the adult children. For example, the literature recognises differences between Western and Eastern cultures in family caregiving much of which could be attributed to ethnic or religious aspects of culture. Douglas (2004) argues that limited variation across people belonging to a specific culture aids in recgonsing the boundaries between cultural impacts and societal impacts upon those people.

This section outlines the demographics of each participant and variation across the sample. However, there are some details about the participants that only become apparent upon considering their portrayals of themselves within the narratives. The demographics here and further situational characteristics from the adult children's narratives are discussed as they pertain to the findings later in chapter 7.

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[5] Pseudonyms were used for all participants to protect their identity in participating in this study.

5.3 Data collection

Data collection occurred in two phases: written accounts for the purpose of tailored interviews and interviews to elicit further detail not provided in the written accounts. The adult children were first asked to write about their experiences of risks. They were then invited to interview to discuss their written accounts further. The following section first explains the process of data collection, following which is a discussion and justification of the two types of data collected. The final sub-section details the process through which the written accounts informed the interview topic guide.

5.3.1 Data collection process

Upon expressing interest in participating in the study in response to the poster, the adult children were sent an information sheet (appendix F) and a cover letter asking them to read through the enclosed information in order to make a fully informed choice about study participation. The adult children were then given a week to read and consider the information before I made contact to discuss their involvement further, answer any questions and complete the consent form (appendix G). Upon completing the consent form, the adult children were asked to complete a demographic information form. They were then given seven days to write about their experiences of risks for their parents with dementia. They were informed that they could write as much or as little as they preferred, and that the risks could be from the past or present and they could discuss potential future risks also. Several of the participants requested further guidance in relation to the word risk – definitions, examples, clarification – I avoided providing such guidance, instead requesting that they take the time to consider what risk meant to them. In some cases the participants requested to provide some examples, to which I would respond that these examples were appropriate to the study. Following the seven days, I contacted the adult children again to request the return of their written accounts via email. Upon receiving the written accounts, a date was then arranged roughly seven days later to interview allowing time for the researcher to read the written accounts and prepare the interview guide. The interview was either held face-to-face in the participant’s home, or via Skype. The interviews were conducted in an informal, semi-structured format through the use of an ethically approved interview topic guide (appendix H) incorporating prompts based on the written accounts (this is discussed later in section 5.3.4). The completion of the interview ended the adult children’s participation within the study.

Table 1 Data collection process

Day 1	Day 1	Day 7	Days 8-14	Day 14	Days 15-21	Day 22
Potential participant sees recruitment poster and emails AA to express interest	AA sends information sheet to student	AA makes contact with potential participant to discuss project, take questions, and complete consent form and demographic information if appropriate	Participant constucts written narrative	Participant sends written narrative to AA	AA prepares preliminary analysis of written narrative to inform interview guide (see section 5.3.4)	AA interviews participant

The following sub-sections discuss in more detail the use of written accounts, interviews and Skype technology, limitations of each method and justification for multiple forms of data collection.

5.3.2 Written accounts

The use of written accounts was adapted from diary method. Diaries offer an understanding, not only of what happened, to who and when, but also how the diarist felt and reflected upon their experience (Alaszewski 2006; Bartlett and Milligan 2015). Hawkes et al. (2009) compared the use of diaries and interviews in their study looking at everyday risk; they note that diarists were better than interviewees at picking up the links between the triggers and the risks that they reported. This suggests the reflective nature of writing a diary allows the participants the time to make links between what happened and how they felt instead of relying on the researcher to make those assumptions and interpretations. Diary method has been used across a range of disciplines in different ways including illness narratives which aim to understand the disruptions an illness can cause (Riessman 2001; Alaszewski 2006). The reflexive nature of diary writing provides a rich context to narrative case studies, and allows for recognising links between events.

While the use of written narratives within this study is based on diary method, I chose to avoid using formal daily diaries because they can often be time-consuming and could be considered to be prescribed by the researcher (Bartlett and Milligan 2015). For example, if I were to ask participants to keep a diary of risk over the space of a week, the participants would feel obligated to write something daily or may not face a risk at all during that week of diary keeping, which would not provide enough relevant data for the study. Therefore, by asking participants to write accounts of their experiences of risk and management strategies, they should be able to write about at least one experience. Even if they felt they had not experienced any risks prior to writing their accounts (this was not the case, as all participants identified at least nine risks), I also asked them to consider the risks they may face in the future.

The strengths of written accounts are affording the participant the opportunity to discuss topics of importance to the participant as opposed to prescribed topics by the researcher and also to afford and encourage reflexivity from the participants. However, there are a number of limitations to using written accounts alone.

One such limitation is that there is a slight bias towards those who are comfortable with writing, although it can be argued that any research method will be biased towards a certain type of participant (Hawkes et al. 2009). Likewise the promotion of the study via social media may have led to a bias of those who were already comfortable with written formats, however as discussed earlier (section 5.2), participants were recruited through both online and offline settings. The participants were informed that their written accounts would be used to shape the discussions at interview, that spelling and grammar were not important and they could write as much or as little as they preferred. This resulted in varying lengths and forms of written accounts across the twelve participants. Some opted to write in simple bullet points, others wrote continuous prose, a couple wrote letters/emails as their written accounts, and one included a poem (of sorts). For the purposes of this study, the main reason for the written accounts was to prepare the participants for discussions surrounding risk and to inform the interview topic guides. Prompts, clarifications and requests for further detail were taken from their written accounts, noted in the topic guide and addressed at interview (discussed later in section 5.3.4). Therefore the length or form of the accounts had limited baring on the overall findings. A final limitation of using written accounts alone is that researchers would potentially be unable to clarify any queries or elicit any further information. Therefore the use of interviews was able to mitigate against this problem and allow for further discussions and details (as will be discussed in the following sub-sections).

5.3.3 Interviews

Interviews are a commonly used method in narrative inquiry; they can elicit high quality data regarding personal experiences if used appropriately. Often attempts have been made to standardise the interview process in order to produce high quality, reliable and valid data for discussion (Silverman 2005). However, the standardised interview is increasingly considered an outdated approach and instead a semi-structured or unstructured approach is favoured amongst social researchers (Holstein and Gubrium 2016). Holstein and Gubrium (2016) argue that by standardising the interview process, researchers may miss crucial information. Through unstructured or semi-structured interviews, the interviewees will start to relax and produce much more organic narratives or accounts as opposed to the more prescribed question and response approach of structured interviews (Polkinghorne 1988). The participants are also afforded the opportunity to reflect on and start to interpret their own narratives (Riessman 2008). Through these interpretations it is possible for the researcher to understand the contextual components to that individual experience. Within narrative research, this is a key part of understanding how individuals respond to different situations and different contexts.

Within this study, to encourage a varied sample (instead of those only local to the study site), the use of Skype technology was employed to enable participation from those further afield than Hampshire (see section 5.2). The inclusion of the option for Skype interviews has aided in geographical diversity which could not have been achieved through face-to-face interviews alone. With Skype technology, it is possible to conduct real-time interviews and through video-calling it is possible to recognise key non-verbal communication which would otherwise be lost by instant message or telephone conversations alone (Janghorban et al. 2014). However, an argument could be made for the relative anonymity such interviewing can hold, despite being able to see each other through video, it is possible that the same authenticity of a face-to-face interview could be lost through the virtual disconnect of video-calls (Sullivan 2012).

There were some challenges in using Skype for interview purposes. Firstly, calls could drop out and then there would entail a discussion of what had just been said prior to the call dropping, thus the constructions of the narratives had the potential to lose their flow. Secondly, the quality of the audio recordings from Skype were not as high as with face-to-face recordings which meant challenges in transcribing. In some cases words were lost as it became impossible to decipher what was being said. I reflected on the use of Skype versus face-to-face interview methods to consider if there had been any impact on the constructions of the narratives. I do not believe that there were differences between the two methods, for example, both Patricia's and Susan's accounts of their parents' driving cessation were of similar lengths and depths despite Patricia having been interviewed by Skype and Susan face-to-face. However it would be difficult to delineate differences without comparing one participant's use of each method – that is comparing a skype and face-to-face interview for one participant. This was not the aim of the study.

A limitation of using interviews alone is that when conducting interviews, whether in an assessment situation or a research setting, it is possible that the interviewee may not always remember sufficient details in retrospect (Hawkes et al. 2009; Jayalath et al. 2016). Although, to reiterate an earlier point, this project is not concerned with finding truth or facts, it is still important to consider as much detail as possible to understand the context of the risk situations. Similarly, there is an immediacy of response associated with interviewing, in this case, the word risk is often understood implicitly and as discussed in chapter 2, is a challenging concept to define. If the interviewees were face with the term risk at interview alone, they may not have had the opportunity to reflect on what this concept means to them. Through affording the participants time to write about risks, they had the opportunity to reflect on the concept of risk. Also interviews often focus on the response to a question or topic of interest provided by the interviewer and therefore may not reflect topics of importance to the interviewee. As with written accounts alone, interviews may hold a bias towards those who are more comfortable with oral communication as opposed to written form which may lead to self-exclusion on the part of the participants.

The following sub-section details how the written accounts informed the interview topic guides.

5.3.4 Creating the interview topic guides

The written accounts collected from the participants were used to inform the interview topic guides. Initially, I read through the written accounts to become familiar with the content. I then worked through each written account to complete the boxes withini the interview topic guide. As seen in appendix H, the boxes included: Risks, probing questions, other questions and a checklist of topics to cover throughout the interview process.

Box 1 provided a list of identified risks the participants covered within their written accounts. Some participants wrote only a series of bullet points which were therefore easily transferred over to box 1 of their interview topic guide. Some participants used helpful headings to highlight the risks they had identified and within these sections, further risks became apparent. For example, Suzie used the heading “Risk of getting lost”, within the section she wrote about various occasions where mum would get lost and the family needed to go and find her. She also discussed additional risks within this section, for example, she mentioned autonomy and independence. So for Suzie’s interview topic guide, box 1. Risks: included ‘getting lost’ and ‘autonomy and independence’. Others produced lengthy accounts of continuous prose for example, one participant used very infrequent headings, and the headings themselves related to the time the situations and risks had occurred (for example ‘past’, ‘present (since moving in with my parents <date>)’ and ‘future’) and therefore identifying the risks required several close reads of the accounts. The initial box served to ensure that during the interview, it was possible to address each risk the participants had covered within their written accounts without having to read through the full accounts during the interview process. However, the risks identified within the written accounts were highlighted in order to find relevant sections within the written accounts for context during the interviews.

Box 2 provided a series of open-ended probing questions. Alongside using a highlighter on the written accounts, box 2 contained examples and quotes from within the written accounts and their page numbers, again to ensure the relevant sections could be easily found within the context of the written accounts. For some questions I would read entire quotes from the written accounts verbatim, for example 'In your written account you said <"What I have learnt is that dementia does not stand still. It is an organic disease with symptoms developing and changing over time. Therefore, risk, and one's attitude to risk, also changes over time (p1).">, could you tell me a bit more?' For others, I would ask about certain words or risks from within the written accounts, for example 'In your written account you mentioned <autonomy>, could you tell me a bit more?'. Upon listening to the responses from the participants, further follow up questions may have been required to ensure full details of the given risk or situation (see appendix H, box2).

Although the participants were asked to discuss risks from the past or present and consider any future risks, I recognised that considering future risks may be a challenge for some of the participants, as in 'you do not know what you do not know'. Box 3 (other questions) served as a reminder to ask about future risks. Additionally, the focus of the written accounts was for the participants to consider risks to their parents, but to get a further understanding of the participants' situations, I also asked the participants to consider the risks to themselves.

The final checklist provided a reminder of the various topics that should have been addressed during the interview. Although, for the most part, the interview topic guide was designed to cover the risks of most importance to the adult children – that is, through their written accounts, the participants would highlight the risks that they wished to discuss - I still wanted to ensure that certain aspects of these risks had been covered. For example, past, present and future risks for the parent, risk management, and risks to the adult children as caregivers for their parents.

5.3.5 Summary: Data collection methods

Using multiple methods of data collection complies with a case study approach, the aim of which is to provide rich and detailed cases in order to delineate between independent factors associated with the individual case and the external factors that impact upon them. In using both written and interview narratives it was possible to form detailed cases of each adult child for comparisons. The written narratives also provided an interview guide based on topics of interest to the participants without being researcher-led as is often the case with structured interview processes. They primed the participants for discussions surrounding risk in affording time to reflect on the concept of risk. The use of both methods of data collection also reduced limitations of using just one data collection method over the other. Using both methods of data collection reduces the bias of those participants more comfortable with either writing or interviews as they would take part in both methods of data collection. The use of interviews provides the opportunity to question and clarify details within the written accounts which would not be possible with written accounts alone. Furthermore the use of both methods of data collection allowed for interpreting how the adult children constructed and reconstructed their narratives of risk. That is, it was possible to recognise changes in constructions of risks when the adult children wrote and reflected upon their experiences and when they were faced with the interviewer.Data analysis

Alongside multiple methods of data collection, I also employed multiple methods of narrative analysis. A thematic content analysis was used to identify the different risks. As previously discussed, a narrative is a meaning structure that typically follows temporal linking of events and actions. In understanding adult children's constructions of risks and management strategies, structure is crucial therefore Labov & Waletzky's structural analysis is used. Following which is a discussion of Baldwin's seven narrative elements with a particular focus on plots, characterisations, and positioning of the narrator and the audience.

5.3.6 Thematic content analysis

Fristly, a narrative should be viewed as the whole and the sum of its' parts. Secondly, a collection of case studies were used to identify differences and similarities between the adult children as a culture. Therefore, the study employed thematic content analysis to recognise the reoccurring themes of risk and narrative elements within the collection of written and interview narratives. Thematic analysis in narrative enquiry is wholly focussed on content, that is what is being said, and is often entirely descriptive in nature (Riessman 2008). However, without attending to content it may be impossible to identify how and why words, structures and narrative elements are used to produce an account. That is, content provides the context upon which other narrative analysis methods can be used.

5.3.7 Structural analysis

The structural analysis (Labov and Waletzky 1997) comprises of identifying and interpreting five structural elements:

1. Orientation – this is where the narrator establishes the story and orientates the reader or listener to the "person, place, time and behavioural situation".
2. Complication – the series of events as they unfold.

3. Evaluation - the part of the story that “reveals that attitude of the narrator to the narrative by emphasizing the relative importance of some narrative units as compared to others.” (Labov and Waletzky 1997, pp. 37). This can be achieved in a variety of ways and is a key element within narratives that maintains interest or focus within the story.
4. Resolution – this is typically the end of the story that describes the final outcome of the event.
5. Coda –typically an additional element that acts to return the story to the present moment.

Within the narratives presented for this study, the orientation of each story typically set the context within which the risk has occurred, the complication was the risk that happened, the evaluation revealed how the participant perceived the situation and the resolution often discussed the management strategy that was put in place. The coda, as an optional extra within a narrative may have been provided by the participant to reveal whether or not that management strategy had been successful.

This stage of analysis was important for discerning the structure of the narratives and to understand how each element of the narrative related to each other in order to convey the story as a whole (Polkinghorne 1988). Not all of these structural elements are necessary nor do they need to appear in the above order to construct a narrative. However analysing each structural element allows a closer understanding of the order and sequence the participants present their accounts in (Coffey and Atkinson 1996).

Through examining the structure of the adult children’s narratives, it was possible to recognise how they presented their accounts, links between events and actions and the importance of certain concepts within the account over others. I have here presented an introduction to the use of structure in narratives; these are later demonstrated in context of the data within this study (chapter 8).

5.3.8 Narrative elements

Baldwin (2013) discusses seven elements of narratives as: the plot (the sequence of events), characterisation (the characters as believable and relatable), genre (the categorisation of narratives that define the expectations of the narrated to), point of view (the perspective of the narrator), rhetoric (the argument or point of the narrative), authorship (the person(s) who has constructed the narrative) and readership (the consumer of the narrative). Baldwin holds that these seven elements are crucial to any narrative both in constructing the narrative and in understanding the narrative. For this section, I consider each of these narrative elements in the context of the research questions and what these elements may provide for analysis of the data.

Plot is used to demonstrate the sequence of events and how these events relate to each other (Baldwin 2013). In this sense, analysing the structure of an account or narrative can be used to demonstrate how each part of the account relate to inform the whole. Through the plot, the audience can also hold certain expectations of what may or may not happen next. In understanding the plot it is possible to recognise the events and the sequence of these events that led to the conclusion of the account.

Characterisation refers to the use of characters within the account. Some narratives can be plot-driven often where the sequence of events occurs to a person regardless of other characters, others a more character-driven and focus on how the actions of other people may drive the plot forward (Baldwin 2013). Baldwin (2013) discusses the importance of characterisation is in how the characters are presented and developed to produce trustworthiness of the account. He goes on to explain how characterisation is used as “a rhetorical device to persuade the reader as to the appropriateness of the response to the situation” (Baldwin 2013, pp. 15). In this sense it is important to recognise and acknowledge the purpose behind how and why characters are presented within narratives as an act of persuasion.

Genre refers to the style of the narrative, and holds with it certain expectations (Baldwin 2013). For example, by categorising the genre of a story as a psychological thriller, it is possible to expect that there will be twists and turns and the audience should expect the unexpected. In the context of this project, I deemed genre as not particularly conducive to the analysis of the adult children’s narratives as it was expected that they would all follow the same theme of risk and were all produced as autobiographical in nature.

Similarly, point of view, which refers to the perspective of the narrator, may not be entirely relevant. The point of view would always be that of the adult child as the narrator of their accounts. However, it is important to recognise that the account is produced by the participant and is designed to convey their point of view. This would be important for considering truth or facts, however that is not the aim of this project, instead I recognise that the accounts of risk presented here are one-sided and that the participants are using narrative devices to persuade the audience of their point of view.

Rhetoric is large part of narratives. It refers to the art of (per/dis)suasion that the narrative or account is credible (Baldwin 2013). This can be achieved through logic, that is, built on reason, objectivity and evidence, or emotion, that is, the narrator aims to invoke an emotional response in the audience such that they feel that the argument is credible (Aristotle 1991). There are numerous rhetorical devices, far more than the scope of this thesis could discuss. This project is primarily focussed on recognising how structure, plot and characterisation can be used to form an argument as part of the constructions of risks and justification of management strategies. However in acknowledging the ways in which rhetoric can be used to persuade the audience, attention is given to rhetorical devices and their effects on the analysis process. This feeds back to an earlier point (in section 5.1.2) that narrative inquirists should be cautious in over-analysing or over-empathising with the narratives presented to them.

Furthermore, narratives are always constructed by an author; they have a particular point or purpose to the accounts that they aim to convey through narrative devices to an audience (Baldwin 2013). There is always an aim in mind; likewise, there is always an audience in mind in constructing a narrative (Baldwin 2013). As discussed earlier in section 5.1.2, the narrative construction is bound by the context within which it is created and always aims to persuade an audience of the argument the narrative is constructed to make. As a narrative researcher, these two points are paramount to understanding and interpreting how and why the narrative has been constructed.

The adult children used their narratives to not only construct a risk, but also to justify their management strategies and decisions. Within their narratives there are four key narrative elements that they draw upon: structure/plot, characterisations, positioning of themselves as the narrator and positioning the audience (as society). The following main findings draw upon these four elements, however the adult children also use various rhetorical devices which are discussed throughout.

5.3.9 Analysis process

The analysis of the data occurred through five stages (see table 2 below for summary of all stages).

The first stage was to prepare the data following interviews. I started by transcribing the interviews verbatim[6]. I then read the transcripts alongside listening to the recordings to become familiar with the content and made notes regarding how the participants vocalised the content of their accounts which might convey sarcasm, discomfort or emphasis, for example. After several

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[6] With the expecion of one participant who had a Parkinson's Disease induced stutter – in this case it was deemed appropriate to remove repetitions of words or pauses that were obviously associated with Parkinsonisms from the transcription.

readings, I highlighted the risks and management strategies discussed, through thematic content analysis. This included both risks that were explicitly discussed, for example, getting lost, but also risks that were implicitly identified, for example as part of getting lost, the participant may have discussed how certain management strategies may have been inappropriate because they restricted autonomy or independence.

For the second stage, I used structural analysis (section 5.4.2) to identify the five structural elements (orientation, complication, evaluation, resolution and coda). Again these were highlighted to recognise the order in which they appeared for each account.

In the third stage, I identified and highlighted the use of each of the five narrative elements described in section 5.4.3 (plot, characterisation, rhetoric, authorship and audience) that were pertinent to this study.

Once this had been achieved for the first eight participants, stage four involved identifying the different structures and narrative elements the adult children used within the context of the content of the narratives. That is, whether certain structures or narrative elements were used more commonly for certain types of risks, situations or management strategies. For example, the standard structure of orientation, complication, evaluation and resolution was more frequently used for risks pertaining to safety. Whereas more complex structures involving several complications and more evaluation were more frequently used for non-safety risks.

The fifth stage focussed on addressing *why* these differing structures and narrative elements were used for different purposes, risks and management strategies. In regards to the example above of the use of the different structures for safety risks and non-safety, the question in stage five was that of why are the participants consistently using these different structures for the two different types of risks? It was during this final stage that further concepts of responsibility and uncertainty became apparently important within the risk narratives. For example, one participant may use characterisation of others and the positioning of themself within their narrative to argue that they had to manage the risks for their parent because there was no one else available to take responsibility. Whereas another participant would produce accounts about another person managing the risks for their parent, characterising the other person as being capable of risk management and positioning themself as an onlooker of the situations and how they unfolded. In doing so, both participants constructed their narratives very differently, thus demonstrating the importance of responsibility within their risk narratives. Likewise, there was a series of accounts where the complication was left unresolved which were frequently coupled with the use of rhetorical questions. In identifying this pattern, the question became that of *why* was this the case across several participants? I interpreted this to demonstrate a lack of certainty in how to proceed with the risk, and the rhetorical questions were actually the participants genuinely asking how to manage the risk. In light of identifying these additional concepts of responsibility and certainty/uncertainty, I revisited the collection of narratives to identify where these concepts occurred and how they were constructed within the narrative. Table 2 provides a summary of all stages.

Table 2 Interview analysis process

First eight participants				
Stage 1	Stage 2	Stage 3	Stage 4	Stage 5
Transcription, thematic content analysis to identify risks	Structural analysis	Identification of narrative elements	Identify structure and element use in context of content	Preliminary interpretation of why structures and narrative elements were used for which purpose
Break in recruitment, review of progress, decision to collect further confirmatory data		**Final 4 participants**		
		Repeat stages 1 – 5 (as for initial 8 participants)	Confirm findings from first 8 participants	

As explained in section 5.2, preliminary analysis began initially with the first eight participants. During the course of learning my analysis methods in practice, I grew concerned that I may require further participants and restarted recruitment. While continuing recruitment for the final four participants, I began to recognise the different structures and narrative elements within the original eight participants. The final four participants then served to confirm the findings from the initial eight.

For the purposes of this study, adult children aim to argue (or convince the audience) that a risk they perceive is a genuine risk and to justify their use of management strategies for supporting their parents with dementia. How the adult children use different narrative elements to persuade their audience can aid in understanding social constructions of risk and expectations from society. For example, as discussed earlier in section 5.1, the adult children may use restricted narratives should they perceive their audience to have a shared understanding, and more elaborative narratives if not. The focus of this analysis is therefore on how the adult children use structure, plot and characterisation to construct their narratives. However, all seven elements are important as they are used by the participants to construct their narratives. Therefore I considered all seven elements in the analysis of the twelve narrative case studies. The content of the narratives is not the focus of the emerging themes in this analysis; instead the content is firstly used to inform the interview topic guides, and secondly to add context to the themes of structure, plot and characterisation. However, there were some themes of social influence or impact that the adult children referred to explicitly within their narratives, therefore these are addressed in a short descriptive chapter next (chapter 6). Chapters 7 and 8 explore the structural analysis and narratives elements as the majority of the data analysis and findings. In recognising that narratives are produced with an argument in mind, analysing the narratives for structure and narrative elements is appropriate for interpreting how the adult children construct risks and justify their management strategies. In acknowledging that all narratives are constructed with an audience in mind, it is possible to theorise on the implications of these social constructions of risk for interpreting wider societal understandings of risk and responsibility in dementia care.

5.4 Reflexivity

An important aspect of conducting qualitative research is recognising the presence, impacts and positioning of the researcher. Therefore reflexivity is crucial to address the impacts of the researcher and any potential limitations. As an adult child caregiver myself, albeit for a parent with a different diagnosis – not dementia, I recognised that some of the challenges I had faced would be similar to those of my participants. In this sense, I could be considered an insider of the culture of adult child caregiving. Additionally my prior work experience has been predominantly within observational dementia research where I frequently conducted interviews with family caregivers. My prior experience with adult children brought to light various challenges they faced in regards to continuing to provide care for their parents with dementia, the challenges of maintaining their safety and a lack of meaningful resources to aid them in care provision. For example, it would be entirely plausible that I would have a negative perception of how HCPs lack a supportive attitude towards adult children as caregivers through personal experience and discussions with participants in previous studies. However, to balance, I also reflected upon my work within the NHS and alongside HCPs, and the challenges I recognise in how HCPs are expected to work. It would not have been possible to have completely bracketed off these previous experiences but through such reflections, it was possible to attempt to draw a wider contextual understanding of the differences between how family caregivers and HCPs practice care for a person with dementia. In fact, the above examples shaped my consideration that family caregivers, HCPs and people with dementia adhere to independent cultures.

Through both my prior experience on a personal level and previous involvement with adult children as caregivers for their parents with dementia, it is possible to consider myself as an insider of the culture of adult children as caregivers. It is possible that this would have affected my style of questioning, for example, if I recognised a situation as being similar to my own or previous caregivers I had conversed with, I may not have requested further detail or clarification. However, I believe this potential limitation may be mitigated somewhat as my participants were unaware of my personal and prior work experiences, therefore the participants would have been more likely to construct their narratives for a person outside of their culture.

Additionally, there were aspects of myself that could not be removed from the research process. For example I presented to my participants as a PhD student researcher, that is, they recognised that the study they were participating in was part of my PhD (as outlined in the Participant Information Sheet). The idea of being a 'PhD student researcher' may present in two different ways. On the one hand, the participants may consider a *PhD* researcher to have a high level of knowledge and expertise not dissimilar to my argument that HCPs have a different knowledge base to family caregivers. This could therefore have led the participants to treat my line of questioning in a potentially similar style to that of Adams (2001) CPNs, whereby the participants may have felt a power differential and resisted certain questions. On the other hand, the participants may have placed more emphasis on the idea that I was a *student* researcher and therefore considered me to have limited knowledge and still learning. This could therefore lead to quite an opposite power differential in the sense that the participants would position themselves as a teacher figure. In light of the aims of the study, to understand societal expectations of risk management for their parents with dementia, either presentation of myself as a PhD student researcher would still position me as an outsider to the adult children's culture. They would therefore still construct their narratives as though I was a part of wider society and have perceptions of those understandings which I would have shared and those which I would have not.

Further examples include my age which was similar to two of the participants, therefore their choice of language and humour may have been directed towards myself. Also, two participants recognised that I was from the discipline of Health Sciences and therefore used acronyms from within the NHS that perhaps other people would require spelling out or further explanation. However, I do not believe these potential cultural alignments affected the integrity of the data necessarily, as all the participants still used similar structures and narrative elements for the same purpose and to the same extent.

Throughout, I kept a reflexive journal which aided me in recognising how the study had progressed from initial ideas to final decisions. For each interview I also kept field notes regarding the nature of the interviews including: how I considered the rapport had built between myself and the participant, my own interviewing style and how this developed throughout the course of interviewing multiple participants, and my initial thoughts regarding the interviews. For example, one participant appeared particularly defensive when I asked questions and I reflected upon why that may have been the case, whether it was the way I had framed questions or whether my appearance or conduct had affected the interview. In this case, after analysing the data, re-listening to the audio recording, I concluded that the participant was experiencing multiple challenges and stresses at the time of interview. The nature of their conduct, I believe was not necessarily aimed at myself, but more the situations and challenges they had recently faced.

5.5 Ethical considerations

The study received ethical approval from the University of Southampton ethics committee on 25th January 2017 and approval for one amendment on 8th June 2017 (see appendix I).

Informed consent

Informed consent is a crucial aspect of research, the Good Clinical Practice guidelines (NIHR 2012) described valid informed consent as: fully informed, voluntary and subject to capacity checks. I ensured that each participant had read and understood the information sheet provided and that their participation in this study was entirely voluntary.

Potential participants were sent a letter of invitation and a participant information sheet. Participants were then given at least 48 hours to read the information and discuss it with their families and friends before I contacted them again to answer any questions. I then ensured they had read and thoroughly understood what they were expected to do should they participate in the study. They were then requested to complete the consent form and indicate that they had read, understood and agreed to each clause and return the consent form in a stamped-addressed envelope.

Support for the participants

Although the participants within this study would not be deemed “vulnerable” in terms of cognitive impairment, I would consider that any participant who is providing sensitive and personal information should be treated with respect and caution. As discussed earlier in chapter 4, one major justification for this study is the need to understand that adult child caregivers can be struggling with burden. Therefore, it was important to consider this challenge when addressing the adult child caregiver participants. As such, should a participant have become upset or distressed during the interview, the interview and audio recorder was stopped and the participant was offered the opportunity to withdraw from the study entirely, return to the interview at another time or continue with the interview after a break. Two participants became particularly upset during their interviews. In both cases, the interview was paused and the participants were offered the opportunity to stop or take or break. Both preferred to continue. The participants were offered verbal information (which was also sent by email post-interview) regarding local services that may be suited to supporting their needs.

Research should not cause unnecessary stress and discomfort. During the process of recruiting one of the participants into the study, the participant had a family emergency and was clearly struggling to find the time to be able to complete the interview part of the study. There was regular communication and ‘putting off’ the interview until it was apparent the interview was producing unnecessary stress for the participant. I made the decision to offer the participant the option of not completing the interview which she accepted. The balance here was between trying to gather as much data as possible whilst not causing unnecessary stress.

Support for the researcher

Within ethical research, a lot of focus is on the phrase “do no harm” and this is often considered to be referring to the study participants, however, it is equally important to maintain the safety and well-being of the researcher. I complied with the University of Southampton lone working policy regarding face-to-face data collection at home visits. Should any sensitive or distressing information be brought to light within an interview, I was to comply with safeguarding measures and discuss any research difficulties with my supervisory team. This was not required.

Anonymity and confidentiality

All data (written and interviews) was treated as anonymous and confidential. Participants chose their own pseudonyms and all data pertaining to that participant was stored under their pseudonym apart from personally identifiable data which was stored separately. Participants were informed that anything they discussed within the study would be treated as confidential, however, if they discussed anything that should cause the researcher (me) any concern for someone’s well-being, I had a duty to report it to the relevant social services who would be able to provide them with appropriate support. This was not required within this study.

In data reporting (within this thesis and any relvant publications) the narrative data is reported under the pseudonyms the adult children chose. Any details that may be considered to be distinctive to the adult children's narratives (such as names of characters and locations) were removed from the data. In this case, the important aspects of the data were noted, for example "<husband's name>" or "<location – long distance>".

'Over-sharing' and the research experience

As this study aimed for collaboration in data production through the interview process, it was necessary for the researcher to build a good rapport with the participants. Although this rapport can provide the participant a comfortable environment to discuss their experiences openly, there have been cases in the literature where the researcher has taken advantage of over-sharing. By over-sharing, I mean the participants have discussed more sensitive details than they would have liked upon reflection (Willig 2008). Therefore, each participant was given the opportunity to read their transcribed interviews to ensure they were comfortable with their disclosure and to ensure the researcher had captured the conversation as they were without altering the meaning of the discussions. Any queries were to be discussed between the researcher and interviewee until an agreement was met. Participants were reminded that they could choose to withdraw at any stage without giving a reason. The challenge in checking back with participants is that data is then open to reconstruction and negotiation between the researcher and interviewee, which in itself may not stay true to the original interview. None of the participants asked for changes to be made and indeed, some preferred not to 'put themselves through' reading back over their interviews due to the emotional content and potential for distress.

Lost interview data

Unfortunately, following one of the interviews, which had been particularly distressing for the participant, the interview audio file became corrupted and irretrievable. I discussed the lost data with the participant and offered her the option to redo the interview which she declined as she felt that the interview had been difficult enough the first time and preferred not to do it again. The challenge was deciding to be honest with the participant who had an emotional time during the interview. The participant appeared grateful at the honesty and preferred not to redo the interview process, however was happy for the previously completed written narrative to be used for analysis.

5.6 Summary: Methodology and methods

This chapter has described and discussed the methodology and methods employed within this study. Initially the chapter discussed the methodological assumptions, in particular how Douglas' Cultural Theory and Bernstein's theory of language coding have shaped the study design. By recognising language codes it was possible to identify the shared (or not) understanding between adult children and their audience. Through a constructivist standpoint, the project addressed adult childrens' independent constructions and reconstructions of risks and how these may be shaped by social and cultural norms. The case study approach allowed for a detailed understanding of each adult child in terms of their characteristics and similairites and differences across the collection of cases. Narrative inquiry was used to understand how the adult children produced their narratives and how they constructed and reconstructed risks and justified their management strategies. The importance of these constructions and reconstructions was that they were produced with an audience in mind, in this case society. Through analysing how the adult children constructed their narratives, it was possible to recognise whether they believed that society had a shared understanding of dementia care or not. Furthermore, it was possible to recognise how the adult children perceived societal expectations in how they impacted upon their constructions of risk narratives.

Twelve cases with limited variation allowed for comparisons between cases within the same cultural boundaries. The twelve cases also provided replicability for theoretical generalisation. By using both written and interview narratives as produced by the adult children, it was possible to analyse how the risk narratives could be constructed and reconstructed. This was not for the purpose of truth-finding or corroboration of facts, but instead to understand how multiple truths could be constructed.

Through thematic content analysis, structural analysis and analysing the use of narrative elements, it was possible to understand how the adult children constructed their narratives. It was then the reasons why the adult children constructed their narratives the way they did that enabled an understanding of the perceived societal expectations as impacts upon their narratives.

The following chapters demonstrate the use of the methodology and methods employed within this study and findings. Chapter 6 provides a relatively short description of some themes of explicit impacts from society, including societal misunderstandings of dementia and dementia care, impacts from the media and popular literature and other people's experiences. Although the themes discussed within chapter 6 were not a result of interpretative analysis, it was appropriate to include this brief chapter to address the potential societal expectations and impacts that the adult children recognised and explicitly discussed.

Chapter 7 addresses the concept of responsibility. Although the adult children were not asked about explicitly about responsibility, the theme of responsibility was consistent throughout all the narratives. The adult children used different characteristics and characterisations of others to position themselves within their narratives. In positioning themselves within their narratives, the adult children were asking the audience to recognise their varying levels of responsibility. These levels of responsibility then impacted on how and why the adult children were able to construct risks and justify their management strategies.

Chapter 8 pertains to the more implicit impacts from society upon the adult childrens' narratives and the content of risk. The chapter starts with a description of the themes of risks and use of background information. Following which are several sections that demonstrate the structural analysis and use of narrative elements (in particular: plots, characters and positioning the audience). These sections demonstrate how the structures and narrative elements were used by the adult children to construct a risk and justify their decisions. After which is a discussion and demonstration of why the adult children constructed risks and justified management strategies in the way they did by comparing constructions of health/safety risks and non-safety risks. With the audience (or society) in mind, the analysis shows that society likely recognises health/safety risks as more important than non-safety risks. The discussion chapter (9) positions the findings within the literature and in the context of sociocultural theories. The final chapter (10) concludes the findings of this study and hightlights the limitations and potential implications of the findings.

Chapter 6: Explicit impacts from society or culture

The participants made multiple explicit references to societal impacts including: media, other people's experiences, societal understandings and popular literature. I therefore include these within this descriptive chapter as part of the narrative thematic content analysis because the adult children recgonised these impacts from society on how they may shape their decisions surrounding risk for their parents with dementia.

6.1 Media

The media can hold negative assumptions of dementia which in turn could impact on caregivers. For example, Patricia discusses how she and her family had been considering paid care for mum

> *So I suppose I'm worried about the risk of other people and trusting, trusting other people to come in and look after her in place of us. Erm you know just the really sort of basic risks if you read too much Daily Mail, you just think that everyone is just out to* <laughs> *and unfortunately my dad does so he's, you know he's not that in favour of getting carers to come into the home because you know he's worried about them taking advantage or like you know so you have that that kind of worry. – Patricia (interview)*

She recognises that reports in the media may impact on decisions surrounding paid care and implies that she considers her dad is negatively affected by such stories. However, she also has reservations about trusting paid care. She may recognise that negative thoughts of paid care could be fuelled by the media, but maintains reservations.

Susan similarly notes her concerns for trusting paid care

> *Obviously there's enough extreme abuse on the news, these things on the news that - well obviously I mean that is a worry but I think it's probably a lot rarer than… you think. But,* […] *– Susan (interview)*

Susan uses the stories of abuse on the news as evidence for her concerns about paid care. Although, like Patricia, she notes that not all media should be trusted implicitly and she considers that the news would be highlighting extreme cases, she goes on to say 'but' and then conveys her concerns about abuse for her mum should she have paid care. In both Patricia and Susan's accounts, they acknowledge that news in the media can be misleading, but this acknowledgement is not enough to curtail their concerns. Therefore media may still have an underlying impact on their decisions.

Two of the adult children discuss using social media platforms as a tool for support and advice, for example, Jodie spends a lot of time researching different methods of support for her mum. She discusses a few helpful tips from peers on social media that she has attempted to implement. However, there are also negative aspects associated with social media support. Patricia speaks of her experience of social media

> *Erm and I joined a group on Facebook which I thought would be helpful but actually it's not really because everybody's experiences of this is so different erm and then quite often you get people going in there and who talking about their mother-in-laws or you know who are just really kind of, you know just they haven't really got it what they seem to be is just kind of annoyed by it or you know someone's behaviour and so I think I'm going to leave that group because I don't find that particularly helpful for my* <laughs> *sanity. – Patricia (interview)*

The media impacts upon the adult children. Here the discussion has been about those particular cases where the adult children explicitly acknowledge these impacts upon their own perceptions of risks for their parents. The adult children use social media in attempt to find peer support, however note that these groups may not always be useful.

6.2 Other people's experiences

Some of the adult children also rely on other people's experiences to form part of their discussions around certain risks or concerns. For example, Lucie describes her friend's experience

> *my friend's grandad has dementia, and he's a lot further along than my mum is but I've seen him like pretend but nearly glass my friend in the face. Because he's erm getting really angry and frustrated he's almost had this aggression towards her, even though he sees her every day, because he can't remember things that's his way of, of dealing with it, because I know that can be a factor of the condition is that they can become angry or irritable so I think as much as I don't like being like that towards my - I also worry like that my mum could be like that towards me or towards my family members. – Lucie (interview)*

Although she has not experienced her mum being aggressive or violent with her dementia, Lucie has a fear that mum could become aggressive based on her friend's experience of her grandad's dementia.

Similarly, Carol comments

> *I know I'm lucky because there are many examples of people with dementia becoming aggressive, but he's not like that at all. – Carol (written)*

Here Carol recognises that her dad has not become aggressive, but in mentioning that there are examples of people with dementia becoming aggressive, there must be an underlying concern that this could happen.

These examples may represent a societal understanding or expectation of people with dementia to become aggressive, and is often common across the media (particularly social media) where caregivers share their stories. It may also demonstrate a cultural view. With family caregiving as a culture, peer support and advice may often be sought, but amongst the benefits of advice from those with lived experiences and in similar situations, it is also possible to be faced with negative accounts that in turn impact negatively on the caregiver. The adult children may seek to learn from other people's experiences or are faced with them when discussing situations within their own practice of care for their parents. Much like with media impacts, these held negative assumptions associated with societal understandings of dementia and can impact on how the adult children understand their own parents' dementias.

6.3 Societal understandings

Similarly the adult children may also recognise societal understandings. For example, Patricia discusses situations of being asked inappropriate questions

> *So I remember quite early on one of my friends who was just a bit glum but you know her immediate reaction saying "oh does she still know who you all are?"- Patricia (interview)*

This question refers to one of the often more feared symptoms of dementia across family members. Patricia described the question as insensitive. Although at the time, mum still knew who Patricia was, it is possible that this type of question (which is common in society) would spark a concern and affect Patricia. Similarly to Carol's above comment, Patricia need not have mentioned this incident as it was not paramount to the topic of conversation and happened a long time ago, but in mentioning it Patricia may demonstrate that this comment remained with her through her caregiving journey.

Lucie, as the youngest participant in this study, has a slightly different experience to some of the other adult children in that her mum has young-onset dementia and Lucie was a teenager when her mum started experiencing symptoms. Lucie demonstrates a societal lack of understanding of young-onset throughout her narrative, commenting that no one would know there was anything wrong with her mum.

> *Erm and I think it's difficult because obviously a lot of people, if they aren't familiar with the condition, or if she isn't prepared to say to someone in the*

> *bank or in the shop that she has this condition, then obviously people will sometimes look at her in a very confused way, 'cause they're like "well you don't look old enough, and you don't look ill" so that's, that's a big issue - Lucie (interview)*

She frames this societal lack of awareness or understanding as increasing risk to her mum. Because people do not recognise that mum could be living with dementia, they may not be able to provide appropriate support to her.

She later draws on societal understandings, or lack thereof, of young-onset dementia again

> *my step-dad his mum has just been diagnosed with it but she's like 84. So I understand it was sad for him, but in my head I'm like "well she's 84. Like that's a lot older. Like my mum's not even 60" so I find myself almost being selfish with that, and I don't like being like that but I can't help it it's like an instinct, if someone said something to me about it. – Lucie (interview)*

Again, Lucie demonstrates that society's understanding of young-onset dementia may be limited. She also aims to argue that her situation is different to others because her mum's age is so young in comparison to late-onset dementia.

Societal understandings of dementia may not be entirely accurate and the adult children recognise these within their own narratives. They may, however, still impact upon the adult child negatively or may also be considered as an external threat or risk to their parents with dementia.

6.4 Popular literature

Three of the adult children make reference to different books regarding dementia. Roger explains that one of his relatives had written a book regarding her own experience of caring for a family member with dementia. Roger had not yet read this book but wanted to in order to draw from it comparisons to his own experiences.

Kate makes reference to the author Atul Gawande, a surgeon and health researcher who has written several books presenting case studies and reflections from his own practice. In particular his book *Being Mortal* draws upon the contentious issues surrounding end-of-life care and aims to challenge expectations of the role of medicine. Kate says

> *Now he just doesn't go, so he gets no exercise and no stimulation and it's like his world has just… it's become that chair… and if he was in a chair like that in a nursing home he would get some stimulation, other people would be talking to him, and I'd feel a little bit happier about his quality of life, even if he just spent most of the day watching television, if that's what he wanted to do, you know, I'm with Atul Gawande on the whole it's not what my quality of life*

> *would be, it's about his quality of life - if that's what his quality of life is, that would be, that's fine. – Kate (interview)*

Kate draws on her reading of Gawande's work to justify her consideration that a good QOL is not the same for everyone.

Jodie too draws on her research into dementia care, which she would put into practice when providing care to her mum and in supporting dad to understand positive practice of dementia care for his wife. In particular she references *Contented Dementia* by Oliver James, a popular book amongst family caregivers. Jodie says

> *I had read a couple of books and quite a lot of stuff online. Erm and one of the turning point books I read was the one by Oli – Oliver James Contented Dementia and I really took to the erm their method erm SPECAL method but also sort of the three main stays which were to not contradict, not erm not ar – no that's the same thing, erm not question erm and sort of make them the expert you know sort of ask them for their opinion on something to still validate their thing. – Jodie (interview)*

The three 'golden rules' of the SPECAL principles that Jodie is referring to here are: "1. Don't ask questions, 2. Learn from them as the experts on their disability, 3. Always agree with everything they say, never interrupting them," (James 2009, pp. 3). Again, Jodie demonstrates drawing on popular literature to justify her decision to use the methods she employed with her own parents.

Both examples here draw on popular literature to aid in justifying their approaches and understandings of their parents. Both hold more positive aspects in comparison to media influences and other people's experiences.

6.5 Summary: Explicit impacts

The aim of the study was to understand how adult children may be impacted by cultural norms and societal expectations when managing risks for their parents with dementia. The majority of which were implicit and subtle that required interpretation through the use of narrative inquiry methods. However, this initial findings chapter highlights the explicit impacts of societal 'knowledge' upon the adult children's experiences. The adult children make note of impacts of the media and social media as potentially negative. They draw upon other people's experiences in order to understand their own parent's dementias, however these may also hold negative assumptions. Finally, they are able to justify their management strategies further through popular literature and demonstrate how such literature has impacted upon their understandings and care practice in a positive way. This perhaps demonstrates a hierarchy of useful resources the adult children may draw upon where media is the least helpful, social media can provide support but typically does not, likewise other people's experiences and expectations often impact negatively and popular literature such as self-help resources for caregivers may hold the most positive impacts.

Chapter 7: Narrating responsibility

The adult children were asked to discuss their experiences of risks for their parents with dementia; they were not directed to discuss responsibility for their parents. Through analysis of the narratives, the theme of responsibility was consistent thus demonstrating the importance of responsibility in risk narratives. Every participant positioned themselves within their narratives at varying levels of responsibility for their parents with dementia. They used situational and contextual factors, narrative elements - particularly characterisation of other people - and perceived societal expectations to present themselves at these varying levels of responsibility for their parents. Inherent within responsibility is the notion of accountability, through presenting themselves at varying levels of responsibility, they then required justifications for their actions.

This chapter discusses the situational/contextual information the adult children used to position themselves within their narratives. Following which is a discussion of how the adult children are then required to justify their management strategies because of their positioning within their narratives.

7.1 Constructing responsibility

The adult children relied on a number of perceived societal expectations of responsibility in positioning themselves within their narratives. They also drew upon narrative elements such as plot and characterisations of others to do so. The factors affecting societal expectations of responsibility, apparent from the analyses of these narratives, were: how instrumental the adult child was in the diagnosis process; whether they consider themselves to be the caregiving type; how they characterise their other parent (whether capable of providing care, or not); how they characterise their siblings; distance to parent; working life; whether they had children or not; employed paid care; and POA. These factors are discussed in turn.

7.1.1 The diagnosis account

Several of the adult children provided an account of their parents’ diagnosis. Those who were instrumental in their parents’ diagnosis may have anticipated providing care or support to their parent with dementia. For example, Mary noticed subtle changes in mum that led to mum attending a GP appointment and eventually receiving her diagnosis. Mary had previously been supporting mum and visiting frequently so when mum was diagnosed, the amount of care and support she provided increased. Whereas those who were not instrumental to their parents’ diagnoses experienced a sudden realisation that they would have to provide care to their parents. Carol is the primary caregiver to her dad with dementia. Dad's nurses (for eye appointments and other health problems) would comment that his memory was poor and suggested having it assessed, Dad made the decision to visit the GP for a memory assessment.

> *A specialist then came to his house, she said he had Alzheimer's disease and prescribed Memantine. I was with him for that appointment and started to realise I needed to be with Dad for any visitors really, as I understood then how much he struggled with knowing where (and when) he was. – Carol (written)*

Although both adult children took on the caregiving role and learned how to provide care to their parents through experience, it could be considered that Mary was more prepared for her role of caring for mum than Carol.

For those adult children who already provided care or support to an ageing parent and those who noticed the symptoms of dementia which in turn led to their parent's diagnosis, there was an anticipation or expectation of ongoing or increased care upon diagnosis. For those who were not instrumental in their parent's diagnosis, who had not previously cared for or considered care for their parents, the diagnosis of dementia formed a sudden realisation that caregiving would be required. Both the adult children expecting a diagnosis of memory problems and those not expecting the diagnosis still may end up with equal amounts of responsibility for their parents with dementia. However, those who were not expecting the diagnosis often formed accounts of uncertainty in their actions. This notion of uncertainty is discussed further in chapter 8 (section 8.3.4) and is an important aspect of the adult children's narratives (much like responsibility) when considering how they construct their narratives for an audience.

7.1.2 'The caregiving type'

Some of the participants had a background in health or social care; these adult children presented an expectation from 'others' (often unknown, but could include themselves, their parents, siblings, HCPs or society) that they would either provide care or have knowledge which would help with caregiving. For example, Kate draws on her knowledge of healthcare systems to aid her in providing care to dad

> *Um, so sometimes they look to me for my pseudo-medical knowledge about things because I can look things up in a BNF and say, "yes that drug is for your heart dad" – Kate (interview)*

She also refers to ‘QOF points’ – quality and outcomes framework – an incentive programme in England that rewards GP practices for quality of care[7]. This demonstrates her understanding of healthcare systems and may inform a societal assumption that because she has expertise in healthcare, she should be more responsible for her parents whereas those who did not have this prior knowledge would not consider this as reason for higher responsibility. However, in comparing their narratives, those who had limited knowledge of healthcare systems may have struggled more in taking on the caregiving role than those who did, for example Carol states

> *I am not a natural carer or nurse-type person, but Dad and I are fond of each other. He’s always telling me he loves me & he’s very grateful to me for visiting.- Carol (written)*

Although Carol is not ‘a natural carer’, she is primary caregiver to dad. By stating this, the audience can expect that her new role has been more of a challenge than those who would be considered ‘the caregiving type’. Because she has stated that she is not a natural caregiver, she then justifies why she continues to provide care to dad by conveying his gratitude that she does provide care as a form of reciprocity. This in turn impacts on how the adult children provide care to their parents. Kate uses her knowledge of healthcare systems to engage with the most appropriate HCPs to get the care dad requires. Whereas Carol asks for a lot more advice and support from the local authority to learn about the types of care her dad could receive.

The idea of a ‘caregiving type’ has a standing in society; societal expectations of caregiving types may be higher than those who are considered not to be ‘caregiving types’. This may increase the pressure on those caregiving types to provide more appropriate care than those who are not. The adult child who positions themselves as a caregiving type within their narrative may then risk the audience expecting them to act in a certain way over those who do not position themselves as such.

Interestingly, those women who did feel that they were the caregiving type need not mention this. Instead society views women as more likely to be naturally care providers. Therefore if a female is not a caregiving type she may feel the need to disclaim it. The male participants also did not make mention to being the ‘caregiving type’ instead they either provided care to their parents or positioned themselves as having less responsibility. Although only one participant described this concept of ‘caregiving type’, other female participants made mention to social norm expectations of females being more likely to take on a caregiving role.

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[7] QOF points – https://digital.nhs.uk

7.1.3 Gender

Two of the adult children made mention to gender as part of the reason they provided more care than their brothers. Ellen mentions that perhaps there was less expectation of her brothers to provide care (discussed later in section 7.2.2). Susan states that even if her brother lived closer, she would still be more likely to provide health and wellbeing types of care but her brother may have increased support surrounding finances and mum's legal affairs. Roger is a son with only brothers and therefore the gender expectations do not apply to his situation. George has a sister and once his dad received his diagnosis, between the family it was decided that mum and dad would move to be closer to George's sister. This could portray some gender expectations, however George also explains that his own health would impact on how he could support his parents (discussed later in 7.1.6).

Jack made the decision to move in with his parents despite being male and having a sister. The reasons were because his sister had a family of her own and lived a long distance away, therefore it would have been more challenging for her to uproot her family to move closer to her parents. However, Jack does suggest that the care his sister would expect to provide would be very different from the care Jack provides. He comments

> *And I keep, like my sister would feel like she couldn't do much 'cause she was six hours drive away. And sh- there would be a sense of "well if it's left to dad and* <Jack> *then nothing's going to happen."* <laughs>*. And I could see her frustration in that. Because she get - because she wants to change things. She wants to - she's a very active – she's an activator and she'll be like "well, this needs to happen". – Jack (interview)*

He explains that he finds himself defending his decisions to his sister who has different expectations of how Jack and dad should provide care to mum. Her expectations are that Jack should be responsible for learning as much as he can about mum's condition and enacting guidance and advice from what he learns. Jack however argues that it is difficult to research dementia when you are actively living with the situation. Jack's argument here demonstrates how there may be differences in the ways that he and his sister would provide care to mum in the same situation. He does not explicitly talk of gender differences, instead he talks in terms of his sister's personality which may implicitly be related to gender.

Gender was mentioned explicitly by several of the participants, however other factors were also important to acknowledge as impacting on care responsibility decisions, therefore suggesting that gender alone does not dictate who will be more likely to have increased responsibility.

7.1.4 The other parent

Where the other parent is still alive, it is typically held by society that that parent would be primary caregiver to the parent with dementia. However, whether the adult child positions the other parent as appropriate for the role of primary caregiver or not within their narratives typically depends on their characterisation of that other parent as physically and mentally capable of providing care. Where the parent is portrayed as physically and mentally capable, they are considered to be primary caregiver and the role of the adult child is to provide support, for example Jack

> *Where if dad needed to go somewhere or erm so I mean yeah if something happened to dad that would be a pretty crazy thing to do but how we would – what would be the consequences if dad had to go into hospital for whatever reason? Erm yeah where could mum go? What would happen to mum? What would that look like? I don't know.- Jack (interview)*

The audience can infer that Jack's dad is healthy because Jack comments that the idea of something happening to dad would be 'a pretty crazy thing'. Jack's dad therefore can be assumed to be primary caregiver to mum. This is further evidenced because Jack does not know what would happen should something happen to dad. He does not position himself as primary caregiver, nor does he consider that he would take up that role should dad no longer be able to.

Where the other parent is characterised as physically frail, there is consideration that other family members or the adult child themselves are then responsible for both parents. For example George writes:

> *Physically my father is very fit for a man of his age and very mobile, but received a formal diagnosis of Vascular Dementia and Alzheimer's disease in the autumn of 2016. He showed symptoms of memory loss and behavioural changes over a period of about 3 years, after being taken ill during a bowls match. My mother is very sharp mentally, but suffers from arthritis in her knee and shoulders, which seriously affects her mobility to the extent that she needs to use a wheelchair when out of the house. They have been a married couple for over 65 years. – George (written)*

Through describing his parents in this way, the audience is able to draw comparisons between both parents and conclude that mum would struggle to provide appropriate care to dad in the physical capacity. Therefore mum's responsibility for dad is reduced and as George admits in his narratives, his sister has a high level of responsibility for both parents.

Where the other parent is characterised as mentally and physically incapable of providing care to the parent with dementia, again the adult children typically present themselves at a higher level of responsibility. For example Kate, whose mum has mental health problems, and Jodie draws on her concerns for her father's memory meaning she and her sister are portrayed as taking on more responsibility.

The ways in which the adult children characterise their other parent then impacts on how the audience perceives that other parent, which may in turn impact on the level of responsibility the audience assigns to that adult child. If the other parent is characterised as physically and mentally capable of providing care, then the adult child's responsibility is reduced. If the other parent is characterised as physically or mentally incapable, then the adult child's responsibility for their parent with dementia, and often the parent without, is increased.

7.1.5 Siblings

Characterisation is also used to position siblings as more or less responsible. Those adult children who have no siblings can position themselves at higher levels of responsibility than those who have siblings. For example Kate is an only child and with this is an expectation that she should provide more care than those who have siblings.

Those that have other siblings can portray themselves and their siblings as sharing responsibility for their parent(s), for example Jodie often has concerns that she should be doing more to match her sister. She had previously explained that she deals with a lot more of the health and wellbeing aspects and

> *my sister's been trying to sort out all the financial stuff, so just making appointments with each of the banks er for example to get the LPA registered so that my sister can take over the control of the money in order to pay the care home, you know, all those things have come up all at the same time. Making appointments to go and see the solicitors to work out what we need to do erm and as I say, she's got an understanding boss, but she's taken a huge amount of time off work. And so there's a little bit of me that feels guilty that you know my sister's doing so much, I've got to be able to do as much as I can on the other side of things. – Jodie (interview)*

The audience can assume that both sisters share responsibility for mum and dad but that their responsibilities are different - Jodie manages health and wellbeing and her sister manages finances. However, Jodie takes this consideration further and reflects that she experiences guilt if she does not match the amount of care her sister provides.

The adult children can also position themselves as having more or less responsibility than their siblings, using arguments such as distance to parent, working life and whether they have children or not. These are discussed in the following sub-sections.

7.1.6 Distance to parents

One factor that impacts on expectations of responsibility levels amongst siblings is distance to parents. For example, Jodie's brother lives in a different country, therefore society can expect that he has limited responsibility for daily care in comparison to Jodie and her sister. George lives a long distance away and therefore it is expected that his sister (living almost next-door) has a higher level of responsibility for their parents' daily care needs.

> *In June 2016 they sold their house in* <location 1> *and moved to* <location 2 – over 200 miles from location 1> *to a bungalow approximately 300 meters from my sister's home, in order to get the help and support of family. – George (written)*

George explicitly states that his sister has a higher level of responsibility for the care of mum and dad as she lives very close. When discussing the decision for his parents to move closer to his sister, George explains that at the time of the decision he was undergoing assessments for Parkinson's Disease. Therefore, the audience can understand that it was more appropriate for George's parents to move closer to his sister.

Kate lives at one of the longer distances from her parents (similar to George), but without siblings, cannot reduce the expected level of responsibility through distance.

7.1.7 Working life

The adult children's working life impacts the adult children's narratives in two ways. The first is that their working background demonstrates their caring nature and understanding of care systems as described in the above section (7.1.2). The second is those that are self-employed are expected to hold more responsibility in daily care to the parent with dementia than those who are employed. For example, Patricia

> *So I had a job but my boyfriend asked me did I want to kind of you know start this company with him and work from home and so erm part of my reason for thinking well it would be good, it was the kind of flexibility I would have to try and erm see more of her be in a position where you know theoretically we all have the internet, I can work from anywhere. So I could start working from there. Which was quite ideal, I mean that's not really the case now I don't get any work done when I go there now. – Patricia (interview)*

The audience can understand that self-employment can allow for autonomy and flexibility in working hours which would increase the self-employed sibling's level of expected responsibility over those who are not self-employed. Initially, Patricia appears to accept this higher level of responsibility due to her working flexibility. However, later when asked about risks to herself, she says

> *I suppose I feel that I am a person at risk. In the short term er financial burden. Trying to start up your own business and also care for your mum with dementia when you're the sort of main go-to person of your family means that quite often I just feel like I've just got quite ill carrying quite a heavy burden and I'm kind of being pulled in several directions. And you never really feel like and you know at times I'm definitely not working as hard as I should be on the business, but then equally I feel like I'm not giving her time and attention she deserves – Patricia (interview)*

Perhaps demonstrating how assumptions about self-employment may be flawed in that in order to be financially stable within self-employment, one must work enough hours to make money. An adult child caregiver who is self-employed is responsible for ensuring their work succeeds financially, but also balance the increased level of responsibility for the parent with dementia due to flexibility of hours. Patricia concludes that she feels torn between not producing enough hours at work and not providing enough attention to mum either.

7.1.8 Children

When comparing responsibility between siblings, it is possible that when one sibling has children and another does not, the one without children may experience higher levels of responsibility. For example, when Patricia talked about managing mum's leaving home and getting lost, she explained

> *Essentially we just try to manage it by being there more. But that's obviously quite a personal strain on our lives and that's not that easy for my sisters who obviously have children and school runs to manage and that kind of thing. – Patricia (interview)*

She implicitly draws on society's understanding of managing children and school runs to imply that it may be considered easier for Patricia to take responsibility for mum at home and maintaining her safety regarding leaving the house. This expected responsibility is increased further because Patricia is also self-employed as discussed above.

7.1.9 Paid care

Some of the adult children had employed paid care for their parents with dementia and one had recently moved their parent to residential care. With this additional care or support it could be expected that the adult child's responsibility level would reduce where the paid care alleviates some of the daily care required. However, there are some challenges involved. For example, trust of paid carers is required to ensure the paid carer is providing the appropriate care require. The role may also change to a care manager which holds with it different responsibilities for a parent's care in ensuring the right kind of care is provided at the right time. For example Ellen

> <Carer> *needed some persuading. So I worked-, actually I worked with* <care agency manager> *from the agency, to say "look – you know - it's important to us that she showers every day, she's not continent, she always showered every day, that's what's going to happen." – Ellen (interview)*

Ellen demonstrates how her role may not be to provide personal care to mum but that her role is that of a care manager to ensure mum receives the personal care Ellen expects her to receive.

Despite having paid care and support in place, both Mary and Carol discuss how if anything were to happen they would still be the first point of contact and therefore the paid care does not alleviate all pressures and concerns. However, often the employment of paid care changes the role of the adult child from that of a caregiver to a care manager as with Ellen which holds with it different types of responsibilities.

7.1.10 Power of attorney

POA holds with it expectations of another level of responsibility. Those who had POA for their parents spoke of it with an air of authority, where POA grants the ability to make decisions regarding health, wellbeing and/or finances for one's parents, there is an expected level of authority, control or power over a parent's affairs. Where George is not involved in the daily care of his parents, he mentions POA at several points almost as a way of asking the audience to recognise that he does still have responsibility for his parents.

Mary is heavily involved in mum's daily care, however recognises there are certain aspects of mum's care she is unable to attend to.

> *He's* <husband> *taken over more because he's had to in terms of the appointments and the liaising with the powers-that-be because of his power of attorney thing that's where… I mean I'm allowed, I'm allowed to talk to the GP surgery, I've got, my name's on there, I can ring them and talk to them, but otherwise from the sort of legality perspective that's got to be him or his brother. – Mary (interview)*

Mary discusses how her husband and his brother have POA and therefore regards them as having ultimate authority and responsibility over the care provided to mum.

There are many misunderstandings surrounding POA and throughout the narratives, these misunderstandings are quite apparent in that the parents often struggle to assign POA to their children because of concerns of their children taking over. This coupled with the reverence with which the adult children discuss POA could represent the societal view that POA is a higher level of authority than the standard daily care of a parent with dementia and that this level of authority should grant with it a higher level of respect.

7.1.11 Summary: Positioning responsibility

The adult children all draw upon similar factors to position themselves within their narratives. These include both situational and contextual factors, such as distance to parents, and use of characterisation, for example in portraying the other parent as more or less capable of providing care. The situational factors used hold with them societal expectations, for example whether the other parent is alive and capable of providing care to the parent with dementia (or not) impacts directly on society's expectation that the adult child be held to higher or lower responsibility. In positioning themselves at varying levels of responsibility, the adult children also produce an expectation of accountability for their actions. Therefore, the ways in which they position themselves within their narratives has an impact on how they must justify their management strategies. However, each of these factors are not independent of one another and typically interact. That is, the adult children never isolate a single factor to present themselves as higher or lower responsibility, instead they use a combination of factors to present themselves as such. This is demonstrated in the following sections which focus on specific case studies to demonstrate how positioning of the adult child in terms of responsibility impacts on their risk narratives.

7.2 Responsibility and constructions of risks

The above section provides a description of the themes the adult children used within their narratives to position themselves at varying levels of responsibility for their parents with dementia. This section demonstrates the impact of differing levels of responsibility upon the risk narratives through three cases: Jack who positions himself at a low level of responsibility for his mum, Ellen who positions herself as at a high level of responsibility for mum, and Lucie who changes her positioned responsibility depending on the situation.

7.2.1 Jack – limited responsibility

Jack's mum has young-onset dementia and lives with Jack's dad who does not have dementia and is still physically and mentally fit to provide care to mum. Jack presents his dad as primary caregiver to mum throughout his narratives and considers his role as supporting of dad, and mum by extension

> *One of my concerns is how to help sustain Dad and keep him healthy, fit and strong for Mum.*

Jack has a sister who has her own children and lives a long distance from mum and dad, thus his sister's responsibility for daily care is reduced. When his work contract ended, Jack was in a position to move in with his parents to provide them more support.

> *So I guess it's challenging 'cause I'm in that mode where I've come down to be helpful and then you kind of think you know you're being helpful because you're here and everyone's like "oh that's great because you're here" but you don't actually feel that useful because sitting in the back of a car so that dad can go shopping doesn't feel like you're going "oh yeah well I'm superman aren't I?" you're like "oh yeah, I'm just sitting in a car babysitting mum" as it were. So you know that's good, that's helpful but it's not particularly a great lifestyle choice or one that you can just think "oh yeah I'll just do this for ten years" whatev- you know. So there's that thing of how do I help?*

He reflects on societal considerations of Jack as being a 'hero' in moving in with mum and dad, but that in practice Jack is struggling to find a role that would be of most help to his parents. This is a recurring theme throughout Jack's narrative, the idea of trying to find his role in providing care, but he always draws on the support he provides to dad, for example

> *You don't know what normal is anymore. So yeah. I – I've – yeah – I've – I do stuff like go and do a bit more cooking, just because I know dad will appreciate coming in for lunch and I – I'm doing what mum would have done <laughs> so it's a bit weird isn't it? "oh I'm doing… I should go and put the washing on then."* <laughs> *do you know what I mean?* <laughs> *and you're like it's just a bit of a funny role reversal.*

Jack describes a role reversal which is common amongst adult children providing care to their parents. Interestingly, his role reversal is not necessarily a discussion of parenting a parent with dementia as is typical; instead he considers that he replaces mum's role within mum and dad's relationship to the extent of cooking dinner for dad or doing laundry. Again this support and care is predominantly discussed as being for dad.

In another reflexive discussion, Jack says

> *But you still gotta go "wait, I've still got to make wise, sensible, helpful decisions that don't just mean I grow into a hole but still help me look after myself, but also keep dad functioning and happy and thinking about what he ne- what he wants out of this and what we can do and also, you know, engaging with mum and giving her time and adapting your life so that she can still be part of it."*

This sentence summarises Jack's responsibilities, firstly to himself, secondly to dad and finally to mum. This is not necessarily a negative comment on Jack's caregiving style, he clearly loves his mum and wants what is best for her, but his responsibilities are different to the majority of the other adult children in this study. Jack relies on his dad as being primary caregiver to mum and constantly describes wanting to maintain that situation. When reflecting on what plans would be in place should anything happen to dad, Jack struggled to find a solution. Although Jack is living with his parents and provides some care to mum, should dad no longer be able to be primarily responsible for mum, Jack does not consider that he would step in as primary caregiver to mum. He thus positions himself as limited in responsibility for mum.

Jack does not always agree with dad's decisions about mum, he tries to make crisis plans and think about the future but finds these discussions difficult to present to dad

> *So then you have to compromise in some way, erm and again with dad wanting things to just carry on as normal as they are erm intervening's difficult when it's not your house and you might think "oh I might do this differently" but then it's not my place to say.*

Jack draws on societal understandings that moving into a parent's home, especially when at least one parent is mentally and physically capable of looking after themself, that it is not appropriate to intervene or make decisions. Jack describes several times in his narrative, a worry that he is 'nagging' dad.

Jack presents himself as limited in responsibility to mum. Although he does regularly take care of mum so dad can do other activities, jobs or tasks, his care to mum is more of a support to dad. He regularly discusses trying to find his role in the new family dynamics with moving in with his parents and with mum's dementia. He frequently demonstrates concerns of something happening to dad and aims to maintain dad as mum's primary caregiver. This reduced responsibility and accountability therefore impacts upon his risk narratives.

Jack describes a situation where his dad had decided to take mum to visit a bird sanctuary because she had been interested in bird watching around the time of her diagnosis. Jack went with his parents and describes the visit

> *So we'd gone over that way. Erm and again, dad's quite brave 'cause rather than going "oh that's sounds like a big deal, I think we'll stay in today" he's like "yep, come on let's go. See- let's see if mum can cope"* <laughs> *and so you're like "ok". So we go over there and we – there's no back up plan – there's just "let's go walk and we'll see" - you know and the first thing you get to is a big hill with roots over it and you're like "we'll just, tackle it" and you're thinking "this probably isn't the best idea"* <laughs> *and mum's just looking angry and cross <laughs> but dad's pleased to be outside and nature and <laughs> and you're like "ok well". So yeah we just kept walking and when there was a seat to sit on we'd, we'd sit on a seat and give mum a little rest. Erm but yeah, I mean, that was a funny day because I was thinking "what if we can't get back*

> *to the car?" "what if mum just refuses and hasn't got the strength in her legs to carry herself? We can't carry her" erm we couldn't get the car to her because there wasn't any road nearby. So we had to kind of almost keep marching her like a wounded soldier until we got back* <laughing> *and then we had the issue of it's hard for mum to get in the car anyway, so when she's exhausted and she's irritable trying to get her to actually get in the car and lift her leg to step in it and twist round and all the actual complicated movements you don't realise that it involves in just trying to sit down into a car just went out the window. And then we were like – we spent ages in the car park just waiting for mum to try and get in the car and she was getting cross and angry and yeah protesting and then dad was getting cross and we were like "we're running out of options. What do you do?" So yeah, it was the sort of thing we did. It's nice to be outside <laughing> but you kind of, you go through a situation like that and you kind of learn from it and think "yeah maybe that was a bit too much" but who knows what's too much? That's what's funny. – Jack (interview)*

From the initial sentences in this quote, Jack constructs his dad as making the decision to go for the walk, which Jack accepts despite potentially having reservations. Jack evaluates the day and not having a back up plan in case something went wrong while they were walking. He confirms his retrospective concerns by presenting complications that occurred during the walk and considers how they may learn from the situation. Throughout the account, Jack presents his own reservations, but where dad is portrayed as the primary caregiver, Jack accepts his decisions and supports them. In doing so, he is able to reflect on the challenges associated with dad's decision instead of focussing on the consideration that mum would have liked this trip and it may have increased her QOL. In accepting dad's decision, he affords himself freedom from justifying the decision to go walking which would have required favouring non-safety aspects of the risk over safety aspects. This balance between safety and non-safety risks is returned to in the following chapter.

Through portraying himself as not the primary caregiver, he reduces his responsibility for the decisions made within the account and is therefore not required to justify decisions.

7.2.2 Ellen – high responsibility

Ellen titled her written narrative as '*Appetite for risks relating to my mum,* <name>, *who has dementia*'. The title recognises that different individuals will have different 'appetites' in the face of risk in dementia care. Throughout her narratives, Ellen demonstrates an enablement approach to risk for her mum. She often describes taking certain risks that may have an impact on other risks, but she does so with much more certainty than the majority of the other adult children in this project. The reason Ellen may hold more certainty about her risk decisions could partially be from her wealth of experience as the caregiver with the longest time providing care not only to her mum but also to her dad with dementia prior to his passing away. Ellen also had paid help – a live-in caregiver – which may also affect the role Ellen has as a caregiver to mum. These two aspects may afford Ellen the ability to appear more confident and certain in her decision-making throughout her narratives.

Ellen simultaneously provided care to both her mum with dementia and her dad with dementia prior to his passing. She has provided care to her mum for over eight years and demonstrates a range of experiences throughout her narratives. For example, in recognising the different presentations of her parents' dementias and the changes over the course of the dementias resulting in very different risks and ways of managing risks. Her final written statement summarises her experience and knowledge in providing care to her parents

> *In conclusion, I should say that my view is, and has always been, that to live as full a life as possible you can't eliminate all risk. If you can it's important to identify the risk but it's then a call whether to take steps to minimise/remove it because, by doing so, you might remove the risk but also remove one of the things that makes life worth living (like driving or chocolate!). Once you've sorted the basics – a roof over their heads, heating, food and personal care – that's what you have to think about and review as things change and this most awful of diseases progresses.*

Ellen is the only participant who provided a clear recognition of her own approach to risk. Although other participants implicitly provide discussions surrounding risk enablement and risk aversion, none explicitly state a summary of their approach to risk with such insight as Ellen. Through her narratives, she provides a great deal of advice to her audience, positioning herself as the expert in providing care to her parents with dementia and the audience as being able to learn from her experiences and advice. This carries with it that air of certainty in the face of societal expectations and pressures which sets her apart from the other adult children in this project.

Ellen describes noticing symptoms of dementia in both her parents which led to attending the GP for assessment, Ellen was very much a part of the dementia diagnosis process. Ellen describes a point where she (with her parents) made the decision to move her parents into the annexe of her own home. As the only daughter, Ellen makes her role clear

> *especially for women I think, because I think we're programmed that we're the ones who do the caregiving and I've got two brothers, so there's you know, in my head, however ridiculous it is, there's still this sense well you wouldn't expect them to do it, they're boys.*

She draws on gender norms within society that daughters are more expected to provide care to their parents than sons.

Although Ellen appears accepting of gender norms as part of the reason for her caregiving role, she also discusses her decisions to maintain her parents in the community, despite receiving 'permission' from her brother that she did not need to. When discussing the positives and negtives associated with residential care, Ellen discusses how her brother provided options of residential care and asked her

> *"do you not think there would just be more stimulation for her in a care home?"*

Through her account, she reflects on his question and concludes

> *I think what he was doing, was he was giving me a permission to not carry on with this and not feel that I had to.*

She later describes regret at not reassuring her brother that she was happy to continue caring for mum. But through the rest of her narrative she demonstrated her ability to maintain mum in the community. Through gender norms and expectations of Ellen as a daughter with brothers, it would be Ellen that would provide care to mum and dad.

With both parents having a diagnosis of dementia, Ellen easily characterises her dad (when he was alive) as lacking the ability both physically and mentally to provide care to mum. For example she recounts a situation where mum had a headache and dad gave mum a morphine patch as a painkiller for the headache. Society recognises that morphine patches are the strongest form of pain relief and are inappropriate in the treatment of headaches. In positioning her dad as not capable of providing care to mum with dementia due to his own dementia, Ellen is then able to easily justify the decision for paid care. Her parents received various paid care along the progression of their dementia culmintating in mum living in Ellen's annexe with a live-in carer.

Although with paid care and especially at the level of live-in care, there could be a societal expectation that Ellen's responsibility is dramatically reduced, there are different risks and responsibilities associated with employing care services. Ellen notes fears of 'unscrupulous carers' and describes situations where she has had to manage the care mum's paid carers provided (discussed earlier in section 7.1.9). Although Ellen's responsibility to carry out day-to-day care activities is reduced by having paid carers, her responsibility for the care they provide remains; therefore Ellen is positioned as the care manager for mum.

Another justification for employing paid care is in Ellen's positioning of herself as not the personal caregiving type.

> *I mean in terms of, what, in terms of the personal care, and, I want to be a daughter. Um, and I, I want, you know, I… I… I'm not good at it really. I'm, I'm not patient enough, I don't think. You know, I'd be rushing a lot more than*

> <carer> *does. And actually, I don't, and my mum doesn't seem to mind, and my dad, you know, I don't think he would have minded really in terms of their, um, you know, how they would feel about me doing personal care for them, but, well a) I don't, I wanted to be a daughter, not a personal carer – I don't think I'm the best person for it. And also, I didn't want to begrudge what I do, because erm, whereas I don't now, I kind of feel this is perfect 'cause I'm reassured that they're ok. And that reassurance is easily come by to me 'cause I can just poke my head in and say, "everything alright?" and I- you know, I can actually sit there and be daughter, which is what I want to be. Although of course, she's got no idea that I am her daughter.*

Ellen also discusses being a grandparent and the importance for her in being able to spend time with her grandchildren and support her adult children with childcare. She describes not wanting to 'begrudge' spending time with her mum and instead enjoys the ability to live her own life while knowing that mum is cared for in the way she expects . In a final note she reflects that she is fortunate in her position of being able to afford bespoke care for her mum which allows her the freedom to enjoy other important aspects of her life such as being a grandparent.

Ellen portrays herself as the primary caregiver for mum and her dad when he was still alive through the factors demonstrated above. In the following example, Ellen was asked about the decision to employ formal caregivers for her parents with dementia despite her dad's resistance.

> *Yeah, he was always a step behind. But, I can't tell you how much he c - and he did, certainly over 24 hours, and he only had 7 weeks with it, before he went into hospital but again, he just really enjoyed the fact that he wasn't responsible, you know, and I think even being here without 24hour care, he would have been. But there was one afternoon when, which I didn't mention but, one afternoon, when he was here with mum and we had the carer, we had the carer that stayed with us for 18 months but* <husband> *and I had popped out, only for a couple of hours it was Winter obviously they moved here in December and the carer used to have* <coughs> *excuse me, a couple of hours off two or three hours off every afternoon. She had a house, a flat in <local area>, so she used to go home, or she had friends who were carers, she was she used to go out most days, she had a car. And so we both went out and we both said to both of them before we went out you know "well we're just popping out" but, I think what must have happened was my Dad must have gone to sleep, and then woke up and it was dark, because it gets dark early in the Winter, and he's thought, "oh my goodness, they haven't come back! Now I've got" so he, he did his best to get my mum, and he did manage to get her into bed but she had no clothes on, 'cause he could take things off, but by then he couldn't put anything on her* <laughs> *so when we came back, about 5 O'clock, he was still padding around trying to, there was clothes everywhere* <laughing>, *she was nude in bed.* <laughing>. *And it was like* <laughs>. *So he, I think, was always thinking "we're alright, we don't need, we're fine with what we've got." But when they had the next, when you up the ante, and certainly when we had the, the two big moves for us were the night carers, and that was obviously great for them because as much as I'd say either pull, push a button*

> *on your wrist, because they had that wrist thing, or call me if you can. And either they'll ring me and I'll come or I'll come 'cause you've called me. But I think he used to try and not do that,* (I:mm). *So when he had the night carer, there was something there if he needed it. And similarly when we got the 24hour care, and very quickly he got into the kind of "oooh, I can ask for whatever I like, I've not got to cook any more, I've not got to…" So I think he did have quite a nice time. He was always a bit behind, there was always a bit of pushing going on. – Ellen (interview)*

Where Ellen has made the decision on behalf of her parents to employ paid caregiving as a management strategy to the risks they had encountered, she must provide much more justification for making the decision. She provides an example of what happened when there was not full-time paid care to demonstrate the risk that dad would not be able to manage alone. She evaluates dad's thoughts that he could manage mum's care alone. She evaluates another management strategy they had used in the alarm pendant that could contact Ellen in an emergency and considers that dad would not use it. This demonstrates to the audience that Ellen had attempted other management strategies that could be considered as less extreme than paid care. She argues that they were not enough and therefore a more appropriate solution was the paid care. She resolves the account by justifying her decision to employ paid care through dad's response and enjoyment of it.

In comparing the two accounts, I have provided two polar examples of Jack who portrays himself as having little to no responsibility and therefore accountability for his mum, and Ellen who constructs herself as having the highest level of responsibility for her parents. Jack's account requires limited justification of actions because Jack did not make those decisions, in this sense he has reduced his social responsibility and therefore can simply evaluate his dad's choices. Ellen's account however, requires much more justification to prove that her management strategy was required and appropriate.

7.2.3 Lucie – changing responsibility levels

Often the adult children would move through different levels of responsibility within their narratives, depending on the situation within the account they were constructing. For example, Lucie has reduced responsibility for her mum with dementia due to her age and because she lives away from her mum and step-dad during term time. Lucie's step-dad is able to provide care to mum and is presented as mum's primary caregiver. Lucie discussed a situation where mum became upset on the tube because it was so busy. When asked how she managed the situation, Lucie says

> *so thankfully my step-dad was with me and I hadn't seen her get like that for a while but it's just reassurance. So normally it would be like physical contact with her. Erm just reassuring her that "it's ok. We're just going to do this and then this" So I always try to explain it in a slightly simpler way. And then I try and say what we're going to do before we do it. So I'm trying to almost prepare her for it. – Lucie (interview)*

Although Lucie describes the methods she uses to manage the situation (reassurance and preparing mum for the situation), she starts her response by saying that she was thankful her step-dad was there. This presents her step-dad as having the primary responsibility for managing mum in that situation. It also reduces Lucie's responsibility for being required to manage the situation, therefore the information on how she manages the situation that follows holds less expectation of responsibility from the audience. In this case it is Lucie's prior portrayal (through the rest of her narrative) of her step-dad as having more responsibility for mum that aids her in presenting herself as at lower expectations of responsibility in this situation.

When presenting a different risk, Lucie positions herself as having higher responsibility for her mum.

> *When I was with her a few weeks ago we went shopping and we'd gone into* <supermarket> *or something and then went to a clothes shop and then in the clothes shop, she was trying on something and then left all her stuff from* <supermarket>*, in the carrier bag in the changing room and she completely freaked out and neither of us realised that she'd forgotten it, so actually it wasn't even her to blame, like I'd completely forgotten that she had it in the first place. And the minute we got in the car she had a complete freak out about it, she didn't know where it was so we had to drive back to the shop, but the whole way there she was thinking and saying to me that someone will have taken it, someone will have taken her stuff 'cause I think it had like she's in it that she'd just bought or something, something more expensive than just food shop and erm and she was really freaking out and saying that "the lady in the shop will have taken it, or a customer will have taken it and they won't care whose it is" and things like that. And it was, I found it really weird, 'cause normally it's me that jumps to that conclusion, but it was her, so then I had to almost calm her down and reassure her like "no the lady in the shop will have known that its yours 'cause you were just in there and it will still be there when we go back" and things like that. Erm so it's weird that when it's her worrying about it, I actually downplay the situation. But if it's me that's worrying about it, I completely take it to the next level. – Lucie (interview)*

Lucie initially shares responsibility with her mum for having forgotten the shopping bag. Although the audience would recognise that mum's dementia could place her at lesser responsibility for remembering the shopping. Because there was no one else with them, Lucie becomes responsible for calming mum down and aiding her in finding the lost shopping. She admits that she had to suppress her own instinctual reaction to the situation to ensure she was able to help mum.

Lucie changes her levels of responsibility to mum throughout her narrative. This demonstrates that responsibility is not static and can change in different situations.

7.2.4 Summary: Social responsibility is important to constructing risk narratives

The adult children draw upon perceived societal expectations of their circumstances coupled with their characterisations of different people to position themselves at higher or lower levels of responsibility and therefore accountability for their parents. This therefore impacts upon the ways in which they construct risks and justify their management strategies. Those with higher levels of portrayed responsibility must work to justify their decisions to their audience. Whereas this is less expected of those with lower portrayed levels of responsibility. The accounts presented here also demonstrate the importance of viewing the narrative as a whole and the sum of its parts. Previous information from the whole narrative and the ways in which the adult children position themselves and other characters within there narratives impact on how the audience understands the individual accounts of risk. Although understanding levels of social responsibility for parents was not the intent of this project, the analysis of how the adult children positioned themselves and characterised others demonstrated the importance of social expectations of responsibility to the risk narratives. As such, these themes of responsibility are drawn on throughout the following chapter as they relate to constructions of risks and justifications of management strategies within the adult children’s narratives.

7.3 Summary: Narrating responsibility

This chapter described themes of social responsibility and how the adult children used these themes to position themselves at higher or lower responsibility for their parents with dementia. This demonstrates the importance of socially perceived responsibility in constructing risk narratives. Furthermore how the audience perceives the adult children’s and other characters’ responsibility for the parents with dementia impacts on how the adult children justify their risk management strategies.

The project aimed to understand how adult children may be impacted by cultural norms and societal expectations when managing risks for their parents with dementia. This chapter highlighted the theme of responsibility and its relevance to societal expectations of responsibility in risk management. The following chapter forms the main analysis of the narratives in understanding how different structures and narrative elements were used by the adult children in constructing risks. It also draws on the themes presented within this chapter where relevant to the overall narrative construction.

Chapter 8: Narrating risk

Throughout the risk narratives, the adult children clearly distinguished differences between health/safety and non-safety risks. They consistently discussed the importance of non-safety risks and often favoured tham over health/safety risks. This suggests that to the culture of adult children as caregivers, both health/safety risks and non-safety risks are equally important. However, the adult children required much more ‘narrative effort’ - that is the use of more, and different, narrative elements and different narrative structures - to construct non-safety issues as being risks for their audience. This demonstrates that the adult children may perceived that their audience (representing society) hold expectations that health/safety risks are more recognisable and important than non-safety risks.

The narratives also serve a second purpose which is apparent in the narrative effort the adult children required to construct risks. They must also use their narrative structures and plots to justify their management strategies, and more importantly, the narrative effort required to justify management of a non-safety risk was higher than health/safety risks. There are three main categories within which the risk accounts fall: justifying an action (the use of a management strategy), justifying a non-action (where the adult child does not use a management strategy), and justifying the delay in action (either a delay in recognising the risk or barriers led to a delay in risk management).

The following chapter starts by highlighting the different health/safety and non-safety risks. Following which is a demonstration of the narrative effort required to construct these different risks and justify their management strategies. Finally, there is a comparison between how the adult children use this narrative effort to justify a health/safety risks versus a non-safety risk.

8.1 The risks

This initial section provides a list of the risks the adult children cover within their narratives to provide context for ongoing discussions surrounding the differences in narrative elements used to construct the different types of risks.

Health/safety risks included: medications, appointments, comorbidities, travelling, mobility, falls, getting lost, ‘wandering’, road safety, finances, using money, scams, vulnerability to strangers, food, shopping, personal hygiene, home hazards (such as: cookers and cleaning fluids), driving, employment and childcare (grandchildren).

Non-safety risks included: QOL, wellbeing, social interactions, isolation, people noticing dementia symptoms, stigma, anxiety, depression and distress.

Risks to the other parent were also highlighted as impacting on the care the adult children provided to their parents. Eight of the twelve participants also had the other parent alive and often discussed the risks associated with the other parent. Concerns for the other parent included: the financial implications of providing care, the parent reducing their own working hours to provide care and the impact of the parent with dementia reducing or stopping work. Another concern was the physical challenges of providing care in older age, for example Jodie discusses the challenges for dad at having to repeatedly get up in the night to support mum with dementia to go to the bathroom. QOL for the other parent was also discussed (typically implicitly) in discussing trying to find them opportunities to do their hobbies or activities. Where the adult children raised several concerns for their other parent they then had to manage both parents and balance both parents' care or support.

The adult children were also asked to discuss risks to themselves as caregivers to their parents. With some participants, the risks to themselves as caregivers were inherent throughout their narratives. An example is Kate who regularly reiterates the challenges she is facing and the burden she is experiencing at providing care to her parents. Others require the question at the end of their interview to consider the risks to themselves. Interestingly only one participant discussed the genetic risks of dementia and their concerns about themselves developing dementia. A couple of participants commented more on the challenges they face in the change in their relationships with their parents, for example Lucie discusses the future of what might happen with her mum, that mum might forget who Lucie is or become more reliant on Lucie's step-dad rather than Lucie, mum's only child. Some participants consider the risk of potential extra burden should anything happen to their other parent (who is primary caregiver). Carol and Patricia both describe the financial implications of the challenges to themselves in being self-employed and having to reduce hours of work to care for their parents with dementia. Other participants likewise describe the challenges of balancing their working lives with providing care to their parents with dementia, Jodie describes having to take regular intervals off work in order to care for her parents with dementia at various times, but also due to the restrictions surrounding her job role, she discusses taking time off work due to sickness through mental health difficulties and fatigue. Some of the participants discuss the challenges they face in providing care not only to their parents with dementia but also to their own children, Jodie additionally alludes to the tensions between herself and her husband due to the care she provides to her parents. Burden, stress and 'feeling a bit sad' (as Patricia describes it) were common across all the caregivers at one point or another throughout their narratives. The exceptions to this rule are Lucie, Jack, Ellen and George all of whom assume a limited role in caregiving for their parents because another person has ultimate or day-to-day responsibility.

The adult children typically acknowledged that the risks change throughout the course of the dementia.

> *What I have learnt is that dementia does not stand still. It is an organic disease with symptoms developing and changing over time. Therefore, risk, and one's attitude to risk, also changes over time. – Ellen (written)*

Although in their narratives, other participants have described changes in risks over time as dementia progresses, Ellen's narrative consists of a reflection on nine years of experience. Upon asking Ellen about this written comment, Ellen provides a series of examples of past risks and present risks and evaluates the differences between them.

> *You immediately think of what was most panicking, and getting a call in the middle of the night, from dad saying "mum's not in the house, I don't know where she is" you know there's a lake, they lived opposite a lake, you know there's a lake opposite, it's mid-winter, it's raining… that… so that was a very present risk at that point in mum's disease. Erm… now obviously she can't walk, she can't wave, so she can, you know in some ways she can't move really – erm, that's no longer a risk […] But now, you know, you, the kind of risks that I think about now, are things like pneumonia through erm, aspiration of food, or you know, things like that. It would be different risks […] the risk of them not living a life changes over time so if, you know, if what you would do, now really it comes down to trying to think what DVDs mum might, you might put on the TV, that might grab mum's attention for, oh, something like Strictly Come Dancing, has been a complete blessing. Or the Sound of Music, anything with lots of children, and what's the other one, the King and I. Anything where there are lots of children, a bit of singing goes down very well indeed and it, and you can see she just stares at it, whereas if you put what she would have enjoyed before… so we would try in the early days to make sure that she didn't miss an episode of Coronation Street, or or Eastenders 'cause she loved that, but obviously over time, that changes. But in terms of big risks, I think the big ones medication, in the past, they're all gone now, medication, going wandering, erm, and now, obviously with a full time carer and she can't move, that's very different, if that makes sense. It's more about, is she alright, because she can't tell you if she's alright. Is she, is she in any pain or hurting? – Ellen (interview)*

Ellen starts her account by considering the most serious risk from the past, she then moves to discuss the present physical risks. Although both risks pertain to concerns of safety and harm, as the dementia progresses the types of risks are different. Similarly, Ellen discusses how risks surrounding QOL change over time from ensuring mum's safety, now to ensuring she is presented with appropriate stimulation. The main concern Ellen ends with returns the account to health-based concerns as potentially being more understandable to the audience than the risks involving QOL which may not seem like such a high risk. Although other participants discuss past and present risks and demonstrate the changes in risks that they have experienced over the course of caring for their parent with dementia, Ellen's narrative spans the longest timeline and explicitly stated how the risks have changed for her parent with dementia. This example demonstrates how Ellen's attitude to risk has changed over the course of the dementia also, this is in part due to employing a live-in carer and reduction of responsibility on a day-to-day basis (as discussed previously in chapter 7).

Inherent, both explicitly and implicitly, throughout all twelve cases was the risk of their parents moving to residential care. There are several reasons the adult children preferred to maintain their parents living in their own homes over residential care. They discuss the financial implications of moving their parent to residential care, the impact of media surrounding bad residential care stories and the impact of moving to residential care on their parents with dementia (less stimulation, parent not wanting to move or potential disorientation). The inclusion of this brief overview of the risks of residential care is an important acknowledgement moving through the accounts of risks. Where the adult children are socially accountable for not moving their parents to residential care they therefore discuss aspects of residential care, and in some cases structure their accounts around them, in order to orient their audience.

One example of discussing residential care as an option for mum is from Susan, in her written account she writes

> *Abuse comes in many forms and is not always extreme and may be in the form of simply not treating Mum with kindness, dignity and respect or neglect.*
>
> *I hope she gets food and drink that tastes nice.*
>
> *I hope she is treated with kindness, dignity and humility*
>
> *I hope she is stimulated.*
>
> *I hope she is not manhandled when being dressed and washed.*
>
> *I hope carers interact with her while doing such tasks rather than talk over her head or say nothing.*
>
> *I hope she is not over medicated.*
>
> *I hope she is kept warm and comfortable.*
>
> *I hope staff give her access to dental and medical care when required.*
>
> *When she goes into residential care and is unable to communicate I will have to put all my trust in other people and my biggest fear is her wellbeing. – Susan (written)*

This quote encompasses the majority of the concerns regarding residential care from across the 12 participants in the form of a poem. This is the only example of a poem across all participants, but it constructs a reflexive account of Susan evaluating her concerns for mum. Susan starts by discussing how ‘abuse comes in many forms’, she expects that the audience would recognise from the media surrounding abuse in care homes the more physical aspects. However, she asks the audience to move away from these ‘extreme’ forms to consider the treatment of her mum in terms of psychological wellbeing and neglect. Each line starts with ‘I hope’, hope is a conceptual term that can be directly relevant to taking a risk, there is an element of hope involved. She moves through the range of safety and non-safety concerns she has for mum in residential care. Each line represents a different concern or risk, they are only relevant to each other in that they are part of the overarching risk of moving to residential care. Susan ends her poem by evaluating how ‘when’ not ‘if’ mum moves to residential care – suggesting that the move would be inevitable – Susan will ‘have to put all my trust in other people’. Susan throughout her narratives struggles with trust of others especially in relation to her mum’s vulnerability. The final aspect that Susan portrays to the audience is ‘my biggest fear is her wellbeing’, demonstrating how out of all of the concerns she has listed for mum, wellbeing is Susan’s main priority.

By presenting a poem instead of a prose account, Susan constructs an emotively driven account of her concerns for mum in residential care. She has spent time reflecting on and evaluating these concerns thus demonstrating them to be a more important risk at present. Although none of the other participants presented their concerns about residential care in this structure, the themes remain consistent and the main concern is regarding their parents’ QOL and wellbeing in residential care. This is a major part of why they continue to provide care to their parents in the community.

8.1.1 Section summary: The risks

This section describes the risks the adult children discussed within their narratives by way of orienting their audience to the situational contexts within which their narratives are constructed. That is, the adult children discussed a variety of different risks; they constructed both health/safety and non-safety risks for their parents with dementia but importantly discussed risks to their other parent (without dementia) and were able to consider risks for themselves. This demonstrates that for the adult child must not only consider their parent with dementia when making decisions about risk, they must also consider the impacts upon their other parent and themselves. Part of the inclusion criteria for this study was that the adult children would currently (at the time they participated in the study) be providing care to their parents with dementia living in their own homes. Therefore it was not unexpected that the main risk to their parents with dementia was residential care. There were a number of reasons to avoid residential care, but as this was the main risk to avoid in order to comply with social accountability for maintaining their parents at home, the day-to-day risks at home would require management in order to ultimately avoid a move to residential care.

Risks change throughout the course of dementia and with it the adult children's attitudes and approaches to the risks also change. The nature of risk is not static, it is bound by each individual situation. What once was, or had never been, considered a risk may reduce or increase as a risk through the progression of dementia. The approaches to risks, likewise are not static. An enabling approach may be effective in some circumstances but may not be appropriate in others.

8.2 Setting the scene

Further to the content of the narratives as paramount for orienting the audience, the following section demonstrates the importance of recognising the whole of the narrative as well as the sum of its parts, that is where the adult children position different accounts of risks within the whole of their written accounts has meaning. Likewise the adult children may begin their written narratives with a section on background information as to further orient their audience for the accounts that follow. Finally, the section considers comparisons between written and interview accounts in how they shaped they analysis of the overall narratives.

8.2.1 Chronology and severity of risks

As discussed in chapter 5, the written accounts varied in style and length. Additionally, some wrote chronologically starting with the first risks they experienced and moving through to the present before considering possible future risks, the earlier risks often included employment, driving or symptoms of the dementia typically including forgetfulness or repetition or in one case weight gain. Others wrote about the risks that had caused them most concern first, for example Susan who describes in great detail a series of scams and concerns about mum's vulnerability. The amount of examples they provided for each risk also demonstrated the severity and in some cases the participants constructed these longer accounts to justify their perception of that situation as a risk. Some of the participants started in a reverse chronological fashion before moving to other risks that had caused concerns at various points in their timeline for example Ellen who started with 'mum's current condition' and then moved to various previous risks she had experienced with her mum and dad with dementia. This was important when considering the structures the adult children used to construct a risk and will be returned to in the remainder of this chapter where applicable.

8.2.2 Background information

Several participants wrote initially a short background information section to set the scene for the risks they intended to discuss. An example is from George is discussed in chapter 7 (section 7.1.4). George constructed multiple accounts of risks that the audience was required to remember important points from the background information section in order to interpret and understand the situation. For example, when discussing the potential for dad to become agitated when locked in the house, the audience must remember from his background information section that dad is physically fit and mum is physically frail. From this, the audience can understand George's concerns for his mum when his dad goes to kick down the front door.

As with the order with which the adult children presented risks in their written accounts, the use of background information set the scene and provided situational information for the remainder of the narrative. This negates the requirement for such information to be included within each separate account. Also the narrative should be viewed as a whole and therefore previous accounts often build towards a discussion of another account of risk or a management strategy. These initial background sections provide such information that is then referred to or built on throughout the remaining narratives, again this is discussed further throughout the remainder of the chapter where applicable.

8.2.3 Narratives: written versus interview

Although two participants did not complete the interview and some wrote simple bullet points, for those who provided detailed written accounts and completed interviews, there was scope to compare the constructions of risks between the written and interview narratives. These written narratives were coherent and typically produced a structure of situation, complication, evaluation and resolution (the standard Labov & Waletzky structure). Whereas the interview narratives tended to have more opportunity for the participants to reflect and draw in new examples to add to their arguments for constructing a risk or justifying a management strategy.

Through comparing the written and interview narratives, it was possible to draw out differences within the narratives. The differences demonstrated the different processes involved in constructing a written versus an interview narrative. This was often because of the reflexive opportunity to talk through their thoughts of a given risk, for example, within Ellen's written account there appeared no doubt that she would provide care to her parents with dementia, within her interview account while discussing her decision to move mum into her annexe, she reflects

> *My younger brother said "do you not think there would just be more stimulation for her in a care home?" And it did kind of make me think really […] I think what he was doing, was he was giving me a permission to not carry on with this and not feel that I had to. – Ellen (interview)*

Through the interview, Ellen was able to reflect on her brother's comment and present an alternative position that she was not expected to take on the caregiving role. Instead, there had been the option to move mum to residential care which had not been apparent within her written accounts. This additional information was reached through the reflexive aspect an interview affords.

There are also examples of where the adult children have constructed their two narratives for different audiences. While writing about her mum's driving cessation, Mary writes

> *There were a couple of occasions that we followed her, unbeknown to her and on those occasions, she appeared to be safe. – Mary (written)*

By contrast, in her interview she says

> *I actually happened to come up behind her at one time and I was out and about anyway, so I just followed her home. And she was fine. – Mary (interview)*

The phrasing surrounding following mum has altered slightly, instead of 'we followed her', Mary describes that she 'happened to come up behind her' and therefore followed to check she was ok. The second iteration is more socially acceptable in that it does not infer the deception of covertly following mum (deception is discussed later in the chapter, section 8.3.2). Although this project aims not at finding 'truth', this difference in accounts demonstrates the difference in performance of a narrative for an audience. Within an interview, the participant is faced with an audience (the interviewer) and therefore may construct their accounts in a way that is more socially acceptable. Whereas a written narrative does not have that potentially threatening face-to-face interaction.

8.2.4 Section summary: The risks and background information

Through their written accounts, the adult children were able to produce a timeline of risks demonstrating the changes in risks over time. Others presented the most severe risks first as the more important risks they wanted the audience to understand. The adult children provided background information to set the scene for the upcoming discussions of risk. They relied on the audience remembering important details from this background information and other accounts in order to construct a new risk. The constructions of their written and interview narratives may have been different, it is possible that this was due to the capacity to elaborate further at interview in comparison to the written accounts. The adult children were able to reflect on their written accounts and add further detail or insights. A second reason the accounts may have differed is because they were produced in different social contexts and perhaps with a difference audience in mind. For example, in the interview the adult children were faced with their audience and therefore may have attempted to construct a more socially acceptable narrative at interview when compared to written accounts. One purpose of the written and interview narratives was to explore how accounts of risk could be constructed or reconstructed. The written accounts were also used as a priming tool for the interview, that is, the adult children had already considered risks and at interview were able to discuss these further, in more detail. In this sense the use of written and interview accounts fulfilled the purpose of using both.

8.3 Structures and plots

The participants discuss ‘concerns’ and ‘risks’ as separate concepts. They consider a concern to be typically something that singularly does not need to be acted upon but together may pose a risk. A risk however typically requires action immediately. The risks were constructed through one of four main structures or plots. I describe these as: defining incident, building concerns, no complication/resolution-first and no resolution. The defining incident plot followed the standard structure (as discussed in chapter 5) of orientation, complicating action, evaluation and resolution (with optional coda). This plot type typically demonstrated how the complicating action presented a risk that required evaluating and then managing to form a resolution. Through this the adult children could demonstrate how the risk linked directly to the use of a management strategy. The building concerns plot followed a similar structure, however involved several complicating actions and evaluation sections prior to resolution. Often this demonstrated how several risks resulted in the use of a management strategy or how a management strategy may have presented a new risk that then needed managing. These plots tended to use the rhetoric of logic, that is the risk was constructed around evidence (as discussed in chapter 5).

The no complication plot, as the title suggests, did not include a complicating action. Instead the adult children may have been considering future risks. Alternatively, the adult children were reflecting on a management strategy that had been employed with no apparent risk. Likewise the no resolution plot did not have a resolving action which typically reflected a risk the adult children were currently managing and were unsure how to progress. These no resolution accounts typically led to a feeling of uncertainty, about the future or how to manage the situation. The adult children therefore relied on the emotive rhetoric to convey a feeling of unease (see chapter 5). Each plot will be discussed in turn, with examples.

8.3.1 A defining incident

A defining incident is one way in which the participants construct a risk. The defining incident actualises the risk as a one-time situation that the participant must manage and endeavour to not repeat. An example of a defining incident is from Susan when she discusses ‘an incident with the cooker’.

> *We got there, this was me and my husband, and we walked in her kitchen and it stank. We were taking her shopping. And she’s - is a Calor gas and it smells different to mains gas, which is why I didn’t recognise it, Calor gas smells more like rotting rubbish. So we thought her bin needed emptying or there was something really smelly in the fridge and we looked all around. We couldn’t find anything, so we opened all the doors. And just thought whatever it is, we really looked around and couldn’t find anything. So we went out with my mum only really about an hour, and we came back and the smell was really strong again, and then my husband noticed that one of the gas cooker knobs was on but no flame so then we realised it was the gas. So the next door neighbour, he’s retired, but I do know that he was a gas engineer, so we got him round and we disconnected it straight away and as it turns out, I don’t actually think it was my mum that left it on. Because we found out later from her friend that the day before that happened, my sister, who I don’t really, I don’t have anything to do with actually, my sister had been round there with the two grandchildren, and they reported to* <name> *one of my mum’s ladies that reported to me, so it’s not first-hand information, but I say it’s probably right. That the little boy kept running in and fiddling with the knobs, so it does seem likely that it was the little boy that turned the gas on. But the weird thing was my mum hadn’t recognised that there was something smelly, and she actually when we got round there she, she did sort of complain that she had a headache and felt strange which was not surprising really. So even though it turns out it probably wasn’t my mum that left the gas on, the point was she didn’t recognise that actually she was in danger and ‘what was this smell?’ like anyone else would have done. – Susan (interview)*

Through the structure of orientation, complication, evaluation and resolution, Susan demonstrates how the risk of mum not recognising the associated danger of leaving the gas on was enough for Susan (and her husband) to deem the cooker as a risk.

The participants shaped their accounts around a defining incident to construct the risk account to demonstrate the immediacy of required action to manage that risk. Through the structure of situational information, complicating action, evaluation and resolution, it is clear to see how each structural element follows on from each other in presenting a risk. In this type of account, the risk had not necessarily been considered before and the defining incident was the recognition that a risks was present and required action.

Through the defining incident plot, it is easy for Susan to justify the decision to change the cooker. The audience can easily recognise the defining incident (gas being left on and mum not realising the danger) required an action or management strategy to ensure mum's safety. The defining incident plot easily justified the management strategies that the adult children used, the other plots require more effort to justify the strategies.

8.3.2 Building concerns

To construct a risk, the participants may describe several concerns until the risk was actualised. For example, Suzie describes how mum would travel to and from work. In her written account, she says

> *My mum used to get dropped off at work by my dad, but then had to make her own way home. We would all keep our phones on in case she needed us, and a couple of times her colleagues would ring to say they were worried because she appeared confused when leaving work.*
>
> *We visited the bus station with her and wrote all the details of bus stops and the number of which bus to catch to keep in her purse. We put an Alzheimer's card in her purse to show to the driver if she got lost (unfortunately she always wanted to keep it a secret and wouldn't ask for help). We felt that things were going reasonably well, but then found out that she had been walking all the way home every day (3 miles) because she couldn't remember which bus to get on. One day I had spoken to her on the phone (we used to ring her up at work every day to remind her that it was home time) she sounded upset so I went to wait by the bus stop near her house. I waited for 1.5 hours and she didn't arrive. I was walking around the streets with my little boy looking for her for ages. I didn't want to phone my dad or my sister because I didn't want them to worry. My mum then rang me and was crying saying she had just arrived home and had lost her key. She had left work 2.5 hours earlier and I was frantic. – Suzie (written)*

Within her written account, Suzie describes a number of issues with mum getting lost thus demonstrating the severity of the risk. The build-up of concerns is based around one particular activity and the development of the risk with the progression of the dementia.

Within these building concerns plots, there are typically several accounts that follow on from each other. The accounts often follow the structure of situational information, complicating action and evaluation and are typically left unresolved until the final line of that particular section. With the example above, Susan moves through several accounts of mum getting lost following the structure of situation, complication, evaluation repeated for each new example, the final line of the section Suzie describes as 'risk of getting lost', acts as the resolution to the section. She ends the section by saying 'my mum now does not leave the house without one us being with her, this is her choice as much as ours because she does not feel confident to go out alone'. By presenting the series of examples as separate accounts without a resolution, Suzie demonstrates how the accounts are all linked and produce this building concerns plot. By not resolving each account separately, Suzie demonstrates how the risk of mum getting lost was ongoing over a period of time until they were able to find a suitable management strategy to resolve the accounts. The final line also demonstrates further justification for the chosen management strategy by resolving that mum was in agreement with the strategy. Thereby removing any doubt from the audience's mind that this was the most appropriate strategy.

The building concerns plot in this case aims to justify the final management strategy of mum no longer leaving the house unsupervised. Through several examples of the concerns and several attempts at managing the risks surrounding those concerns, the audience can easily recognise the process through which the adult child finally reached their resolution. Suzie provided multiple examples of concerns that led to the ultimate decision as justification because the audience may have perceived the final decision negatively (i.e. confinement to the house).

Another example of the building concerns plot is constructed slightly differently, instead of one activity changing and progressing towards a risk, the adult children could also describe several different concerns that result in a risk. Jack describes several concerns that build to the risk of leaving mum unsupervised. In a previous account in Jack's narrative he describes the risk of mum walking off and leaving the house which formed the conclusion that mum could not be left unsupervised, later he adds other concerns that build into this conclusion.

> *It was quite interesting that day when I saw I'd left the room, just to do something quickly, came back and mum had obviously wanted to think "I still need to go and make this cup of coffee" but was confused about where to pour the hot water. I was like "oh". So those sorts of things you can kind of raise to dad and go "dad, this happened" erm and yet mum had poured the hot water from the kettle into the actual jar of coffee and then was very confused as to what went wrong [...]And then there's the whole health and hygiene stuff so as I said, you come to visit the house but mums confused as to what's dirty and what's clean, so the clean stuff goes back on the dirty side, and you're either washing up several times or the dirty stuff has gone in the drawer and then you're like "oh blimey" like is that – if that was a knife that was used to cut chicken and now it's gone back in the drawer, well who knows what's going to happen next […] so it's it's kind of food hygiene stuff, it's chemicals, it's all sorts of things like that. Even things like mum will think and she'll try to be helpful, so she'll go and grab the washing up sponge but then she won't know what you do with it, so she walks around the house with it. So then this trail of water follows my mum which then suddenly could be lethal for her, 'cause then she could fall over you know break a hip, a leg, an arm or something. Something that's happened so simply from what you don't think is a particularly dangerous object of a sponge, but because of mum's situation because of things could be very different erm and again there's no way of actually ruling*

> *that out, unless you say mum never goes in the kitchen or mum never goes near water or you know. So those sort of things I'm coming into this environment, I'm trying to, working a way through, fortunately nothing's happened so far you know that's put mum in hospital or anything it's more… but yeah its that thing of, in lots of situations you can get everybody talking about how do we solve this? – Jack (interview)*

Jack is describing several concerns that build into the risk of mum being left unsupervised, he provides several examples of these concerns. Through this series of concerns, Jack is building the larger picture of the risks of mum continuing to do typical activities around the house.

Similarly to Suzie's building concerns account, Jack moves through several accounts as examples of the concerns he had for mum. The difference is in the content of those concerns, they were several different concerns for Jack (making coffee, washing up and carrying around a wet sponge); not surrounding the same overarching risk as with Suzie (getting lost). By structuring his account through a series of situation, complication, evaluation repeated for each example, Jack is demonstrating how each example is linked. He describes how through mum's dementia it is tricky to discuss with her options to be able to support her with this range of concerns thus presenting a potential barrier to management strategy (barriers are discussed later in this section). Again, he leaves the accounts unresolved until the end of the section; Jack resolves his account with a level of acceptance that these concerns build up to a larger risk that mum should not be left unsupervised but that in practice managing that risk is difficult. Jack is able to justify the decision to not act by stating that the risk of harm to mum did not come to fruition and therefore the audience can agree that simply recognising and accepting the potential risks is an appropriate course of action. In ending with a question to the audience 'how do we solve this?' this question not only justifies non-action, but also represents a level of uncertainty. Uncertainty is discussed later in this section.

Through building concerns surrounding safety, it is possible for the audience to recognise that there is a risk that requires management. However, some risks are not so easily managed and therefore require justification through several examples that the risk may not be entirely avoidable.

Building concerns may also be used to justify a delay in action. For example

> *And then she would order stuff on her credit card erm, but then completely forget, and so when the letter came through, because she would never want to pay by direct de,err, yeah by direct debit or banker's, you know, normal part of your bank thing, (I:mm) she would always write a cheque and send it. So then, she'd either throw the letter away, or we'd find the letter buried and then followed by a red letter, saying you know, "you haven't paid us therefore you owe us interest," and she would always have paid off the credit card in full, you*

> *know it's not like she didn't have the money, it wasn't, she didn't need the credit side of it, she would just use her credit card, 'cause that's just what she used to do. So, again, it became apparent that she didn't need to use that so we kind of had to try and subtly, introduce the fact that maybe she didn't need to do that, or now, because again she won't remember the fact that she hasn't filled anything in for months now actually now I come to think about it, but when we went round, and we found things filled in we would just take them away and she wouldn't remember that she'd filled them in so we knew it wasn't going to distress her or upset her because she hadn't got a clue. And then we wrote to a lot of the companies and said, "look can you stop the mail order stuff coming through please," so again she then didn't have the opportunity to, to do it and she she's not ever mentioned the fact that it doesn't she doesn't have them. – Mary (interview)*

Mary uses the structure of building concerns with a couple of complicating actions until the risk is resolved. She suggests how it took her a while to recognise the risks in that 'it became apparent' that using the credit cards could be a risk. She also demonstrates a barrier in managing the risk by considering the distress it may cause mum to no longer use a credit card or catalogues. However she is able to justify her actions by asking the audience to consider that mum did not need to use credit cards, and then did not remember nor miss the catalogues.

The use of barriers to recognising a risk (such as the thrown away and hidden letters) and barriers to employing management strategies (such as the potential for causing mum distress) is not uncommon in justifying a delay in action and is discussed further throughout this chapter.

Likewise, the use of deceit as a management strategy is not uncommon and requires justification as a societal view of deception would be considered negative. In order to present deceit as justifiable, these acts of deceit are often discussed gradually as part of the narrative instead of being presented first. Should the adult child discuss deceit first, the audience may take a negative view of the adult child and their actions. However, by introducing the idea of deceit following a discussion of the risks (in this case – continued use of credit cards may lead to more fines and telling mum to not use credit cards may lead to distress), Mary is then able to present to the audience that subtly removing risk items as a form of mild deceit was required to manage both aspects of the risk. She also demonstrated how this deceit did not cause mum distress and therefore was necessary, successful and perhaps socially acceptable in managing the risk.

Each of these examples ends with a coda. Suzie comments that mum lost confidence, Jack comments that no harm had come to mum and asks the audience 'how do we solve this?' and Mary comments that mum no longer remembered. The coda is additional information and is not paramount to the account. However, the adult children include it as a way of further justifying their decisions. For Suzie and Mary it is to remove agency from their parents. They demonstrate to the audience that their decisions to remove agency did not impact negatively on their parents because their parents forgot or had lost confidence anyway. Although the adult children did not need to mention their parents forgetting these situations nor loss in confidence for the construction of the risks or justification that an action was required, the use of the coda is to ask the audience to consider that their methods were appropriate. Jack's coda is used to justify the decision to not manage the potential risks because no harm had come to mum and that this particular risk may not be easily managed. The adult children felt the need to justify their actions further because society may consider their actions to be morally unacceptable or respresent poor care.

These examples demonstrate how the structure of situation, complication, evaluation repeated through a series of examples until a final resolution (whether action or non-action) is reached demonstrate the plot of building concerns used to construct an overarching risk.

8.3.3 No complication or resolution first

No complication or resolution-first accounts start with the resolution, have no complication and require more evaluation to justify why their precautionary approach was a good decision. The accounts with resolution first demonstrate a precautionary approach to a risk, as in the risk has not occurred yet, nor are there any incidents that may cause concern, instead a management strategy has been put into effect prior to a risk being realised. In these cases, the adult children then justify why their precautionary actions were a good decision, these accounts often start with the resolution. The adult child may employ a management strategy but with no complication, as in the management strategy was precautionary. For example George discusses setting up POA for his parents.

> *I: and so when did you set up the power of attorney?*
>
> *P: oh when he was showing signs of dementia and we felt it was you know best to do that. And when it could be said that he still knew what – still had sufficient mental capacity to make a decision to grant us power of attorney and for somebody who knew him well to sign to say that he had. So you know that's probably, erm 4 or 5 years ago. Erm that we drew that up yeah.*
>
> *I: And was he quite comfortable with that? And mum quite comfortable with the the decision?*
>
> *P: yeah I yes yeah. I think my mother was quite relieved actually. That those documents had been drawn up, yeah yeah. – George (interview)*

For George's account regarding setting up POA, there was no 'defining incident' that required this action. Instead setting up POA was a precautionary management strategy. The structure of the account starts with the resolution in the form of setting up POA, there was no complication.

Instead an evaluation of why it was a good decision in that it provided relief for mum and was an appropriate time before dad lost capacity to make the decision.

The accounts that had no complication demonstrated a more precautionary approach to management strategies but still require justification. These accounts typically required more evaluation than any other structural element in demonstrating the appropriateness of the precautionary strategy.

8.3.4 No resolution

The accounts with no resolution are twofold: consideration of a future risk or multiple arguments and counter-arguments which result in uncertainty in how to proceed.

One aim of a no resolution account is to demonstrate a risk the adult child is considering for the future and therefore no management strategies have been put in place yet. Jack was asked about his concerns for mum and dad moving forward, he initially talks about how they have managed so far and the challenges of discussing the condition with his mum who struggles with communication. He reflects on how well his dad has coped and that by moving in with his parents, he feels that dad is more supported. One of Jack's main challenges from his narratives is in how to have conversations with his dad about different aspects of mum's dementia. Part of his response was in considering future risks, which is not only demonstrated by the content of the quote, but also the structure and other rhetoric devices.

> *It's it was the crisis thing again, preparing for a crisis if something, certainly if mum fell and dad couldn't pick her up or the classic from I've heard from other stories is someone has quite a major fall and then they have to be hospitalised and then everything changes from there and things go downhill quite quickly so thinking what would need to be put in place if that happened. Erm having a crisis plan maybe erm 'cause we've talked about crisis plans previously thinking that "what if something else went wrong?" and I guess me not being here meant that well both me and my sister wouldn't be able to help in a crisis so what back up plan has dad got? What contact numbers has he got? Those sort of things. Whereas that's been shelved I guess a little bit by me just being here because I guess I could pick up some of those pieces or I could help play a part in managing stuff. Where if dad needed to go somewhere or erm so I mean yeah if something happened to dad that would be a pretty crazy thing to do but how we would – what would be the consequences if dad had to go into hospital for whatever reason? Erm yeah where could mum go? What would happen to mum? What would that look like? I don't know. Erm yeah so I guess a lot of it's linked around support I think. Yeah. – Jack (interview)*

Jack draws on other people's experiences to convey a risk that has not happened and his concerns around how to manage that. He uses multiple rhetorical questions to present a number of concerns he has surrounding the potential for crisis. He also uses the words ‘I guess’ and ‘I think’ to demonstrate his uncertainty further. He ends with no resolution because no management strategies are in place for these future concerns and to demonstrate further his uncertainty surrounding the risks and management strategies.

The second type of no resolution account is where the adult child may have so many barriers to management strategies in place that they then have to reduce the audience’s perception of the severity of the the risk to demonstrate their own acceptance at not employing a management strategy. In this sense the accounts may demonstrate structurally a resolution, however they have an element of uncertainty. For example Kate describes a series of concerns regarding dad’s medication mismanagement and the limited support they have received from the health services in helping dad to manage his medications. She has also described a number of ‘crisis’ points of hospitalisation. She tries to consider some solutions

> *And so you know, I took him to look at the Sunrise care home, and a bit of me says that he would he would be really well looked after there and many of these problems would disappear. Erm, he probably doesn’t quite have the resources to do that for a very long period of time, so it would be the kind of thing where you’d just blow all of the money from their house in a year and a half and then hope that he was just so demented that you could put him in a really crap state run home for the last phase of his life, that’s the scenario that we’re in, you know he hasn’t got the resources and I haven’t got the resources to guarantee that for ten years we can spend £60,000 a year on good care. So and at the moment he’s not prepared to do that, he’s got enough awareness and I think in some ways I agree with him, that he knows where everything is where he is, you know he can find his way to the toilet, he can get dressed in the morning, he’s in a bungalow, so some of the mobility issues aren’t as bad as they might be otherwise, he knows the area, I think if he got lost he could find his way home, there are lots of reas-, so I think we just keep him there as long as we can, and we put up with medication problems and the crises that they produce, in the knowledge that it’s not really anyone else’s job and I cannot give up my family, to go and live there and make sure he takes his tablets, and that seems to be, that’s the best solution because then I would be there if he went to the cinema, I would actually be there when he got back to make sure he took his medicines, but they won’t have a stranger in the house, because um, my mum used to be a care assistant and she basically thinks that all care assistants steal, because she witnessed a lot of that sort of thing going on so she’s not prepared, neither of them are prepared, to have a live in carer. So what do you do? – Kate (interview)*

The narrative prior to this account had built up enough concerns for Kate to deem considering residential care as a potentially appropriate option. She then presents a series of counter-arguments to justify the decision for dad to remain at home. Alternative compromises are then considered (in the form of Kate moving in or hiring live-in care) but these considerations equally have counter-arguments. Through these arguments and counter-arguments, the account is left unresolved in that none of the management strategies are put into effect. Kate therefore has to justify why these management strategies are not employed which she partially does through the structure of argument and counter-argument. Finally, through demonstrating that she has not addressed the risk of dad remaining at home, she asks the audience to accept that there are no possible solutions to the risks at this time 'so what do you do?'. Through this question, Kate uses emotive rhetoric to place doubt in the audience's mind about how to proceed. If the audience is uncertain as to how to manage the risk, Kate is able to reduce her accountability and her decision can be considered acceptable by the audience.

Although structurally there is no resolution, the implicit decision is that the adult child did nothing. They still need to justify this and rely on emotive rhetoric of conveying uncertainty to the audience to reduce accountability and make their (in)actions acceptable. Instead of being predominantly plot-driven (as with the defining incident or building concerns plots), these no resolution accounts often rely on characterisations. In Kate's example, it is crucial to acknowledge that dad (most of the time) has capacity to make his own decisions, and Kate's mum has mental health problems which can often exacerbate her need to maintain her identity as dad's caregiver. These pieces of information, although may not be apparent from the excerpt above, are provided as background information elsewhere in Kate's narratives. It is then further possible for the audience to recognise that Kate's accountability for her decision to not act on the risk is reduced and is acceptable.

Each of the accounts with no resolution demonstrate a level of uncertainty, whether it be for a future risk or a risk they are trying to manage currently. The lack of a resolution shows that the risk is currently not managed. Each of these accounts requires a lot of evaluation and reflection in considering potential options for managing the risk. Through some of these accounts with no resolution, the adult children may feel a requirement to attempt to justify why these risks are left unmanaged. To do this, they may aim to reduce the perceived severity of the risk; asking the audience to understand that the risk is not as bad as they may have constructed it previously. Alternatively, they may include a series of barriers or external threats that cannot be controlled to demonstrate why they have been unable to consider or employ a management strategy and therefore move to accepting the risk. The rhetorical devices are often similar to accounts where the adult children are justifying a non-action, however the difference is uncertainty at how to manage the risk rather than a decision that has been made to explicitly not act on a management strategy. Such accounts are constructed to give the reader a feeling of uncertainty. The aim of doing so alleviates the adult child's accountability. That is, if the audience is left uncertain as to how the risk could be managed, then they will accept that the adult child has left the risk unmanaged and their account incomplete.

Much like responsibility, uncertainty and certainty are inherent within the narratives of risk. Where responsibility leads to the potential for blame, uncertainty in the face of risk is not unexpected. This concept of uncertainty is most common in the unresolved accounts, however the adult children were able to portray uncertainty in resolved accounts. The purpose of creating uncertainty is to justify their actions further by forming doubt in the audience that they would be able to manage the situation differently. This is discussed throughout the remainder of the chapter.

8.3.5 Section summary: Structures and plots

One of the main methods of analysis for this study was in analysing the structures of the accounts. The adult children produced four different structures or plots within their narratives: a defining incident, building concerns, no complication/resolution-first or no resolution. Each of these structures had different aims in terms of constructing risks and justifying management strategies. The defining incident plot demonstrated how a complicating action represented a risk that required immediate action to manage the risk. This plot made it easy for the audience to understand how an incident led to a management strategy. The building concerns plot typically demonstrated a delay in action, whether it be that the concern was not enough to act on alone but with more concerns the risk then required management. Alternatively, the building concerns plot demonstrated a number of barriers which prevented the adult child from either recognising the risk or acting upon it.

The no complication/resolution-first plot demonstrated how a management strategy may have been employed prior to a risk coming to fruition. These accounts typically relied on reflection and evaluation to demonstrate why this management strategy prior to risk had become useful. The no resolution plot was used to construct a risk the adult child was currently attempting to manage or a risk that had not yet come to fruition but was a future concern. The no resolution plot did not aim to justify action, but instead demonstrate a level of uncertainty about how to manage the risk and often aimed to justify non-action.

The adult children used different plots with specific aims depending upon whether they were justifying an action, delayed action or non-action or presenting a level of uncertainty about how to manage a particular risk.

8.4 Characterisation

Narratives are either plot-driven (a sequence of events and how they relate to each which occur regardless of other characters) or character-driven (the actions of characters impact on the sequence of events), although both are necessary to producing a narrative (Baldwin 2013). As discussed in the previous section, it was possible to distinguish those structures that were typically plot-driven such as the defining incident or building of concerns. However, the building concerns plot did occasionally rely on a more character-driven plot, likewise the no complication/resolution-first or no resolution often relied more heavily on character-driven plots. Within the adult children's narratives, characters were used in a number of ways both to aid the progression of the narrative and to present barriers that may hinder the progression of the account. As discussed earlier in chapter 7, characters could be portrayed in different ways to position the adult child as more or less responsible in comparison to other characters. In constructing a risk, characters can be used to present a risk that the adult child had not previously considered. They may also be used to justify that something is a risk that requires management or a certain management strategy. Conversely characters may act as a barrier to recognising a risk. They may also be used as a barrier to pursuing a management strategy.

There are several characters the adult children used within their narratives, these are: authority figures, the parent with dementia, the other parent (without dementia), siblings and others. Some accounts rely on a single character, others use several different characters. But each of these characterisation served a purpose and could be used to justify the constructions of risks or decisions regarding management strategies. The following section takes each of these characters in turn and demonstrates how the adult children portray the characters and use them as a narrative element within their constructions of risks and justifications of management strategies.

8.4.1 Authority figures

Authority figures are those characters recognised by society as having a certain set of expertise that positions them as having the authority over a given situation. It may be assumed by society that due to the authority figures' expertise, they may only aid the narrative in constructing the risk and justifying management strategies. However, this is not always the case. The following section demonstrates how authority figures can be used to aid the narrative and how they can also present a barrier or hindrance to employing a management strategy.

Authority figures may aid in the justification of a management strategy. An example of this is when Susan describes her decision to find her mum a telephone call blocker system to reduce the risk of mum falling victim to telephone scams (as she had in the past). When asked about the call blocker, Susan says

> […]it was recommended by trading standards. And there's all different call-blockers but trading standards said this is the only one they recommend. Because, you've got internet access and you can set it up at different levels. You can you can just block international calls. That will get rid of a lot. But obviously they're not all, they don't all come from international numbers. You can, you can just block selected numbers, and international, or just block selected numbers but the highest level is where, I've got it set so only numbers that I've put on a list can ring her. – *Susan (interview)*

Susan repeats 'trading standards' to demonstrate how she holds Trading Standard's advice as that of an authoritative figure who can be trusted to provide appropriate information about such services. Susan uses the authority that society places on Trading Standards to justify her actions of getting a call blocker.

Carol similarly uses authority figures in this way to justify her own actions. She is discussing all the different activity groups she has found for her dad to attend.

> *There's a <local> club each Friday close by from 11-4, and he has a taxi there and back. I've organised this and he has no idea how much the taxi or the club costs. Once at the beginning he said it was too much money and I flipped. I asked my sister to speak to him as I couldn't – his doctor at <community mental health centre> had recommended this – he has plenty of money in savings – and he was ignoring the doctor's advice. The outcome was that he now really enjoys his days out at the club (!) – Carol (written)*

Carol has control over dad's finances (discussed earlier in her narratives) which was an agreement reached between Carol, dad and Carol's sister, therefore she is able to spend dad's money as she sees fit. She uses the authority figure (dad's doctor) to justify her decision to use dad's money to fund dad's social activities. She also uses the authority figure to justify her decision to not tell dad about how she was spending his money on his social activities. Although, because this is a mild deceit (as discussed in section 8.3.2) she further removes doubt from her audience's mind with the code explaining that dad enjoys the clubs.

There are several similar accounts throughout the narratives where the participants have used an authority figure's advice to justify their actions. These can be applied for both risks involving safety concerns (Susan's account of scams risk for her mum) or for non-safety related risks (Carol's account of risk of isolation and limited QOL for her dad). Through their accounts, they demonstrate to the audience that the socially constructed authority figures would agree that their actions were appropriate and acceptable.

Although typically an authority figure may be used to justify a particular action, in some cases the authority figure removes responsibility and decisions from the adult child. They then use these authority figures to justify why they did not act to manage their parent's risks. An example of this is from Susan on driving

> *Driving – told to notify DVLA after one consultant watched her trying to drive out of a car park when she attended an appointment alone. She passed a driving test but failed another one a year later and had her license revoked. When she passed we felt this was wrong and worried she would have a… cause an accident. I refused to get in the car with her and told my adult children not to either. She would get lost and I have had to go and 'find her'. – Susan (written)*

Susan uses the authority figure (consultant) to remove her accountability to inform the DVLA that mum was still driving. However, the DVLA did not comply with Susan's perception that mum should not be driving. Because the DVLA is an authority figure on driving, Susan then has to justify why she did not agree with their decision by asking the audience to consider that mum may have an accident (thus harming others, not only mum), potentially harm her adult children or would get lost (meaning Susan would have to find her). However, the decision still remains with the authority figure, the DVLA, and therefore Susan's accountability to others is reduced. Further she still accepts accountability for her children and therefore moves to mitigate the risk to them and herself.

Some adult children are offered advice by authority figures, which initially they may accept because they trust the authority, however the advice may not always be appropriate as they evaluate. Mary provides one example of this, when mum was diagnosed, she was offered the precautionary measure of a telecare system that was being trialled by the authority figure of a dementia advisory service.

> *Yeah, so she's got the telephone which is down, she's got a sort of double length lounge, because it goes down to an extension so it, the the actual alarm box thing sits down at one end of the room, she sits up the other end of the room, she's got a pendant, one for upstairs and one for downstairs and one that she wears on her wrist, she could have had it round her neck, but she chose the wrist, which is fine. Err… and essentially should she ever have a fall or not be able to get to her phone if it's an emergency. On the face of it, nice simple thing, she pushes the the button, it sends a telephone call out to the guys on the other end of the package there* <pointed to corner of room>*, and you know its got er a wide reaching microphone or whatever, they say "can I help you* <name>*?" she has a conversation with them… job done! And then obviously if they ring and there's no answer then they would send out the emergency services. Great! Recommended by the dementia advisory service. Fabulous! … However …* (!) *– Mary (interview)*

Mary constructs this account to initially place emphasis on the dementia advisory service as having provided a theoretically useful device and evaluates the usefulness of such a device. The turning point of '… However…!' demonstrates that the complicating action came after the advice of the authority figure. Through this structure, Mary leads the audience to believe that using the falls alarm device would be the resolution to the account of risk management of falls by presenting the 'resolution' (management strategy) first. By ending her account with 'however' in the way she has, she leads the audience to understand that there is about to be a complicating action that renders the assumption of the falls alarm pendant as a resolution as moot. Mary structures her account in this way to demonstrate how she and perhaps society may expect authority advice to be the most useful and effective, but the turning point of her account provides evidence to the contrary.

Authority figures can be used within the adult children in a number of ways, but each time there is an expectation the the audience would recognise the authority figure as having ultimate responsibility and the highest level of expertise in managing the risks for the parent with dementia.

8.4.2 Parent with dementia

Through justifying their actions, the adult children often discuss how 'obstructive' or 'unaccepting' their parent with dementia was at engaging with a new management strategy. In these cases, the adult child has two choices: to accept their parent's decision or act against it.

In some cases the adult child accepts their parent's decision to not move forward with an action. For example, when discussing mum's diabetes and how they manage it, Roger says

> *I mean I think with having this funny episode recently dad hasn't been testing her blood sugars as much, maybe 'cause she's been quite obstructive. And I saw it first hand on Monday. Where er she was quite quite aggressive towards him and she hasn't done in a while so he basically got like "would you let me do it?" So I would do it. And she said "yeah". But he was just showing me how to do it but she was getting quite aggressive about it. I mean he doesn't test her – fortunately the levels are really good. But so she's mainly managing it through diet. Erm and obviously there is some medication but I can't tell you exactly what medication she's on for it. – Roger (interview)*

Although the expectation from society may be that health should be prioritised above risks of distress, they can recognise that the barriers to conducting the tests are too high - the audience may also assume that people with dementia are 'obstructive' and aggressive (as discussed in chapter 6). Roger need not explain the use of these words further, thus demonstrating that he perceives that society would accept them as part of dementia symptoms. Further, there is a risk associated with aggression to Roger's dad, which he assumes the audience will recognise. Roger therefore uses these assumptions to justify his decision to not attempt to continue the test. Again, he reduces doubt for the audience by providing evidence that the risks associated with mum's diabetes are minimal.

Although a parent with dementia may act as a barrier to the adult child's management of a risk, in some cases the adult child decides to override their parent's decision. An example of such a risk comes from Mary when discussing mum's personal hygiene. Mary has arranged a carer to visit mum once a day for medications, cleaning and company and once a week ensures mum has a shower. She describes mum as being 'quite resistant' to the carer but the carer is persistent in ensuring mum receives her weekly shower. Here Mary describes the carer

> *she's brilliant, she's got the measure of mum anyway, they've, mum probably wouldn't say she necessarily likes her although to be honest she doesn't really remember that she goes in anyway, so, erm… but* <name-carer>*'s very forthright and she won't take any messing, you know if mum sort of says "I don't want to," well* <name-carer> *says "well sorry, but you are". In fact, I was sat with them on Friday, and erm, and I said to mum, "oh, it's tough love, isn't it? Because, you know, we need to do this to get you moving. It's for your own good. We've got your best inten…interest and intentions at heart. So although it sounds like we're being quite bullying, if you like, it's because we need you to move" and she does, she does laughs about it and she says "oh I know, I know"* (I: mm)*, so it's a fait accompli again. If you ask her "do you want a carer?" she'd say "no". But because she comes in every day, she just accepts it.* (I:mm) *We've learnt now that, as cruel as it seems, we almost don't ask her. If, if we need her to do something, it's almost like we just can't give her a choice, we just have to say, this is what's happening.* (I:mhm) *And then she'll be compliant. – Mary (interview)*

Mary's use of the words 'brilliant' and 'forthright' portray the carer in a positive light. Mary also engages with her audience's potential consideration that Mary encourages the carer to be 'quite bullying' in managing mum's care as perhaps inappropriate or negative. To counter this, she justifies the actions by demonstrating that mum can be 'quite resistant', which again the audience may consider to be the case for people with dementia. This is used to justify Mary and the carer's actions; the audience may expect people with dementia to be resistive and therefore Mary can justify the requirement to give her no choice because she then becomes compliant. She also removes further doubt by using examples of speech with her mum as evidence that their 'bullying' is not as bad as it sounds and mum *is in fact* happy with her care.

In a very rare case, it is possible that the parent with dementia makes a decision regarding risk for themselves and the adult child agrees with that decision. Suzie states in the first section of her account

> *When she was diagnosed with young onset Alzheimer's in September 2013, she made a decision within the first few weeks that she was not going to drive again. At that point, we hadn't considered any risk in this area because the illness was in its very early stages. However my mum said that she never wanted to put any other people at risk and so she never drove again. It's much easier to manage risk when the person makes a decision themselves because it seems to take away a lot of the guilt and the worry about how to bring the issue up in the least hurtful way. – Suzie (written)*

This particular account whereby the parent with dementia makes the decision for themselves was rare. This is perhaps because any risks that the parent managed for themselves were therefore resolved without any input from the adult child. Therefore in reality it may not be rare for people with dementia to manage their own risks, but the adult children felt that those risks were not worth discussing for this research project. Similarly several participants commented that their siblings or parents would probably discuss other risks. This was not a requirement of the study. The study aimed to understand how adult children may be impacted by cultural norms and societal expectations when managing risks for their parents with dementia. The focus then is not on corroboration of facts or identifying all risks for their parents, but in how the adult children constructed their narratives of risk and, in doing so, demonstrated perceived impacts from societal expectations.

The adult children frequently characterised their parents with dementia to their audience through words such as 'obstructive' or 'resistent'. They did not need to evidence their choice of these words, therefore demonstrating that they consider that society would understand and expect this behaviour in their parents because of their dementia. In doing so, the adult children may use these characterisations of their parents to justify their actions or non-actions. It is also important to note anomalies in the dataset, for example, risks that the parents themselves managed and consider the reasons why these accounts were rare. Due to the nature of the study, and through understanding narrative inquiry, it is possible that the rarity of such accounts is because the adult children were asked to discuss risks and therefore only constructed risks and management strategies that they themselves were involved in.

8.4.3 Other parent

The other parent is also often used as a hinderer in managing risks for the parent with dementia. For example, Kate was asked about the carer support dad was receiving, she responded

> *Ok, so more recently, because he's had some, I think since I first contacted you, he's had two, emergency hospital admissions. Err he now has, my mother has sent that person away. But he now has a district nurse twice a day and up until I think, last week, he had meals assistance at lunchtime every day as well. But*

> *my mother's sent that away as well, 'cause that's one of the things that she does. She just decides that they don't need things so she stops it. So as fast as I can get help in, they're pushed out. It's like funnel it in through the front door as fast as she's pushing it out the back door. So… - Kate (interview)*

Kate presents here a structure lacking a resolution to present uncertainty at how to progress due to the barrier her mum presents in 'funnelling' out the management strategies Kate attempts to put in place. The word funnel here represents the futility Kate feels in attempting to manage dad's care at home. Within her earlier narrative, Kate discusses her mum's mental health condition (discussed in chapter 7, section 7.1.4). Within this account Kate is able to implicitly draw upon the audience's understanding of mum's mental health which aids in her justification that she can do no more to manage the situation. In her narrative, Kate does not consider mum to be the primary caregiver, however mum feels that being a primary caregiver *is* part of her identity and therefore Kate's challenges to providing care to dad often result from mum as a barrier. Kate therefore conveys that she has a responsibility to find a balance between care to dad and also not upset her mum. The audience can then recognise that these competing responsibilities may result in an inability to manage a risk situation for dad.

Interestingly, the only accounts of the other parent hindering the management strategy decisions were those where the adult children had characterised the other parent as having a mental health condition or questionable capacity. This may demonstrate how the only reason society would consider the other parent as a hinderance is if they were characterised as unable to make decisions on behalf of their spouse with dementia. Therefore it is the responsibility of the adult child to make decisions on behalf of their parent with dementia which may be hindered by the parent without. The adult child then constructs a narrative that creates uncertainty as to the appropriate decision.

8.4.4 Siblings

For the most part though the narratives are constructed around 'we' meaning it was not only the adult child who made the decision for a management strategy, instead the family was in agreement at moving forward in this way. However, there were occasions where a sibling hindered the intentions of the participant. An example from Jodie justifies a management strategy action through the parent without dementia but that is also hindered by her brother. Jodie had previously explained that she had concerns for her dad's memory and wanted to take him to the GP for assessment, but her brother had hindered this by asking her to consider that it was just 'old age'. She then says

> *[…] And this was when my sister and I were saying "look mum really needs to go into respite because dad's health is suffering." Erm and my brother said "no", and because we had to all be in agreement err what happened was, we did nothing until the next crisis, and by then – yeah it would have just been so much easier, it would have been better for everybody if we'd just carried on through. So that was – that makes me so so uptight I can feel myself really really cross about it because it put us back, it put us back like maybe three months and mum and dad suffered in that, in that time things got to breaking point, where dad would admit that he wasn't coping er and then the next day he'd say "oh yeah it's – I can manage don't don't you worry, you've got busy lives. I can manage" and and then you'd turn up and find that he'd been up 'til four in the morning because she wanted to get out the house and go and tell the neighbours to call the police. You know that, that sort of thing. So that was a really difficult time. – Jodie (interview)*

Jodie constructs this account around dad's health as being the risk and her brother as being the barrier to managing the risk to dad. Previously in her narrative Jodie discussed how she and her sister and brother shared POA with the stipulation that none could act alone and all must be in agreement and can therefore explicitly state that her brother acted as a barried. Jodie has no need to justify her non-actions in this situation because the audience can recognise that, without consensus across the siblings, Jodie could do nothing. Instead, therefore, she evaluates and reflects upon the repercussions of not acting as an incident to be learned from moving forward in caring for mum with dementia, but also dad as mum's caregiver. Jodie also uses the presence of her second sibling to demonstrate how it was not just Jodie who felt that a management strategy was required, her sister agreed with her, thus adding weight to her argument that her brother was acting as a barrier.

Siblings can be characterised to both present a barrier to risk management or to demonstrate that the adult child was not alone in their decision and therefore shared responsibility and accountability.

8.4.5 Others

There are 'other characters' that can help and hinder management strategies and be used to justify the adult children's actions. Suzie writes about mum providing care to her children and how she eventually acted to ensure mum was supervised when providing childcare. She initially describes her relationship with mum and mum's relationship with the grandsons.

> *My mum has always looked after my two boys since they were born, and she changed her days at work to care for each of them while I was at university or work. My mum has always been the person that I relied upon for childcare or if one of the boys was poorly, I would call my mum to come and look at them and see if she thought they needed to go to the doctors. She was also there when*

> *both of them were born, so she is a huge part of their everyday life and like a second mother to them. When she was diagnosed, this didn't change[…] – Suzie (written)*

Suzie constructs the account around the importance of mum's role in providing childcare to her grandsons and the relationship she had built with the grandsons from birth. This role and relationship with the boys was so important that even when she was diagnosed with dementia 'this didn't change'. Initially Suzie is painting a picture of a really difficult decision to reduce mum's childcare to supervised as opposed to providing childcare on her own. The role of providing childcare is important to both mum and Suzie, she therefore needs to legitimise her decision to make sure mum was supervised when looking providing childcare.

> *We kept getting phone calls from other parents in the school yard or from teachers to say that the boys were arriving at school an hour early, or that mum would arrive to pick them up from school a few hours early in the afternoon – Suzie (written)*

Suzie draws on external characters; both other parents and teachers who also noticed that mum was struggling with childcare. Both of these external characters have a social responsibility for the boys and Suzie draws on this to justify her decision. This in turn reduces Suzie's accountability and guilt in the use of the management strategy as the audience would be convinced that her decision was appropriate due to the comments from the other characters.

Other characters can also be used as a barrier to the adult child's intentions in managing a given risk. Susan describes how mum had her licence revoked and was no longer able to drive.

> *But the problem was, she had a next door neighbour, and a friend who, she's got a male friend who she's had for quite some time, there's a relationship that's been going on, it's been going on for about 15 years, but he's a married man, he would never acknowledge that he, that she had dementia. So when we sort of saying "no she shouldn't drive" he's there saying trying to get her next door neighbour or trying to help her appeal and telling her who to contact to appeal the decision. And I don't know why they did that. So, the next door neighbour I think realised quickly that actually it wasn't the right thing to do but her friend… was very very difficult about everything we've tried to do because he just wouldn't accept she was losing her memory, so he always undermined us and he didn't back us up. And he cause[d] trouble by just sort of generally just stirring things up and making her have negative feelings towards me and my brother. So I don't speak to him anymore, we had a fall out with him, I mean a really big fall out. – Susan (interview)*

Susan presents mum's male friend as a barrier to not only Susan's management strategy, but also the authority (as it was the DVLA who assessed mum as unfit to drive). Susan portrays mum's friend in a negative light from the beginning of the account (and indeed her entire narrative). She uses rhetorical devices to portray the friend as a 'trouble-maker' and draws upon other characters to legitimise her argument that the friend was a barrier. Firstly, the neighbour initially may have thought similarly to the friend but then aligned with Susan's thoughts, thus demonstrating that Susan was not alone in considering mum should not drive. Secondly, Susan draws on her brother to also justify to the audience that the friend should be viewed as negative and a barrier. Through emotive reasoning, Susan makes the audience align with her characterisation of the friend as negative and a barrier to the care Susan is providing to mum.

Other characters may also be used as help or hinderers depending on this situation. The adult children use characterisations to portray these 'others' in a way that the audience would recognise, understand and accept. In the first example, the audience would empathise with Suzie's difficult decision but also recognise that the other characters had a duty of care to her children which should be conformed with as a societal expectation. In the second example, the audience would again empathise with the adult child, Susan, due to her characterisation of the friend as a barrier to managing the risks for mum.

8.4.6 Section summary: Characterisation

The adult children used many different characters within their narratives: authority figures, the parent with dementia, their other parent, siblings and other people. They often used them to aid in justifying their construction of a risk or use of a management strategy or present a barrier to recognising a risk or employing a management strategy. The adult children used rhetoric devices to portray the characters in a positive or negative light to the audience in order to aid their argument. They draw on societal expectations of particular characters, for example authority figures to justify their decisions. Much like with the plots, the use of characters was to build the adult children's arguments in constructing risks or justifying management strategies.

8.5 Health or safety risks versus non-safety risks

Together, plot and characters are used to construct risks and justify management strategies. However, there are different types of risks: health/safety or non-safety. The risks the adult children discussed also fell into those two categories (section 8.1). Through narrative analysis, it was possible to recognise that there are differences in how the adult children construct a health/safety risk in comparison to a non-safety risk. This distinction has partially been alluded to in the above sections. The following section takes this further to explicitly demonstrate the differences in narrative effort required for health/safety and non-safety risks. The adult children clearly recognised the importance of both as each of them discussed both throughout their narratives. However, they required more narrative effort to construct a non-safety risk when compared to a health/safety risks. They also required less narrative effort to justify prioritising a health/safety risk over a non-safety. This suggests that they perceive that society would be less understanding of non-safety risks, would be more understanding of health/safety risks and would expect health/safety risks to be prioritised over non-safety risks.

8.5.1 Constructing health or safety risks

Constructing a health/safety risk typically requires little narrative effort to achieve. An example of the construction of a safety risk can be found within Roger's narrative. Here he is discussing the risk of mum walking about outside of the home. The following account is from Roger's written narrative, to set the scene he is describing an incident when mum became distressed during an argument.

> *She got upset and walked out of the house - she will often walk away from a situation - obviously there are a number of risks depending on where she goes and what she does. She forgot to close the door so there is a risk of an intruder easily entering the house. Plus all the safety risks associated with not being able to ask for help, get back, cross the road. – Roger (written)*

Roger does not describe the list of risks in great detail, instead relying on the audience to agree that these are safety concerns. Although it could be suggested that through his written account, Roger limited his evaluation of road safety, however, it was discussed at interview also

> *I don't know how aware she is in terms of crossing roads. So that would obviously be a risk for me in terms of her walking round the block and not cross any roads, but to me the risks were around getting lost or disorientated and not being able to come back. Erm and then you know you know risk of danger mainly by road vehicles I suppose. Yeh. – Roger (interview)*

The two accounts require limited evaluation to construct the risks associated with mum walking about. Immediately the audience can recognise the risks that mum could get lost, disorientated or come to harm.

8.5.2 Constructing non-safety risks

Conversely, in constructing a non-safety risk, much more evaluation is required and more narrative effort from the participant in constructing the risk. In Mary's account of isolation and QOL as at risk for mum, she uses more evaluation and fewer complicating actions. When asked about her written comment of isolation and QOL, she says

> <husband> *was having a conversation because as you know, he's got an interest in frailty and things like that, and he was at a conference last week, and he was talking to a nurse who, I can't remember, I think she was a*

> *dementia specialist or whatever, but anyway, she's got lots of experience, and he was talking to her about, you know, mum's version of reality and THE reality. And how very different they are, and she said "but you know, if she's happy in her reality then actually, does it matter that they're very different?" So it kind of put a different spin on it for, for us. Which I agree with, and I you know I said to him, "well yeah, I can get that. But equally with particularly the breakfast and isolation, whilst she hasn't got the stimulation and people there, she wouldn't dwell on it necessarily and go "oh I feel really isolated" but because she is so much more animated and in the moment if you like when she has got stuff going on and she is being stimulated. I still think that that's something that should be addressed" and* <husband> *didn't disagree with me with that, I don't think we should leave her in isolation just because she's happy in her isolation, I think the only reason that she's happy in her isolation, is because, again, she, at that time, she hasn't got the thought process to go "oh I'm on my own, and I've been here all day and I haven't spoken to anyone." Whereas you or I probably would do you know and whilst it's nice to have some time to yourself every so often, I'm sure if somebody stuck me in the same room for 24 hours a day 7 days a week with no one to talk to at all, or like an hour a day, I'd be climbing the walls.* (I:mhm) *but again, that part of the brain seems to have gone so she doesn't realise, does that make sense?* (I: mm mhmm, yeah, yeh.) *So I still think it's really important that she does, you know that we do get her stimulated in some way shape or form, having the company and going out and doing stuff because you can see the difference.* (I: mhm). *She's gone from this like locked in behind the eyes, nothing, to you know "oh yeah look" we went for a drive in the forest last week when her sister was down, you know, just to look at the donkeys and sit by the sea. Okay, who cares she can't remember she's done it, but in the moment, it's great! – Mary (interview)*

Structurally, Mary starts with the counter-argument of mum is fine in her own reality so that she can then discount it and provide evidence that going with the person with dementia's reality is not always the most appropriate decision. The counter-argument is a strong argument and backed by authority figures, however Mary disagrees and requires much more narrative effort for the audience to understand and agree with her. She uses both forms of rhetoric: logic and emotive reasoning - initially, she asks the audience to empathise that being isolated in the same room for hours would lead them to be 'climbing the walls'. She then has to explain to the audience that due to mum's dementia, she may not make the same connection. She then moves to provide logical evidence that there is a cause and effect associated with stimulation making a difference. Finally, she considers that the audience may still not understand or may ask 'why bother if mum does not remember?' which she defiantly responds to by stating 'who cares?' and 'in the moment, it's great!'. The main difference between health/safety risk constructions and non-safety is that non-safety risks are much more morally ambiguous and complicated. The adult children therefore require more narrative effort if they consider that the audience may not understand.

Another example of a non-safety risk is from Suzie

> *Risk of "feeling stupid" and the risk of "other people noticing that I'm doing it wrong"*
>
> *As my mum has always had very good insight into her condition, she is very aware of every single mistake that she makes and how this might appear to other people. We have tried to reassure her and to support her as much as possible, but she will behave in a certain way, and will know that it is not quite right, but will not know what the correct thing to do is. I'm trying to think of a good example of this to share with you……… so an example might be at church when we go up to the front for communion, she knows that there is something that she needs to do and will set off towards the front, but then gets confused and tries to sit down on a different seat- she knows that she was trying to do something and that it has gone wrong somehow, but can't work out where it went wrong. At his point she will start to cry and become extremely distressed, thinking that other people think she is 'stupid'. We have tried so hard to minimise this risk all the way through her illness, and we will scaffold situations to try and eliminate any potential difficult situations. For example helping her out in conversations (at the risk of taking over). These actions have always been with the best of intentions, but you cannot protect your person every minute of the day, and actually you can make things much worse by interfering and trying to make it 'right' all the time. These days if we are at church and she is facing to the back when standing to sing hymns, I just turn backwards with her and we stand side by side facing the wrong way. In the past I would have tried to micro-manage the situation and help her to turn around, which made her feel even more 'stupid' and 'in the wrong' (Stupid is my mums word, not mine). I have found out that nobody actually cares whether we face the wrong way or stand up at the wrong time or sit in someone elses place.*
>
> *I suppose I still do try to manage the situation when we are out in public places because I worry what other people are thinking. The other week at a garden centre, she went and sat down with this elderly man and his wife and tried to give them a plant. I rushed over and apologised and moved her to a different table, but actually- did they care that a nice lady had come to join them…No. That one was my problem. – Suzie (written)*

She explains that mum has good insight into her condition, as her audience may consider that people with dementia lack insight. She explains how this insight presents a risk of distress, again the audience may not have considered that with good insight is the potential for distress. She provides an example and reflects on how challenging it is to manage the risk of mum's distress but without trying to take over. The audience may consider that taking over is not appropriate in situations of non-safety, such as having a conversation, because the potential harms may not be considered as great as for example crossing the road and getting hit by a car. Although this may be true, Suzie is not comparing different risks here, she is presenting an argument to the audience that non-safety risks (such as forgetting words in conversation or 'doing the wrong thing' in church) may cause distress which can be damaging to the person with dementia. Suzie reflects on how she may have managed the situation in the past relying on the audience's shared understanding of social norms that it is considered 'proper' to face the right way in church. That Suzie no longer manages this situation requires justification, which Suzie provides by explaining that nobody cares. In her final example, she reflects further that she may still attempt to manage social situations and the risk of other people noticing that mum does not always act in the most socially acceptable way. But recognises that her attempts to manage such situations may not always be necessary.

Again, the risks identified by Suzie are not related to health/safety and are much more morally complex in how they are bound to social norms. The management of these risks is also complex which Suzie recognises and reflects upon for example balancing managing mum's distress with the risk of taking over. Where these non-safety risks are so morally complex, the adult children perceive their audience to be less understanding of them, there is therefore much more narrative effort required for the audience to understand.

In comparing the narrative effort required for health/safety risks and non-safety risks, it can be considered that the adult children perceive society to be less understanding of non-safety risks. This is further exacerbated by the morally complex dilemmas that adult children face in managing such non-safety risks. The following section takes this further to demonstrate how adult children may balance the two different types of risks; often favouring one risk over the other.

8.5.3 Balancing risks

The previous two sub-sections have demonstrated the narrative effort the adult children produce in constructing health/safety or non-safety risks independently of each other. But when addressing a situation with the potential for both health/safety or non-safety risk outcomes, the adult children must balance the risks and justify their decisions to favour one over the other. An example from Patricia demonstrates an argument favouring avoiding distress (non-safety) for mum at the risk of a potential health concern

> *She got some sort of bowel screening thing through the post the other week erm and I sort of made the decision but thought that it probably wasn't worth her doing and I spoke to my sisters about it and sort of said "I don't think we should pursue this because erm you know" if I thought she was at really high risk then I would sort of go through it, but actually it's quite an unpleasant thing to sort of do the initial screening test it's not nice when you do your own, let alone someone else's. And I said "and how you go through the process of explaining what does he want her to do and have her go through that and then if she needed anything more invasive like a colonoscopy or you know" like I've had quite a lot of those er with my own illness. And I er I just don't think it's something that I would want to put her through. But equally you, you have*

> *that sort of concern in the back of your mind that you what if there was something there undetected? But if she were in pain but you just wouldn't realise it because she's not able to explain what what's wrong. Does that make sense? – Patricia (interview)*

Patricia balances the risk of undetected bowel cancer and the risk of distress and discomfort her mum may feel at attending a screening test. This is a balance between a health risk versus the risk of distress. She starts by setting the scene – that mum received a letter about bowel screening, it could be considered that this is a form of authority figure advice through the assumption that the NHS would have sent the letter. Patricia then takes ownership for her decision to go against this authority advice and not take mum for an appointment. The remainder of the account is Patricia justifying her decision to not take mum to the appointment through constructing distress as the more important risk. Although Patricia takes ownership for her decision, she describes having discussed it with her sister therefore attempting to share accountability for her actions.

She then justifies her decisions by asking the audience to consider that mum is not at high risk of bowel cancer and to recognise the discomfort associated with such tests, drawing on her own expertise by experience. There is then further evaluation to demonstrate her understanding of the risk and her decision through a series of questions which demonstrate her uncertainty at her decision.

It was a challenge to find an account where the opposite argument was formed; that is where a health/safety risk outweighed a non-safety risk. The social dominance of the health/safety risks means that the non-safety risks require no discussion or justification in the same way as above. However, there were accounts where the adult child discussed the non-safety outcomes of the risk as secondary to the safety outcomes. For example, Carol describes dad's increased 'wandering'

> *There's a good community on the estate, and Dad has recently (more so since the last lot of writing I did) taken to wandering. He really wanted to get back to* <town> *where he was born & grew up – and the police have been involved a couple of times.* <Telecare alarm system> *can tell me when he's gone out, before the CCTV tells me – and* <County> *Police have been brilliant in tracking him down.*
>
> *A friend also stopped him in the village when he was about to get in a taxi to* <town>.
>
> *I took him to* <town> *for most of a day last week, we had a ball. I was born there too and we were both talking about the park from our childhood 'gangs' perspective. We're going back in a couple of weeks to do more re-exploring. Hopefully this will divert his need to go back there, thinking it's home – Carol (written).*

Carol starts by discussing the safety concerns surrounding dad's 'wandering' and describes the management strategies she has employed in maintaining his safety (police involvement and the telecare system). However, she does not need to justify these in the same way that Patricia did. The audience must therefore recognise the risks associated with 'wandering' easily, as was apparent in Roger's account (section 8.5.1).

As a secondary consideration, Carol also acknowledges the non-safety aspects associated with dad's 'wandering' in that he may miss his home and the enjoyment dad and Carol had in bonding over reminiscing about their time in dad's home town. Although Carol discusses the non-safety aspects associated with dad attempting to go to the town he grew up in as secondary to maintaining dad's safety, she still acknowledges the importance of this to dad – enough to discuss it with the researcher.

There were several accounts similar to Carol's that non-safety was considered as secondary to health/safety and acted upon but not an argument of favouring health/safety risks over and above non-safety risks. This is perhaps because the adult children did not feel the need to explain the importance of a health/safety risk over a non-safety risks. As a culture, adult children may recognise the importance of both health/safety and non-safety risks but consider that society does not share this understanding and may place more importance of health/safety risks and less so non-safety risks.

8.6 Summary: Narrating risks – not all risks are equal

The adult children discussed both health/safety risks and non-safety risks demonstrating that for the sub-culture of adult children, both are important. However, through analysing their use of structures/plots, characterisations and rhetoric devices to present their arguments to their audience, it was apparent that more 'narrative effort' (use of more narratives elements) was required to construct a non-safety risk as important than a health/safety risk. Likewise, the adult children required more narrative effort to argue for favouring a non-safety risk over a health/safety risk. In positioning the audience as society, this demonstrates that that adult children perceive that society would view health/safety risks as more important than non-safety risks, or at least more understandable.

Chapter 9: Discussion

This project aimed to understand how perceived societal expectations may impact upon how adult children manage risk for their parents with dementia by answering the following questions:

1. How do adult children of parents with dementia construct risk narratives?
2. What are the implications of these constructions for understanding societal expectations of risk in dementia care?

The three main findings were:

1. In constructing risks and justifying the management strategies they used, the adult children drew upon some potential societal understandings of dementia, risks and various media (such as social media, mainstream media including news headlines, and popular literature). They also utilised implicit shared understandings of expert figures to add authority to their justifications.
2. The participants were asked to construct and reconstruct narratives of risk for their parents with dementia, they were not asked to discuss responsibility. However in each of the narratives the theme of responsibility was present throughout, thus demonstrating the importance of responsibility for risk in dementia care. The adult children positioned themselves at various levels of responsibility which impacted on their risk narratives. For example, someone who positions themselves at lower responsibility might not be expected to justify their actions to the same extent as someone with higher levels of responsibility. The adult children could move through different levels of responsibility within their narratives depending on the account and the situation.
3. The adult children required more narrative effort to construct a non-safety risk over the health/safety risks. This demonstrates that the adult children perceived that their audience better understood or placed more importance on health/safety risks than non-safety risks. However, the adult children all spoke of non-safety risks and effectively justified their decisions to prioritise non-safety risks in certain situations. This suggests that to the culture of adult children caring for a parent with dementia both health/safety risks and non-safety risks are important, but ‘outsiders’ in society may be expected to understand and perhaps deem health/safety risks to be more important than non-safety risks.

The originality of this research was in the use of narrative inquiry to explore how adult children construct risk accounts for their audience and in doing so, what this suggests about how they perceive their audience to understand risks and expect risks to be managed in dementia care. Bernstein (2003)’s theory of language coding has not been applied to dementia research before. Bernstein theorises that elaborative language is required when an audience did not have a shared understanding but restricted language is used if a shared understanding was apparent. For this study, narratives were constructed in similarly elaborative or restricted forms depending on whether the adult children deemed the audience (society) to have a shared (or not) understanding of risks for their parents with dementia.

I discuss this in terms of ‘narrative effort’, that is not only the amount of elaboration required but also the use of multiple elements and particular narrative structures to convince the audience of risks and appropriate risk management strategies. The identification of narrative effort is a unique feature of this research. The use of narrative effort firstly demonstrated differences in how health/safety risks could be constructed versus non-safety risks. Secondly, the narratives demonstrated greater elaboration, use of multiple elements and more complex structures when the adult children positioned themselves as more responsible for their parents.

For example, some risks may not be easily defined or apparent. In such cases, the adult children were required to construct ‘building concerns’ plots whereby several concerns amounted to a risk that required management. Likewise these building concerns plots may demonstrate two sides of the argument, that is risks regarding health/safety that may require management in contrast with risks pertaining to non-safety aspects which the adult children would argue to be equally important and requiring management. The societal expectations are that adult children should effectively recognise risks and prioritise safety risks, therefore the audience may not have a shared understanding with the adult children. This in turn means that the adult children perceive that they are required to build complex narratives to counter the societal expectations.

Similarly, if the adult children portray themselves as having a high level of responsibility for their parents, the lengths to which they are required to convince their audience of their decisions are typically greater than those who portray themselves as at low responsibility for their parents. Often in the latter case, there is another person who would be portrayed as having high responsibility for the parent with dementia. The adult child is then free to evaluate risks and management strategies without being required to convince the audience that the decisions were appropriate.

When considering how researchers can understand societal expectations or understandings of a particular phenomenon, it is not always possible to simply ask ‘society’ such questions. This is because logistically it is not possible to ask every person in a given society. Also people may not consciously be aware of the societal expectations and social norms that shape their responses to a particular phenomenon such as risk, risk management and responsibility in dementia care. Equally, asking a group of people (such as adult child caregivers) how they are impacted by societal expectations is similarly inappropriate. In recognising such challenges, novel approaches to methodology may offer insights. Narrative inquiry in this study has been effective in recognising potential impacts of societal expectations and understandings upon adult children as caregivers. This is the first time narrative inquiry has been used to identify the impact of societal expectations on dementia caregivers.

This chapter positions these findings within the context of the literature and theories discussed earlier in chapters 2-4.

9.1 Responsibility and risk

The participants were not asked to discuss responsibility but through their narratives, it became apparent that responsibility was a key aspect of constructing risk. The adult children used a variety of characteristics and factors to position themselves and others at different levels of responsibility for their parents with dementia within their risk accounts. These included: the diagnosis account, whether they were the ‘caregiving type’ or not, gender, distance to parents, employment or self-employment, power of attorney, paid care, characterisations of the other parent (without dementia) and characterisations of siblings. These factors impacted upon how and why they constructed risks in the ways they did and how they justified their management strategies (or not). Some of the adult children portrayed a level of responsibility consistently throughout their narratives, for others the level of responsibility varied between accounts depending on the argument they were trying to form. The adult children demonstrated that responsibilities extended beyond the parent with dementia, to their other parent without dementia, to themselves and to society.

9.1.1 Multiple responsibilities

The adult children were asked to discuss their experiences of risks for their parents with dementia. They were also asked to consider the risks to themselves as caregivers for their parents with dementia. The risks to themselves included: burden, stress and mental health impacts; genetic potential of developing dementia themselves; the change in parent-child relationship; the risk of increased burden should their other parent be unable to continue the role of primary caregiver; financial implications of providing care; impacts of taking frequent time off work to provide care; reduced hours of work; balancing responsibilities for their parents and children; and strains on marital relationships due to providing care for their parents. The present findings demonstrate the ‘balancing act’ of being an adult child providing care to a parent with dementia in line with the literature (Davies et al. 2000; Kjällman-Alm et al. 2013; Vreugdenhil 2014; Johannessen et al. 2015). This balancing act included their social and working lives, the lives of their children, their grandchildren (if they had any) and their parents with and without dementia.

Some of the adult children were able to discuss the risks to themselves within their narratives, whereas some required prompting. However, all were comfortable with discussing the risks to themselves and did not divert away from the question unlike in Adams (2001) study about co-construction of risk between CPNs and family caregivers. Adams (2001) discusses family caregivers avoiding answering questions about their own wellbeing or risks for fear of losing credibility within their narratives. The adult children within the present study did not demonstrate this concern (discussed earlier in chapter 5, section 5.5, and later in chapter 10, section 10.2).

Although the adult children were not asked to discuss responsibility for the other parent without dementia, those who had a second parent who was still alive did discuss their responsibility for them. This could have been limited to providing support or respite for the other parent by supervising the parent with dementia (as with Jack), or could be taking over some of the responsibilities of the other parent to ensure risk management for the parent with dementia was appropriate and effective (as with Jodie). The present study demonstrates an additional responsibility within the ‘balancing act’: the other parent without dementia. The implication of this is that even when there is another parent who may be considered primary caregiver, the adult children may experience additional burden in relation to supporting both parents not just the parent with dementia. Further advice, support and guidance should extend beyond the named primary caregiver, to those who are also providing care (such as adult children) who may be considered secondary caregivers.

9.1.2 Factors used to position responsibility

The adult children positioned themselves at varying levels of responsibility for their parents with dementia through a number of situational factors. Within the literature, there were a number of characteristics that impacted on expectations of adult children to provide care to a parent with dementia including: gender, work, siblings and other family care responsibilities (Finch and Mason 1990, 1993; Cahill 1999; Franks et al. 2003; Hwang et al. 2017; Greenwood et al. 2018; Tatangelo et al. 2018). Within the present study, the situational factors included: how instrumental the adult child was in the diagnosis process; whether they consider themselves to be the caregiving type; how they characterise their other parent (whether capable of providing care, or not); how they characterise their siblings; distance to parent; working life; whether they had children or not; employed paid care; and POA.

Some adult children presented accounts regarding the diagnosis of their parent with dementia. Those who had previously provided care and were instrumental in the diagnosis of their parents may have anticipated that their roles would alter with the diagnosis. However, a couple of the adult children did not recognise the symptoms of dementia prior to diagnosis and therefore experienced biographical disruption. Buri and Dawson (2000) similarly found that family caregivers constructed their identities following a family member's diagnosis of dementia and endeavoured to reconstruct their relationship with that family member. There was evidence of this within the present study, two of the adult children with parents with young-onset (Jack and Lucie) in particular produced narratives that were embroiled with attempting to manage the changes in their relationships with their parents and find a role in providing care to their parents. It might then be interpreted that younger adult child caregivers experience this challenge to their identity and relationship. However, the adult child (Ellen) who had provided care for the longest time (out of all 12 cases) demonstrated similar changes throughout the course of her mum's dementia. She described wanting 'to remain a daughter' which assisted her justification for having live-in care for mum and added later that mum no longer knows Ellen is her daughter. She therefore recognised the threat to her relationship with mum that a caregiving role may bring.

In the study by Franks et al. (2003) there was significant evidence to suggest that with more sisters, expectations of responsibility reduced due to the assumption that another sister would assume primary responsibility. Within the present study this was not the case for Jodie, Patricia and Suzie, each of whom had sisters. Instead of experiencing less responsibility, Patricia felt that she had greater responsibility for her parents than her two sisters. This is possibly because her two sisters had their own children whereas Patricia did not and Patricia was self-employed with more flexibility in her working hours to provide care to mum. However, this study only interviewed Patricia, and not her two sisters whose narratives may provide evidence to the contrary, that is they may also have experienced high levels of responsibility. Suzie and Jodie however did not position themselves at reduced or higher levels of responsibility compared to their siblings, instead they demonstrated a shared responsibility with their sisters. Jodie takes this further to reflect on how she feels she wants to ensure that both she and her sister maintain a balanced shared responsibility and considers that she wanted to match her sister's level of care for their parents. This negotiation of responsibilities is addressed later in section 9.1.3. Interestingly, Jodie also had a brother, but the assumption was that he need not take as higher level of responsibility as Jodie and her sister because he had moved to another country. Franks et al. (2003)'s study only focussed on adult children who were not actively providing care to a parent, instead the questions they posed to their 206 participants were about hypothetical circumstances. Within the present study, all participants were actively providing care.

The study by Franks et al. (2003) also found a significant association between the health of the adult child and expectations to care. This was demonstrated by one adult child in the present study, George, whose parents had moved closer to his sister and not George in part due to his own health status.

Franks et al. (2003) did not find any significant effects of gender, employment, children, distance to parent or number of brothers on predicting parent care involvement. Within the present study and others, the adult children cited these characteristics as part of their positioning of themselves at different levels of responsibility. Ellen and Susan both mention gender norms as to why they provide care above their brothers, this is also noted by Hwang et al. (2017) and Cahill (1999), however, Jack has a sister and he moved in with his parents to provide care. There is the potential that this is due to other characteristics such as his sister has children and Jack's employment contract was coming to an end. Employment, or self-employment played a part for Patricia and Carol who experienced increased expectation and responsibility due to their self-employment status, where their siblings were employees. Likewise whether the adult child had children or not was considered a factor in comparison to their siblings, for example Jack and Patricia, again Cahill (1999) notes that this played a factor in expectations of care provision. Distance was also noted as a reason the adult children may be more or less likely to provide care than their siblings, such as George, Patricia and Jodie. Kate was the exception, she lived at a longer distance from her parents, but did not have siblings and therefore distance did not reduce her expected role and responsibility. Number of brothers was an important part of Roger's narrative, he has two brothers and all three live at a long distance from their parents with dementia, but Roger notes that he takes on more responsibility than his youngest brother. However, he also comments on how he feels his brother may be in denial about mum's dementia and was struggling to accept the level of care and support mum required.

In their paper discussing societal expectations of spouses and daughters as caregivers for their family member with dementia, Toepfer et al. (2013) found that one of the key portrayals of wives and daughters in society is that of having a natural aptitude for caring and an innate intuition in knowing their family member with dementia's needs as they would with their own children. Carol notes that she is not a natural caregiver type, despite having a son. This demonstrates that the societal view of women as having a natural aptitude for caregiving is incorrect, that just because a woman is able to provide care to both her own children and a parent with dementia does not necessarily mean she had an aptitude for it. That Carol felt the need to tell her audience that she did not have a natural aptitude for caregiving may add to Toepfer et al. (2013)'s argument that societal expectation is that of women having a natural aptitude for caring.

Alternatively, Carol uses her argument that dad is constantly telling her he loves her as symbol of reciprocity as outlined by Finch and Mason (1993), that is despite Carol not being the caregiver type, she justifies the care she provides through the value she assigns to dad's appreciation and love. The rest of the adult children did not discuss their natural abilities for providing care, however some noted their backgrounds in health and social care may have aided them in providing care to their parents with dementia. However it should also be noted that these adult children described similar challenges in providing care and managing risks for their parents with dementia. Therefore, although society could expect that those with a background in health or social care may have more of an aptitude for caring, this does not necessarily mean that their experiences would be easier.

Although Franks et al. (2003) demonstrated that factors such as: multiple sisters, health of adult child, gender, employment, having children, distance to parent and number of brothers, independently may or may not increase expectations of adult children to provide care to a parent with dementia; some did not demonstrate significant correlations. Perhaps this was because the study was produced too narrowly through quantitative measures, or alternatively because the study asked people to consider hypothetical scenarios. Instead the present study and some of the literature (Finch and Mason 1990, 1993; Cahill 1999; Egdell 2013; Hwang et al. 2017) demonstrated that where there are a number of different characteristics that can affect expectations of an adult child, these all interact with each other therefore it is not as simple as to say for example, that those living at a closer distance are more likely to provide care than those living at a longer distance. This may be true within siblings, for example if there are two or more siblings, the one closest may provide more care than the one at further distance. But what of those with no siblings who live 100 miles away? Likewise daughters may be more expected to care for parents with dementia than sons, but what of those sons who live closer and do not have children but their sister does? In recognising that there are numerous situational characteristics that may impact on expectations of responsibility and that these are not independent of each other, HCPs may then be able to recognise the most appropriate forms of support or guidance that individual adult children require.

Also noteworthy is that the adult children not only used characteristics to portray their level of responsibility, but also to provide valid reasons as to why they held less responsibility for their parents with dementia. This is similar to the findings Finch and Mason (1993) present in their chapter aptly named *making legitimate excuses* whereby certain characteristics such as distance to parent may provide a valid reason as to why the adult child could not provide care to their parent. In relation to the present study, this demonstrates further the impact of societal expectations in how the adult children may be required to justify their limited role in providing care to their parents with dementia. It also demonstrates that there are a number of factors that society may recognise and accept as an expectation for reduced care for a parent with dementia.

The adult children used their risk narratives to also narrate responsibility. They drew on multiple characteristics and factors to position themselves at varying levels of responsibility for their parents with dementia (and often their parents without). The implications of this finding is that caregiving situations are not all the same for all adult children. The idealistic notion of an adult child - preferably daughter working part-time or retired, with adult children of her own or no children, living next door and able to provide daily care to a parent with dementia - is rare. Instead there is a need for HCPs to understand the situation and context within which care is provided. This should not be limited to 'primary caregiver' instead there is typically involvement from adult children also who may be overlooked when addressing caregiver needs. In order to provide better support to family caregiving situations, there is a need to identify all members of the family who are involved and provide guidance to each to enable the family to work together for the care of the person with dementia rather than exclusively supporting the named primary caregiver.

9.1.3 Changing responsibility

The adult children rarely stuck rigidly to a higher or lower level of responsibility. Responsibilities were frequently negotiated through time (with disease progression) or with other family members. A lower level of responsibility would be if someone else could be considered as the primary caregiver in that situation; a higher level of responsibility would be if there was no one else to take responsibility, or if other characters were portrayed as not having as much responsibility as the adult child. Often responsibilities and levels of responsibility differed between accounts for the same adult child depending on the situation.

As discussed above (section 9.1.2), Jodie was keen to maintain a similar level of responsibility for her parents as her sister. She commented further on how she would focus predominantly on her mum's health and wellbeing whereas her sister focussed on the financial and legal aspects of care for mum. George, like Jodie, described the support he provided to his parents as being focussed on financial and legal aspects, whereas his sister took care of day-to-day aspects. Whether explicitly or implicitly, there were negotiations over the boundaries of which types of care the participants and their siblings would provide. The adult children were also able to position themselves at different levels of responsibility depending on the situation (as with Lucie chapter 7 section 7.2.3). She frequently portrays her step-dad as having ultimate responsibility for mum, however presents several accounts where, because her step-dad was not present, she had temporarily increased responsibility for mum. Responsibility also changed over the course of the dementia progression, for example Ellen demonstrates changes in her role from being on call to dad 24/7 as a caregiver to becoming a care manager when she hired professional care. There are a number of transitions the adult children experience in taking on the caregiving role; some more relevant for specific cases than others. These findings are in keeping with the literature, where levels of responsibility and types of care are negotiated between family members (Finch and Mason 1990, 1993).

9.1.4 Responsibility and accountability

Inherent in responsibility is the notion of accountability and therefore risk of blame. The present study demonstrated that responsibility impacted upon constructions of risks and justifications for management strategies. Those that positioned themselves as having higher levels of responsibility for their parents with dementia typically required more justification for their management strategies than did those who positioned themselves at lower levels of responsibility. As discussed in chapter 3, section 3.3.6, there is a wealth of literature demonstrating HCPs' fear of blame and litigation (Adams 2001; Gilmour et al. 2003; Mitchell and Glendinning 2008; Clarke et al. 2011a; Taylor et al. 2018). Gilmour et al. (2003) also notes that a concern of family caregivers in going against HCPs' advice is fear of blame should something go wrong for their family member with dementia. The present study demonstrates this through the processes the adult children used to justify their management strategies for their audience.

Some adult children also drew upon other characters to demonstrate shared responsibility and therefore accountability for the management strategies used. For example by demonstrating that others shared their thoughts about a particular risk. Clarke (2000) discussed shared accountability or reducing accountability in light of family caregivers making difficult decisions for their family member with dementia. She described permission-seeking from others to aid the caregiver in their justification for acting upon a risk. However, Clarke (2000) found that this was in order for the family member to preserve their prior relationship with the family member with dementia. The present study takes this further to demonstrate that this 'permission-seeking' may be connected to the level of responsibility that the adult children experienced. That is, they used other characters, who aligned with their decisions, to share responsibility and therefore accountability. This may be due to the potential for blame. Furthermore the adult children frequently engaged with their audience to ask rhetorical questions asking the audience to consider how they may act in a given situation. Through these rhetorical questions, the adult children were asking to a certain extent for permission from the audience and asking them to understand their decisions.

This ‘permission-seeking’ from the audience was especially apparent in the use of deception. The literature notes that deception is often used in family dementia care, especially in the case of risks (Berry et al. 2015; Russell 2018). Russell (2018) argues that although society views deception negatively, sometimes deception is necessary to reduce distress. This was apparent within the present study where the adult children had to argue that deception was the only management strategy to ensure the removal of a risk whilst minimising distress. The adult children also used their parents’ memory problems and lack of deficit awareness as a form of management strategy. This was often to reduce the audience’s concern that the parent would become distressed at the removal of a particular risky activity. This concurs with the work of Berry et al. (2015). In the present study this information was typically included in the adult children’s accounts in the form of a coda, demonstrating that it was not a necessary part of the risk account. Instead it was a secondary potential outcome that the adult children felt their audience should be made aware of. Therefore there are some management strategies that adult children may choose to use for a given risk that society may consider to potentially cause distress and therefore may view negatively. An example within the findings chapter 8 section 8.3.2 is Mary’s removal of mum’s credit cards and shopping catalogues. Mary used the coda to demonstrate that the deceit did not cause distress and was therefore acceptable for managing the financial risk.

Accountability is inherent in responsibility for risk management. The adult children demonstrated a recognition that society expects them to be held accountable for their actions. They used their narratives to justify the decisions that they perceived that society would expect them to be held accountable for. This finding mirrors Finch and Mason (1990)’s two consequences of societal expectations: 1. Because adult children are expected to ‘do something’ to care for their parents, they must determine what to do, and 2. Get society to accept their actions. Within the present study, the adult children not only successfully constructed risks (that is, they accomplished their aim of making their audience understand and agree that a situation was a risk), they actively justified their actions upon the risk to their audience. The question posed by Finch and Mason (1990) as to whether these consequences occur consecutively or in parallel is returned to later in section 9.4.

9.1.5 Uncertainty

Another concept that is inherent in risk and especially in responsibility for risk management, is uncertainty (as discussed in chapters 2 and 3). Uncertainty is a product of not knowing whether a risk is a risk until it actually happens (Lupton 2003). Uncertainty is also a product of not knowing how to act upon a risk (Clarke et al. 2011a). Uncertainty may also lead to helplessness (Day 2013). Uncertainty was rife throughout the adult children's narratives. However, some adult children were able to position themselves as more certain of their decisions depending on the risk they were constructing and the decisions they were aiming to justify. They typically used certainty when they considered that their methods would align with perceived societal expectations. Uncertainty was often used where they were less convinced and required the audience to agree that a decision could not be reached or to counter societal expectations through planting doubt in the audience's mind about how to proceed.

Within the narrative structures, there were several risk accounts that held no resolution in how the risk was managed or whether a situation was a risk; these typically considered future risks or present risks that were as yet ineffectively managed. Drawing together the future and dementia progression, uncertainty must be a constant factor for the adult children. Some of the adult children were reluctant to consider risks in the future of their caregiving for their parent with dementia which is similar to Hwang et al. (2017)'s argument that the adult children had limited foresight into their parents' needs. However, the notion of not considering future concerns or risks for some adult children within the present study was a form of self-preservation or coping mechanism. They did not wish to burden themselves with anxiety over risks that may or may not happen in the future.

If the accounts had a resolution, the adult children could be more certain of their management strategies. That is, by structuring the account as having a resolution, they effectively demonstrate that the management strategy resolved the risk. However, some still presented an element of self-doubt, therefore demonstrating that absolute certainty could not always be achieved. Often an account could have a resolution, but uncertainty arose if the adult child perceived their decisions to be socially acceptable. The adult children's perception that the audience may assign blame or that the adult child had not managed their parents' care effectively impacted upon how much certainty they could convey in their account. In this sense it could have been expected that those who positioned themselves with higher responsibility and therefore higher accountability may have exhibited more uncertainty within their narratives. This was often the case. For example Kate in chapter 8 section 8.3.4, who held a higher level of responsibility for her parent with dementia and therefore experienced higher levels of uncertainty in how to manage the risks.

However Lucie too demonstrated uncertainty in her accounts, despite positioning herself at a lower level of responsibility than some of the other participants. The adult children frequently instilled this sense of uncertainty in their audience in order to justify their decisions surrounding management by leading the audience to be empathetic to their situations.

One participant, Ellen, predominantly produced an air of certainty throughout her accounts. By constructing her narrative around her care to both parents with dementia, Ellen demonstrated a wealth of experience which could again have helped her in positioning herself as an authority on dementia care. Alternatively it is perhaps because Ellen was the only participant to have employed live-in care for her mum. As discussed in chapter 7 (sections 7.1.9 and 7.2.2), her role changed from caregiver, to care manager. She then became the authority over her mum’s care and this may have helped her portray a sense of certainty to the audience. By positioning herself as care manager, which aligns with a more professional approach to risk management, she produced accounts differently to the other adult children. By aligning to a professional position for her audience, she is able to convey more certainty in her risk narratives. Finch and Mason (1993) discuss a fine balance between independence and dependence and how taking responsibility for a family member may lead to a parent’s over-dependence on their adult children. The change in relationship experienced through dependency may cause a shift in power and control. Ellen’s role changed to care manager, and with it came an increase in control over how mum was cared for. Ellen worked with the care agency to ensure they provided the care that Ellen deemed most appropriate. With this higher level of control over the situation and the expectation that professional caregivers would do the right thing, Ellen may have been able to produce more certainty within her narrative. The rest of the adult children were unable to do so. As with the examples provided above (Kate and Lucie), there was much less certainty about how to provide care. This may also be due to this balance between dependency and independency and consequences surrounding control. For example, Kate talks about her parents seeking her advice on medications, but rejecting the idea of Kate taking control of medication management. Nor did Kate want to assume control, instead preferring her parents to maintain independence. In not taking control of such risks, Kate is left with uncertainty both in whether the risks are effectively managed but also in her decision to not take control.Douglas’ Cultural Theory suggests that people have a responsibility to adhere to their culture’s values, expectations and norms and not doing so would leave the person open to blame. The adult children demonstrated on a cultural level that they are expected to provide care or support to a parent with dementia. However, they were also able to effectively shift responsibility to others for example if another family member was portrayed as an appropriate caregiver. The shift of responsibility was further apparent should the adult child believe that the risk had not been managed appropriately or effectively. In such cases, the adult children were able to characterise this other person in a negative light and cast blame upon that person, as they did not comply with the adult child's values and expectations of how a risk should be managed. This was especially apparent in cases where the adult children considered that their own expectations aligned with societal norms, for example in the case of Susan who felt an injustice when her mother was allowed to continue driving by the DVLA. She drew on the societal norm of a safety-first approach (as demonstrated in Risk Society), with little narrative effort required, to convince the audience that her mother should not have continued driving.

9.1.6 Section summary: Responsibility discussion

Responsibility is a key aspect of risk in dementia care. Adult childrens' responsibility extends further than for their parent with dementia, to themselves and their parent without dementia thus adding to the challenging balancing act of providing care even if they are not named as primary caregiver. There are multiple characteristics and factors that impact upon societal expectations for the adult childrens' levels of responsibility. These are not only used by the adult children to position themselves at greater responsibility for their parents but also to provide justifiable reasons why they have reduced responsibility for their parents with dementia. Regardless of the motives for using characteristics to present themselves at more or less responsibility, the findings demonstrate that the idealistic notion of an adult child caregiver is rare. The level and/or nature of responsibility may change over time and are negotiated either over time or between family members. There is a need for HCPs to recognise that responsibility is not static and not the same for all adult children. Inherent within responsibility is accountability and risk of blame as evidenced by how the adult children constructed their narratives. This suggests that there is a clear societal expectation that the adult children who take responsibility for the care of their parents should also be held accountable for their actions. Thus burden associated with caring for a parent with dementia may in part be due to societal expectations that adult children should care and should do the right thing but there is definite uncertainty about what that right thing is (discussed further in the following sections and final chapter).

9.2 The search for advice: experts and society

The adult children were able to draw upon experts to add authority to their narratives thus demonstrating how society may expect a reliance on expert advice in managing risks. They also explicitly described perceived societal misunderstandings of dementia and impacts from the media.

9.2.1 Experts and authority

The adult children sometimes required HCPs to identify risks for them such as Susan with mum's driving, this is consistent with the literature (Clarke et al. 2011a). However, more often, the adult children spoke of personally recognising risks and deciding to act upon them with limited input from HCPs. This adds to the argument that increasingly, risk management in dementia care is the responsibility of the family caregivers through self-reflection, self-regulation and responsibilisation. However, there were opportunities for the adult children to argue their case for a management strategy through the use of HCPs as authority figures.

Within the adult children's narratives, the voice of authority was not solely that of HCPs, instead a number of other characters could be presented as authority figures. The ways in which the adult children used authority figures within their narratives was not often for risk identification, but typically for justification of the risks they identified themselves and also the management strategies they used (see chapter 8, section 8.4.1). The use of these authority figures demonstrates societal views of some characters as having authority, for example Susan's use of Trading Standards which the audience can identify as being the voice of authority on telephone systems, or the DVLA as the authority on driving assessments. The adult children may use these 'societal others' to justify their management strategies, as with Clarke (2000).

9.2.2 Societal (mis)understandings of dementia

Within their narratives the adult children used characterisations of other people to present as barriers to recognising risks and to managing risks. The parent with dementia could be positioned as a barrier to risk management, which is cited within the literature (Gilmour et al. 2003; Mitchell and Glendinning 2008; Clarke et al. 2010). However, these typically refer to the parent conducting covert activities despite family caregivers or HCPs' advice. In chapter 3, it was argued that this could be because the person with dementia perceives care and support as interference and a threat to their independence. Within the present study the parent with dementia could often be labelled as 'obstructive' to care and the adult child's decisions. The adult children did not defend their use of the word obstructive and rarely gave examples unless prompted to.In some cases it was possible for the adult children to overcome this barrier presented by the parent. A frequent example was that of personal care. The adult children required little narrative effort to justify their decisions to ensure their parent's personal care or hygiene, demonstrating that society would deem personal hygiene as more important than the parent's decisions. Society may also adhere to assumptions of dementia meaning lack of insight or capacity to make decisions (see chapter 3, sections 3.1 and 3.3.1) and therefore accepts that these decisions must be removed from the parent with dementia. The adult children were able to rely on societal understandings that the nature of dementia could cause a parent to be obstructive to care. They also rely on society's misinformed assumption that all people with dementia lack capacity. This therefore reduces the narrative effort the adult children required to portray their parents as a barrier to risk management. This was especially apparent in risk situations that society would expect to be managed for example, personal hygiene (section 8.4.2) or changing a cooker due to risk of carbon monoxide poisoning (section 8.3.1).

Within the literature there is discussion of stigma as having a negative impact upon adult children in particular and increase their experience of burden when providing care to a parent with dementia (Cecchin 2001; Kahn et al. 2014; Clayton et al. 2017; Greenwood et al. 2018). The adult children within the present study also made comments regarding people's lack of knowledge regarding dementia, for example Patricia's friend makes an unhelpful comment. This engages with societal understandings of dementia and how they have impacted negatively upon the adult children's own experiences of providing care. Thus demonstrating that societal understandings may be both inaccurate and unhelpful.

The adult children typically present as individual separate cases; as they were asked to draw upon their own experiences, this could be expected. However, there was evidence of some of the adult children positioning themselves within their culture of caregivers by drawing on the experiences of others in similar situations. This form of peer support is increasingly adopted by adult children in particular (Wasilewski et al. 2018). This in turn led the adult children to consider hypothetical risks surrounding dementia based on societal expectations. The example within the findings (chapter 6, section 6.2) is that of aggression. Aggression *can* be a symptom of dementia, however is often misunderstood by society who assume that all people with dementia *will* become aggressive. By noting concerns about aggression because they know people who have experienced it in their family members with dementia, the adult children demonstrate a potential societal misunderstanding of dementia which may cause undue concern in their own caregiving practice.

Lucie also considers social stereotypes that all people with dementia are old. She comments on her experience as being very different due to the young-onset of mum's dementia. She is perhaps alluding to the idea that society would expect all adult child caregivers to experience risk in dementia in the same way but that Lucie has experienced very different challenges due to her age at the time of mum's dementia onset.

Together these examples may demonstrate the adult children’s perception that society is still misinformed of dementia and explicitly demonstrate how these societal misunderstandings of dementia have impacted negatively on their experiences of caregiving.

9.2.3 Media impacts

The use of media examples of negative cases of care in residential care is cited by the adult children on occasion as a reason they maintain their parents in the community (chapter 8, section 8.1). This is consistent with findings from Hwang et al. (2017) who argued that media stories of cases of abuse in care homes exacerbated adult children’s reasoning to maintain their parents at home. Thus these findings demonstrate further the impacts society has on care decisions by adult children. Hwang et al. (2017) also notes that this maintenance of parents in the community can in turn lead to increased burden, therefore an argument that society needs to be more understanding and critical of the media they are presented with. A couple of adult children within the present study note their use of social media as a form of peer support or a research tool in aiding them to provide care to their parents. One participant noted that she had decided to remove herself from such social media platforms ‘for her own sanity’, demonstrating that some ‘peer support’ may in fact have negative effects on the adult child’s wellbeing and the care they provide.

Several of the adult children also make reference to the books they have read or used as research in providing care to their parents with dementia and how these have impacted upon their understandings and practice as caregivers. For example, Kate references Atul Gawande’s work in her understanding of QOL as different for different people, likewise Jodie draws on Contented Dementia (Oliver James) and ‘the SPECAL approach’ to providing care to a family member with dementia. Both note that these books have had a positive effect on the way they perceive their family member with dementia and how they provide care.

9.2.4 Section summary: Explicit impacts discussion

The adult children recognised a shared understanding of expert opinion with their audience and used this to add authority to their accounts. Thus demonstrating a shared societal expectation of experts as having an authority on dementia care and risk. They also demonstrated within their narratives themes of potential societal (mis)understandings surrounding dementia, for example that all people with dementia are considered aggressive, obstructive to care or are old. They note media (and social) contributions to their constructions of risk, however they regard these information sources with caution. More prominently they consider other people’s experiences as they align themselves culturally speaking with peers, choosing to utilise family, friends and other caregivers' experiences to construct their own experiences of risks. They perhaps value experts by experience moreso than, for example, HCPs who are experts through qualifications. Perhaps upon becoming a caregiver for a parent with dementia, adult children may attempt to align themselves with the culture of adult child caregiving. However, there may be challenges in doing so, for example, not all, or perhaps none, of their usual social circles will have experienced dementia caregiving first-hand. The adult children may then seek to find sources of advice and support (such as social media platforms) or alternatively rely on societal understandings and mainstream media that may be ill-informed. It is important then that appropriate advice or guidance should be provided to adult children as caregivers.

9.3 Not all risks are equal

Upon analysing the narratives for structure and characterisations, the adult children demonstrated how they required more narrative effort in order to construct non-safety risks and justify their decisions for favouring such risks over health/safety risks. This therefore demonstrates that the adult children perceive that society would be more likely to understand health/safety risks than non-safety risks.

9.3.1 The ultimate risk

The ultimate risk identified by participants was that of their parents moving to residential care. The adult children appeared to fear the notion of moving their parents to residential care which fed their decisions to continue to maintain their parents in the community for longer. This was impacted upon by financial concerns, fears of lack of stimulation within residential care, and concerns of abuse by residential care staff.

From a Governmentality perspective, it is easy to recognise how residential care was deemed as the ultimate risk. This may be due to the UK government attempts to reduce the economic burden of dementia care by holding family caregivers as responsible for their family members with dementia's care. With government policy and societal pressures to maintain care in the community for as long as possible (Pickard et al. 2007; Egdell 2013), perhaps the fear of their parents moving to residential care was in part due to societal pressure. This may be further reinforced through media coverage of inadequate care or abuse in residential care homes. A limitation of this insight is that the participants were currently providing care, that is their parents had not yet moved to residential care. However, one participant was included, whose parent had recently moved to residential care and one participant was included when her parent had paid live in care. In both cases, their roles may have altered to that of care manager, but they were both still actively involved in making sure the care their parents received remained in line with the adult child's expectations and values. The continuation of care roles and burdens (albeit altered) following employment of care (live-in or residential), and construction of narratives in which adult children are still accountable for their parents' care might suggest a governmentality that holes adult children responsible and accountable for their parents' care, regardless of social care provision.

9.3.2 Narrative effort to construct a risk

The risks the adult children chose to discuss were not unexpected in light of the literature. Similarly to previous findings, they identified both health/safety risks and non-safety risks (Clarke 2000; Gilmour et al. 2003; Dickins et al. 2018). However the narrative effort the adult children required to construct a non-safety risk in comparison to a health/safety risk was greater, thus demonstrating the potential societal view that health/safety risks are more important, or at least more recognisable and less ethically-controversial. This is similar to Clarke et al. (2011a) and Clarke and Mantle (2016) where care staff recognised that understanding health/safety risks was easier than non-safety risks and were therefore easier to manage. The adult children in the present study recognised the differences between health/safety and non-safety risks as evidenced by their differing constructions. Further, when discussing a safety risk, a consideration of non-safety risks may be presented as secondary to the primary risk of health/safety. These required minimal narrative effort because the audience would potentially recognise the health/safety risk as paramount and therefore a small reflection on the non-safety risk was all that was necessary.

The adult children typically constructed a risk through the defining incident or building concerns plots (chapter 8, sections 8.3.1 and 8.3.2 respectively). Through these plots the audience are able to interpret a form of cause and effect in terms of management strategy use. This is not dissimilar from the discussions of two of the models in chapter 3, section 3.2.2: MacLeod and Stadnyk (2015)'s model of HCPs' risk assessments for older people and Cott and Tierney (2013)'s study of family caregivers of people with MCI. Both studies describe the use of 'red flags' to highlight a risk that required management. In the present study, the adult children used defining incidents to demonstrate a risk that required management. MacLeod and Stadnyk (2015) also describe 'yellow flags' as potential risks that required monitoring until they increased to being a 'red flag'. Cott and Tierney (2013) similarly found that 'red flags' could be dramatic – requiring immediate attention – but also gradual – a gradual recognition that the risk required action. The participants in the present study demonstrated a monitoring process of gradually recognising that a risk required action through the building concerns plot.

However, the adult children in the present study also used this process of gradually identifying concerns to justify a delayed action in response to a risk. Thus the building of concerns or identification of red or yellow flags is not just a cognitive process the adult children go through independently of society. Instead, the adult children use it to justify their inaction to their audience who may perceive that a particular risk should have been acted upon sooner. The process the adult children go through is therefore one not only of risk-identification, but also of justifiable defence against society who may consider that they should have acted sooner. The need to justify their decisions may be in part due to the adult children being carers of parents with dementia and not MCI, whereby dementia has greater assumptions of requiring care and management. Alternatively, this finding may have been due to the methodology and methods of the present study. Cott and Tierney (2013) used grounded theory to identify the processes through which family caregivers recognised and acted upon risks, whereas the present study used narrative inquiry to understand how adult children constructed risks for their audience.

The adult children in the present study (except one) never reached the final stage in Cott and Tierney (2013)'s model where continued unacceptable risk led to residential care. In part this is due to the participant inclusion criteria as those providing care in the community, not in residential care. They therefore either have to justify their decision to not act upon the risk to return it to an acceptable level, or they have to ask the audience to recognise that there is nothing more to be done.

9.3.3 Dilemmas in balancing health/safety and non-safety

The adult children frequently balanced health/safety risk outcomes against non-safety outcomes, often favouring the non-safety outcomes. This is similar to the family caregiving literature for caregivers of people with dementia, MCI or older people (Clarke 2000; Robinson et al. 2007; Cott and Tierney 2013; Dickins et al. 2018). The adult children required more narrative effort to justify their decisions to act in favour of non-safety outcomes over and above health/safety outcomes. They typically emphasised that distress was a more severe risk than for example, missing a health appointment, but then had to provide justification of this decision. Therefore demonstrating the societal expectation of a safety-first approach and that health/safety risks should be considered as more important. This may in part be a demonstration of risk society, whereby society focuses on negative consequences of risks and an expectation to minimise health risks due to public health messages, instead of recognising that some risks are worth taking for the wellbeing of a person with dementia despite the potential consequences.

The safety-first discourse is long-standing through Risk Society Theory and further encouraged through governmentality regulation and serveillance. The adult children recognised this throughout their narratives and often used this discourse to their advantage when arguing the appropriateness of their management strategies. However, the cultural perspective of the adult children was that both non-safety and health/safety risks were equally important which may give rise to a discourse of non-safety as important. Within the current policies, guidance and education provided at a societal level (through various charities' movements and initiatives), the non-safety aspects of dementia are increasingly highlighted. With time, this may give way to a new societal understanding of dementia and a balance in recognising and expecting management of both health/safety risks and non-safety risks. Which, in turn, may alleviate some adult children's perceived pressure from society to maintain a safety-first approach to risk management.

To balance, another reason for the necessity for more narrative effort when favouring non-safety risks, there may also be another dimension at play when managing non-safety risks. That is, the moral and ethical complexity of decision-making in the face of risk. The example from Mary (chapter 8, section 8.5.2), demonstrates two sides to the argument regarding isolation which Mary poses as 'mum's reality' and 'the reality'. The argument within this account is not of balancing safety in comparison to non-safety, but that of recognising and managing a non-safety risk in its own right. Where the audience may not acknowledge or prioritise non-safety risks, Mary must first argue that there is a risk. The complexity of the situation is mirrored in the complexity of Mary's account of presenting a counter-argument and her argument that isolation is a risk. In doing so, Mary must then justify her management strategies. Finch and Mason (1993) found that society expects adult children to provide care for their parents, but are less certain about how they should provide care. Mary's account demonstrate that even if society does not immediately recognise the risk, understand the complexities of that risk, or have an expectation of how that risk might be managed, the expectation that Mary is responsible and accountable still remains.

9.3.4 Changing risks

In the present study, the adult children demonstrated on multiple occasions how risks changed through the progression of their parent's dementia, and with it their management styles required change also. This is similar to the findings of Berry et al. (2015) whereby their family caregiver participants moved through several transitions in how to manage care surrounding functional decline for their family members with dementia. In the first stage they support family members to make their own decisions much like with Suzie's mum who was able to make a decision for herself initially. In the second stage, the family member's awareness of their deficits is 'spotty' and therefore supervision increases, again this was apparent with a number of the adult children within the present study who recognised that their involvement needed to increase. Within this stage, Berry et al. (2015) note that the family caregivers considered barriers to risk management including the family member with dementia. Within the present study, the adult children noted a number of different barriers to not only recognising risks but also managing risk. The final stage in the model involved more caregiver management as the family member with dementia lost insight into their condition and the risks associated. Berry et al. (2015) note that deceptive management strategies would then increase in order to reduce distress for the family member with dementia. Again, several of the adult children in the present study discuss deceit as a strategy or used their parents' lack of awareness of their conditions to their advantage in managing the risks. Similar to the findings of Berry et al. (2015) the adult children recognise that their management styles and strategies must change as the risks changed through the course of dementia.

9.3.5 Section summary: Risks discussion

An ultimate risk throughout the adult childrens' narratives was that of moving their parents to residential care. They also constructed both health/safety risks and non-safety risks which was not unexpected in light of the literature. However, the amount of narrative effort required to construct an non-safety risk was typically higher than that of health/safety risks thus demonstrating that society would find health/safety risks more familiar. They also demonstrated how risk changes through the course of dementia and therefore management strategies required altering to maintain risk management. The adult children all recognised that non-safety risks were just as important as health/safety risks but through the structures of their accounts demonstrated that they considered that this did not align with societal expectations. In some cases, the adult children were able to use their cultural values to push back against societal expectations and defiantly demonstrate that they recognised that society may not understand their decisions, but that they maintained their decisions as appropriate. Although they recognise the dominant governmentality of safety-first, they place importance on their cultural values. That they have to argue so defiantly, demonstrates the grid/group argument of Douglas (2004). That is adult children may have smaller numbers (low group) when compared to wider society but push to demonstrate high authority as experts by experience (high grid).

Typically however, the narrative effort required for non-safety risks over health/safety risks demonstrates the complexity of decision-making in risk management. Where society may expect the adult children to do something, but may lack certainty about what that thing should be, the adult children may be faced with increasingly complex dilemmas without guidance to justify what is the right thing to do. Regardless, they may be able to justify these decisions and, in some more complex dilemmas, demonstrate a recognition of two sides to the argument. Again through

Douglas' grid/group, the adult children demonstrate high authority by acknowledging several sides to an argument that perhaps society may not consider. In terms of narrative structure, this is achieved through presenting an argument that society may expect, followed by the counter-argument with evidence that aims to justify a decision made that society may not have expected but could still understand and accept. The adult children therefore recognise and acknowledge the dominant governmentality of safety over non-safety, and organise their narratives as such by presenting safety aspects first. They then construct their counter-argument by drawing on cultural values to demonstrate their authority on the matter, and also through narrative techniques, for example, by asking the audience what they would do in that position.

9.4 Summary: Discussion

This chapter has discussed each of the key findings independently within the context of the literature. However, the findings are not entirely independent of each other; through the theories introduced in chapter 2 and discussed throughout chapters 3 and 4, it is possible to draw together the findings to consider societal expectations and their impacts upon adult child caregivers of parents with dementia.

Responsibility in the face of risk is abundant and accountability is inherent. Self-regulation (governmentality) extends also to the regulation of one's dependents. The adult children are therefore expected not only to take responsibility for their parents but also effectively manage their risks. The problem with this is the line between independence and dependence and balancing regulation without taking control. As with Finch and Mason (1993), the expectation from society is that adult children will take responsibility for their parents, with this comes the pressure of accountability. In presenting themselves as responsible for their parents with dementia, the adult children leave themselves at risk of societal judgment and blame.

Beck argues that through modernity within Risk Society, people are becoming increasingly mistrusting of experts and therefore through self-reflexivity are searching for alternative sources of information (Beck 2013). The findings presented here demonstrate on the one hand that they look for sources of information (whether through the media, social media or popular literature) but they view these with caution. On the other hand, they use experts to add authority to their accounts, thus suggesting that expert opinion still has a place in society and experts are a part of the apparatus of government and control (governmentality). Through Cultural Theory it is possible to recognise that adult children are their own culture, and when seeking information and advice may be more reliant on peer-support and experiences.

That society may recognise the importance of health/safety risks as more important than non-safety risks may be parallel to Risk Society theory where there is a safety-first expectation. However, as a separate culture, adult children recognise the importance of both and therefore aim to justify decisions associated with non-safety risks. There is therefore perhaps a tension between their own cultural norms (derived from experience) and their perceived expectations from society. By drawing on all three sociocultural theories it has been possible to recognise the dissonance between societal expectations and the adult children's cultural values, and consider how this is reflected in the participants' narratives. The adult children recognise and acknowledge the dominant Risk Society theory notion and governmentality of safety over non-safety. However, through constructing their narratives to demonstrate their expertise by experience (higher grid), they are able to claim authority on risk management for their parents. In doing so, however, they open themselves up to blame where wider society (higher group) may disagree. This in turn can cause a tension between adhering to the expectations of society and adhering to their cultural values as evidenced by the adult childrens' narrative constructions. The dissonance between societal expectations and the cultural norms of the adult children may lead to uncertainty and increased burden. Burden as discussed by Savundranayagam et al. (2011) is multi-dimensional. The authors describe differences between spouses and adult children in terms of relationship burden and stress burden. The present study demonstrates an additional dimension to burden: pressure from society. Perhaps the burden experienced by adult children is not entirely due to the challenges of managing risks for their parents with dementia, but also from societal expectations and responsibilisation. As promised earlier in section 9.1.4, I would like to return to the question posed by Finch & Mason (1990) as to whether the two consequences (work out what to do and societal acceptance) occur consecutively or in parallel. Based on the findings from the present study, I believe the answer is both. The adult children must, to a certain extent act independently from society in that they work out how to act on their own. They consider factors that society may not expect (such as non-safety). At the same time the adult children are aware – whether consciously or sub-consciously - of the expectations of society (as demonstrated through their justifications, for example when favouring non-safety over health/safety risks). Due to the methodology employed within this study, it is not possible to understand exactly what happens in the moment an adult child makes their decisions regarding a risk. However, the findings demonstrate the participants' awareness of societal expectations which I believe are likely to have an impact in that moment.

The next chapter will highlight the conclusions, limitations, recommendations for future research and implications for practice.

Chapter 10: Conclusions, limitations and implications

The aim of the study was to understand how adult children may be impacted by cultural norms and societal expectations when managing risks for their parents with dementia. The study therefore employed narrative inquiry to explore how adult children constructed narratives of risk for their audience – in this case the wider society of which they are a part. This final chapter draws conclusions from the findings, addresses the limitations of the study and provides suggestions for future research and implications for practice.

10.1 Conclusions

. The findings demonstrate the importance of responsibility in managing risk for a parent with dementia. The adult children could position themselves at varying levels of responsibility for their parents through drawing on societal expectations of legitimate reasons for reducing care. Accountability is inherent within responsibility and therefore the adult children felt a requirement to justify their decisions about managing risks. They are able to use their perceptions of societal (mis)understandings of dementia, stereotypes and authority figures to aid in their justifications. When constructing risks, the adult children use more narrative effort to construct a non-safety risk in comparison to health/safety risks. This demonstrates that they perceive society to be more understanding and accepting of health/safety risks and health/safety risk management, but less so about non-safety risks.

The originality of this study was in demonstrating how it may be possible to explore the impact of societal expectations on the construction of risk for parents with dementia through the novel use of narrative inquiry. The findings of similar elaborative and restricted uses of narrative structures and elements to construct risks and justify management strategies for an audience (society), are concordant with Bernstein's theory of language coding. The narrative effort required by the adult children to construct their risk accounts demonstrated that which they perceived to be a shared understanding (or not) with society. This methodology may require further practical application to demonstrate its effectiveness in exploring societal expectations and impacts.

A further original contribution within this thesis is through applying three distinct sociocultural theories of risk to theorie societal expectations of responsibility, risk and risk management in dementia care, in regards to adult children of parents with dementia. It has been possible to consider that overarching societal expectations of risk and risk management in dementia care may be engrained through the dominant discourse of safety-first as in Risk Society Theory, and enforced through governmentality regulation and surveillance. However, the potential for the adult children to counter this dominant discourse stems from their cultural values and expertise by experience (low group/high grid) through which they are able to argue and justify their decisions to oppose societal expectations of health/safety over non-safety as evidenced within their narratives. Such dissonance between societal expectations and adult childrens' cultural values could lead to unnecessary burden as adult children are required to both determine how to manage risks and justify their decisions to society. The adult children may draw upon their identity of experts byb experience as a coping strategy in the face of such burden. Additionally, providing a voice to experts by experiences, may help change societal attitudes. Therefore a theory of risk is proposed that cultural values can provide a means through which it is possible to counter dominant safety-first discourses prevanlent within risk society and reinforced through governance. However, where carers are held accountable, they require considereable narrative effort to justify prioritising non-safety over safety risks.

10.2 Limitations

The findings, although theoretically generalisable to perceived societal expectations are not without their limits. These are addressed alongside reflections on the project.

This study is limited to adult children living within England only. The study was conducted exclusively with adult children and therefore no comparisons can be drawn to either other countries' societal expectations nor to how adult children experience these expectations in comparison to spousal caregivers. The sample of adult children had limited cultural diversity in terms of ethnicity or religion, again this does not allow for comparisons between different ethnic groups. However, these limits may also be a benefit when exploring a topic as large as societal expectations and understandings, it was important to draw boundaries in order to explore how perceived societal expectations impact within a particular cultural group.

The sample is small, in keeping with case study approach and qualitative research in general. In regards to a case study approach, it could be argued that the sample of 12 was in fact too many to afford a full understanding of the participants' narratives as a whole and the sum of its parts. That is in providing examples from the participants' narratives, the length of the quotations was a challenge to manage and the data may be considered unwieldy due to the analysis approach adopted. Likewise, the quotations may also demonstrate examples of multiple arguments which may have easily led to tangents within the main points I was trying to make. However, through a sample of 12, and maintaining a focus on the key research questions, theoretical generalisations were possible.

Most of the perceived societal expectations identified in this study are discussed elsewhere throughout this thesis. However, there was one expectation that I myself had when recruiting participants to this study that I found was not the case and therefore wanted to include it despite not having discussed it within my literature review. The present study intended to exclude participants whose parents had moved to residential care, because the expectation was that they would be experiencing less burden at the time of the interviews and perhaps remember their time caring for their parent with dementia differently. One participant (Jodie) had very recently moved their parent with dementia to residential care and was still providing care to a parent that she suspected was having problems with his memory. Jodie's narratives came as a surprise, because when discussing her current care for her parent, she described multiple challenges surrounding her new role in managing the care mum received in residential care. Thus perhaps suggesting that when a parent moves to residential care, burden does not decrease, instead the burdens of care and/or responsibility change with the new role. Equally, the study did include those adult children who had paid care for their parents in the community. These again could have been considered to have a reduction in responsibility and burden, however, again the adult children demonstrated that there was a change of roles and with it came different responsibilities and burdens. I believe this demonstrates the sheer complexity in the care adult children provide to their parents with dementia, it demonstrated the importance of recognising the rigidity of inclusion/exclusion criteria within research.

It is also important to recognise the limits of narrative inquiry. That is the search is not for truth; the use of narrative elements, such as plot and characterisations, are all produced from the point of view of the author (the adult child) and with an audience (the researcher and society) in mind. The value of such an approach is in recognising the arguments the adult children are trying to make and that these are due to their perceived expectations of their audience. A potential limitation of such an approach is that I was the audience in all interviews. Therefore, I was a factor in how and why participants produced their narratives the way they did. I highlighted in chapter 5, section 5.6 my reflections on how I might have impacted on the study, and believe that the most important consideration related to how the adult children positioned me as their audience. It is possible that they would have constructed different narratives for someone else. However, as discussed (chapter 5, section 5.6), whether they considered me a PhD student researcher or student, considered my age as similar or not to their own, noted that the study was part of the Faculty of Health Sciences or not, their use of narrative structures and elements across all twelve cases remained consistent, which suggests that they positioned me as not having a shared understanding, and part of wider society.

My interview style also changed over the course of interviewing the participants. Initially, I felt it was important to reiterate key points of the interview as the adult children were talking however, this resulted in a lot of repetition and often reconstructions on the part of the adult children who attempted to clarify points I may have incorrectly inferred. I soon realised that the importance of the data was not what was being said, but how and why. In the end the adult children all used similar narrative elements, and used them in similar ways to argue their points which perhaps reduces this limitation as the findings were theoretically generalisable.

One final, but important, limitation of the methodology used within this study is that the narratives produced by the adult children are from their point of view alone. The societal understandings and expectations are the adult childrens' perceptions and may not be used as evidence that all society understands dementia, dementia care and risk in dementia care in this way. However, the adult children all positioned themselves in relation to similar societal expectations and understandings in producing their narratives. Their perceptions of societal expectations shaped their narratives and therefore may shape the care they believe society would expect from them for their parents with dementia. The findings therefore demonstrate the pressures (whether perceived or real) that adult children experienced, which may be one reason for increased burden in providing care to their parents.

10.3 Future directions for research

Within this thesis, I have highlighted some of the limitations of this study. The study did not aim to compare between spouses and adult children, nor did it aim to address cultural diversity in the sense of, for example: ethnicity, religion or gender. However, in light of the present findings, these diversities may have implications for the narratives provided by adult children and may be addressed through further studies.

In light of relatively recent social movements to engage the public in dementia awareness and understandings (such as the Dementia Friends campaign), it would be interesting to see if this has an effect on producing a more supportive and understanding society for adult children as caregivers. Likewise as non-safety risk narratives become more prominent, there may be a shift in expectations in society which could alleviate perceived societal pressures and reduce burden.

Future research may endeavour to explore how true the societal expectations, that the adult children perceived within this study, are. Perhaps large surveys of society exploring understandings of dementia and expectations of adult children's risk management for their parents with dementia (such as in Finch and Mason (1990)) may shed light on whether the findings in the present study are adult childrens' perceptions only.

10.4 Implications for practice

HCPs may be able to provide better guidance to adult children according to their individual situations/circumstances such as distance to parents, number of siblings, having their own children, and working lives. For example, using skype technologies may help to include adult children who may not always be able to attend face-to-face consultations between HCPs and their parents with dementia.

The “ideal scenario” of an adult daughter living nearby with reduced responsibilities (such as retired, adult children themselves or no children) is rare. Likewise even when a spouse is named primary caregiver, there will likely be support from adult children who not only have a level of responsibility to their parent with dementia, but also the parent without. In recognising these two important aspects of adult childrens’ practice of dementia care in the community, it may be important for support and education to be provided to the whole family unit. That is not just named primary caregivers and not just family caregivers who are able to attend appointments with the person with dementia. Indeed there are a number of resources that are available to anyone who is experiencing dementia (the person with dementia and their family members) through dementia advisory services and national helplines (such as Alzheimer’s Society) to name a few. However, through the evidence provided within this study, I suspect that some adult children are not aware of such services.

The adult children’s search for supportive resources may be a risky path if they focus too much on media and social media supports because these can often be embroiled with inaccurate or unhelpful information (such as examples of distressing experiences). Instead, HCPs may guide adult children towards such resources as popular literature which may prove to be a more supportive guidance. Alternatively, education packages based on popular literature and research literature may prove effective in reducing burdens of uncertainty and societal pressures by uniting adult children together as a culture and increasing their confidence in the face of risk management for their parents with dementia. Likewise these educational packages may extend to friendship networks so that adult children can remain well supported by those with whom they associate.

Where adult children are at risk of heightened burden due to perceived societal expectations and pressures, there needs to be a greater societal education that non-safety risks are as important as health/safety risks. This would mark a societal shift and may take years to fully come to fruition; however the process for this is already in motion. From a governmentality perspective, education alone may not be entirely effective when the dominance of safety risks is part of the apparatus of government, public health and healthcare services. Therefore society is all responsible and held accountable for health/safety risks. However, through reducing the burdens created by lack of societal understandings, it may be possible to reduce fear of blame, guilt and uncertainty for adult child caregivers therefore enabling them to continue providing care for longer.

For the adult children, it is important for HCPs to work to reduce the experience of societal pressures and expectations. However, there may be challenges in power between HCPs and family caregivers and over-regulation through a governmentality approach may cause adult children to dismiss expert advice. As Finch and Mason (1993) suggest, society is willing to accept guidance and advice, but less willing to accept hard and fast rules. The challenge then for HCPs is that they are a recognised expert authority on dementia; therefore the support they provide to adult children may be seen as an authority enforcing rules. To reduce burdens surrounding risk management, there should be more support and guidance in suggestions of how to manage risks, but these suggestions should adhere to the values and expectations of the adult children as a culture instead of potential wider societal expectations. For example, guidance should allow for balance between health/safety risks and non-safety risks in order to demonstrate to adult children that it is acceptable and perhaps the norm to manage both and that they should not fear wanting to address both.

10.5 Final summary and conclusions

A key strength and original contribution from this study is the use of narrative inquiry to explore how the adult children constructed risks for an audience, as part of wider society, through narrative effort. Therefore, how the adult children constructed their narratives for society allows an interpretation of how the adult children perceive societal expectations and understandings.

There is an expectation that adult children should be held responsible and therefore accountable for their parents with dementia in the face of risk. This is demonstrated through the participants' narratives in both how they construct a risk and how they were required to justify their actions. Their narratives demonstrated uncertainty about how they should effectively and appropriately manage risks for their parents with dementia. However, through their narratives, the adult children demonstrated a requirement for more narrative effort when constructing a non-safety risk in comparison to health/safety risks. Thus suggesting that the societal expectation is that of a dominant safety-first discourse. However, the adult children's culture recognises both health/safety and non-safety risks as equally important. The perceived dissonance between societal expectations and adult children's cultural values may increase pressures and lead to additional burden in risk management. With growing policy and societal pressures to maintain parents with dementia in the community, adult child caregivers need to feel that how they manage risks is acceptable. This is turn may aid in reducing associated burdens and enable them to provide care for longer.

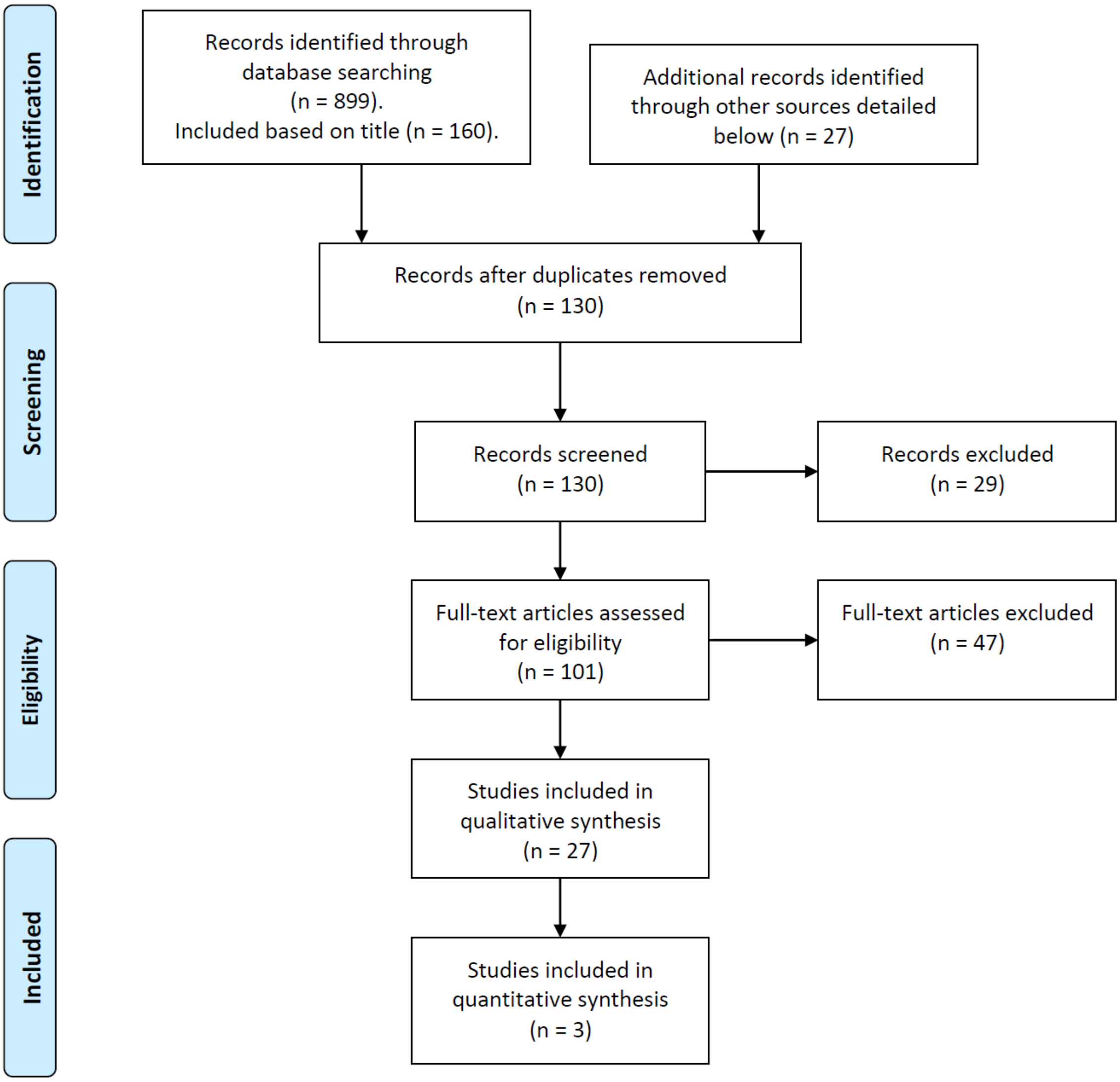
Appendices

Appendix A Literature review search strategy

The search for literature occurred in several stages and through differing strategies.

Search 1: Risk in dementia care

Search terms: “risk manage*” AND dementia OR Alzheimer* Synonyms that were also considered included safe* but this would then include vast amounts of literature pertaining to the safety of drugs trials. The word risk* alone would also increase the volume of literature pertaining to *risk of* dementia, therefore the phrase “risk manage*” was used.



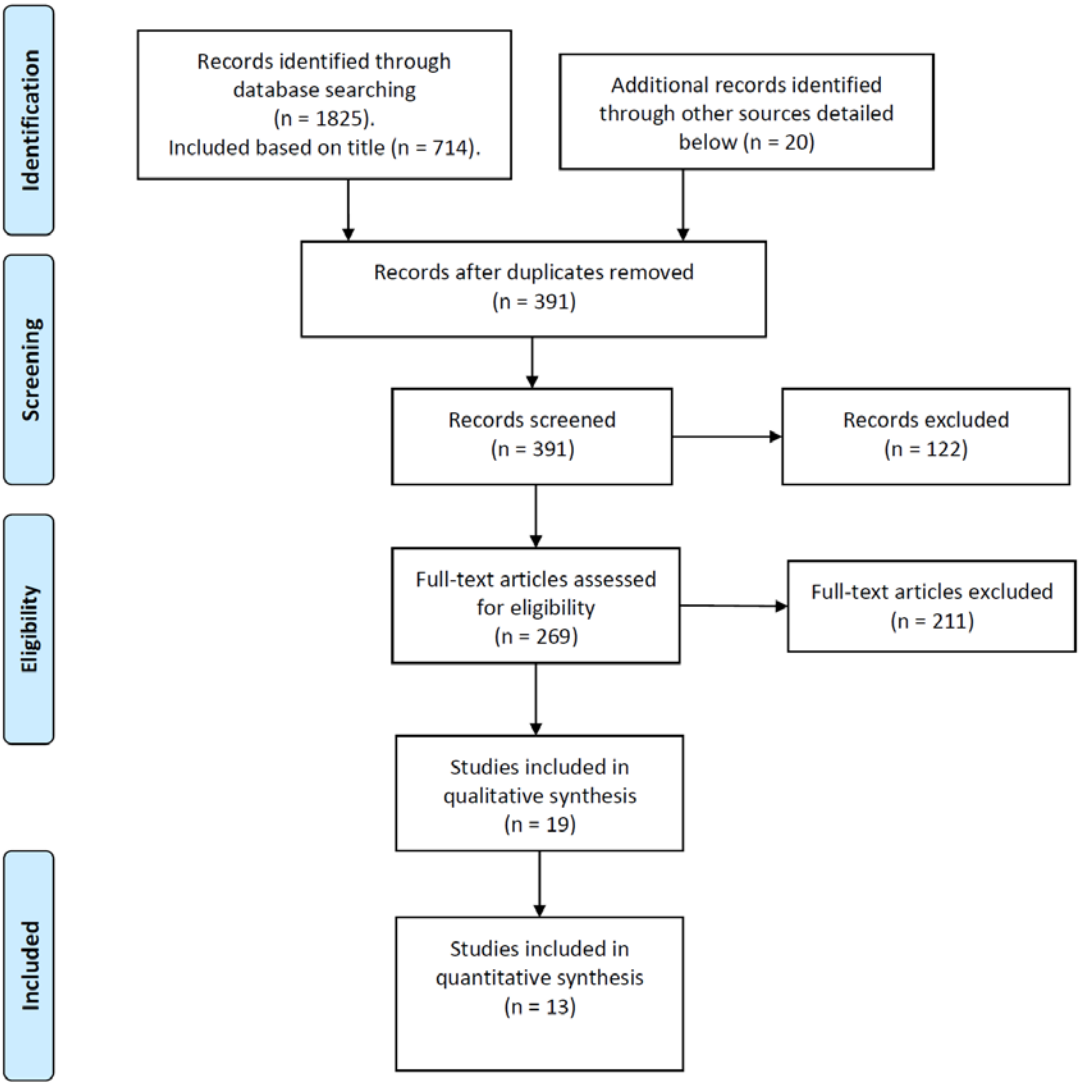
Reasons for exclusion were: inpatient/residential setting, risk of comorbidities, risk of dementia, not dementia-specific, not based in Western population, not related to risk, or interventions.

Search 2: Adult children as caregivers

Appendix A

Keywords: “adult child*” AND dementia OR Alzheimer*

This provided a starting point for attempting to learn as much as possible about this population of caregivers in dementia care. Additional synonyms that could also have been included son OR daughter, produced over 31,000 results. Where the purpose of this literature review was to start to understand the scope of literature regarding adult children as caregivers for their parents with dementia, the above search highlighted the key themes in the literature and therefore no further search with additional synonyms was conducted.



Reasons for exclusion included: not dementia-specific, interventions, not adult children, not in Western population, inpatient/residential setting, or risk of dementia.

Other sources

Other sources of literature included: searching reference lists from key papers, searching cited lists of key papers, searching reference lists of key authors, searching for relevant papers in the journal Health, Risk and Society, finding relevant policies and government or third sector reports, and identifying best-seller popular literature.

Search 3: Risk as a general concept

The search for literature, books and theories pertaining to risk as a general topic did not stem from search strategies as with the above two topics.

Initial attempts to source literature pertaining to risk as a general concept cast a wide net in my naïve attempts to begin to understand risk a lot of which were not included within this final thesis. Those that were referenced included a book by Chicken and Posner (1998) titled The Philosophy of Risk, and Fischoff et al (1984) paper titled Defining Risk.

A hand search of the journal Health, Risk and Society, provided an understanding of various theories and models of risk identification and decision-making which could be applied to various health contexts.

Such papers as Mitchell and Glendinning (2008) aided in identifying key sociocultural theories (Risk Society Theory, governmentality and Cultural Theory) and risk theorists or authors (such as Deborah Lupton).

In addition to reading papers and books from the original key authors of sociocultural theories such as Beck, Foucault and Douglas, I sought papers and books which provided critiques of the original theories. For example, Ulrich Beck: A critical introduction to the risk society by Mythen (2004).

Search 4: responsibility and uncertainty

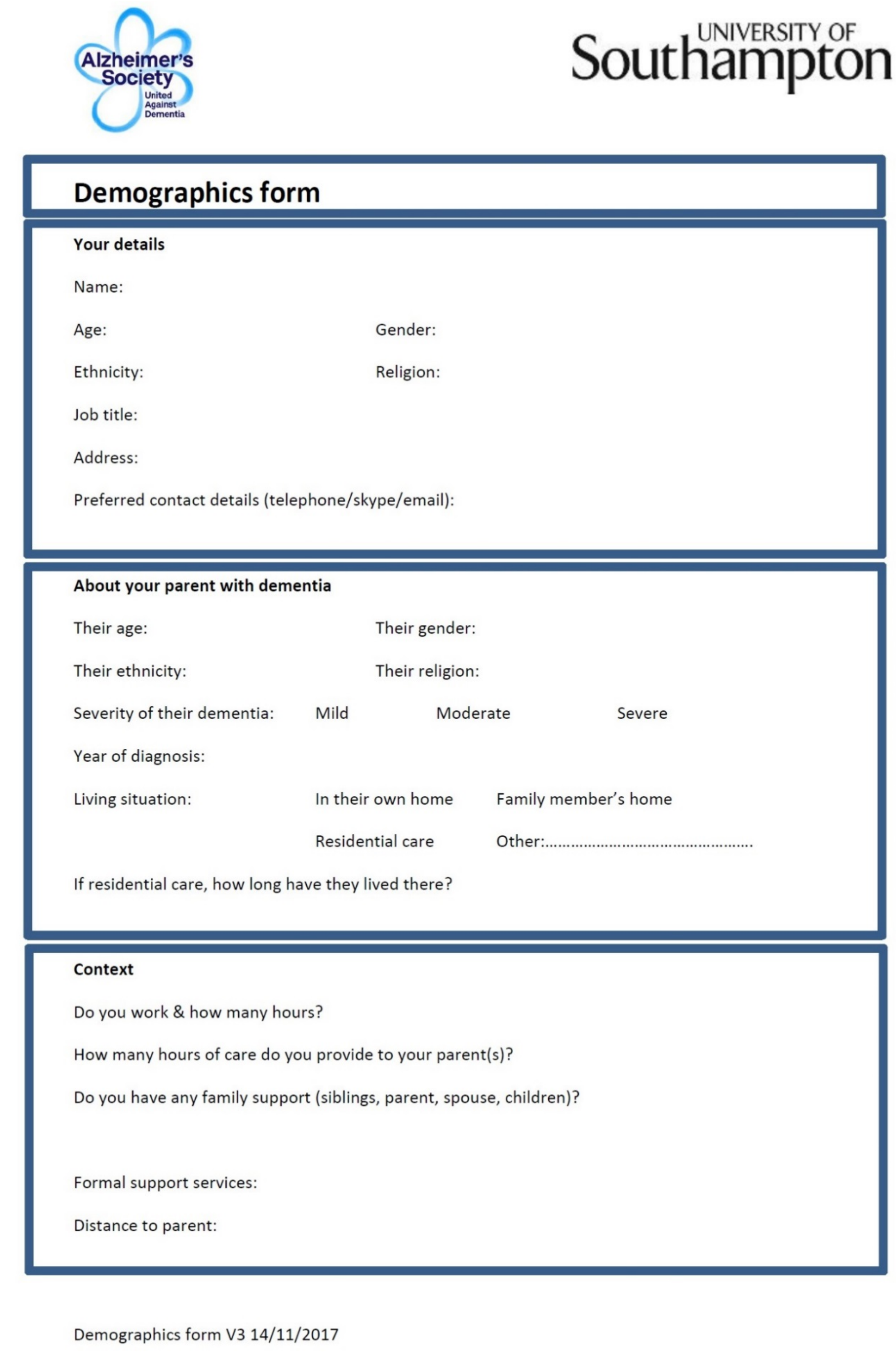
Upon analysing my data, the concepts of responsibility and uncertainty became increasingly important to understanding my findings. As such, I revisited the literature I hade previously identified through the above search strategies. As these concepts of responsibility and uncertainty are so relevant to risk, risk in dementia care and adult children as caregivers, there were many papers that were directly relevant. Prior to analysing my data and concluding my findings, these papers may have only been discussed to a limited extent, but following data analysis, more extended writing about these papers was required. For example, the study by Franks et al (2003) was found in the original literature search strategy (2 – adult children as caregivers). In an early draft of my thesis prior to data analysis, reference to Franks et al (2003) would have served the purpose of recognising a motivation for adult children to provide care to their parents with dementia was due to obligation. Following data analysis and recognising the processes through which the adult children within my study presented themselves as more or less responsible for care than other characters within their narratives, a further read and discussion of Franks et al (2003) aided in understanding my findings further. Therefore a larger section surrounding the paper by Franks et al (2003) was required in both the literature review and the discussion chapters of my thesis.

I also conducted a second hand search of the journal Health, Risk and Society to identify papers that may pertain to responsibility or uncertainty but not necessarily dementia. For example, Zinn (2008) paper titled Heading into the unknown: Everyday strategies for managing risk and uncertainty. This paper was not related to dementia care, but risks as a general concept.

Additionally, some key authors were suggested by my supervisory team and colleagues for example, the work of Finch and Mason. I may not have found this work through search strategies as above, but this work proved paramount to my understanding of my findings.

Again, further papers were identified through references lists and citation lists.

Appendix B Demographics form



Alzheimer's Society United Against Dementia

UNIVERSITY OF Southampton

Demographics form

Your details

Name:

Age: Gender:

Ethnicity: Religion:

Job title:

Address:

Preferred contact details (telephone/skype/email):

About your parent with dementia

Their age: Their gender:

Their ethnicity: Their religion:

Severity of their dementia: Mild Moderate Severe

Year of diagnosis:

Living situation: In their own home Family member's home

Residential care Other:…………………………………………

If residential care, how long have they lived there?

Context

Do you work & how many hours?

How many hours of care do you provide to your parent(s)?

Do you have any family support (siblings, parent, spouse, children)?

Formal support services:

Distance to parent:

Demographics form V3 14/11/2017

Appendix C Recruitment poster

Alzheimer's Society United Against Dementia

UNIVERSITY OF Southampton

How do you keep mum or dad safe when they have dementia?

Why? There are currently limited resources available to specifically help sons & daughters with safety for their parents with dementia.

Who? Anyone over the age of 18 years who provide support to their parent(s) with dementia.

What? You will be asked to write about your experiences of risk and safety for your parents with dementia and then discuss those accounts with the researcher.

How? Interviews can either be face to face or over Skype.

Contact:

Miss Amelia Abbott (PhD student)
aca1g15@soton.ac.uk
07794304914

Supervisors: Dr. Lucy Brindle; Dr. Rosalind Willis

Recruitment Poster V4 16/05/2017

Appendix D Participant demographics

	Adult child				Parent with dementia						Situation		
Pseudonym	Relationship	Age	Ethnicity	Religion	Relationship	Age	Ethnicity	Religion	Severity of dementia	Time since diagnosis	Work hours (per week)	Hours of care (per week)	Distance to parent
Mary	Daughter-in-law	51-60	White Caucasian	Church of England	Mother-in-law	81-90	White Caucasian	Church of England	Moderate	2 years	<10	10	<10
Carol	Daughter	51-60	White Caucasian	None	Father	81-90	White Caucasian	Church of England	Severe	5 years	*	14	<10
Ellen	Daughter	61-70	White Caucasian	Church of England	Mother	91-100	White Caucasian	Church of England	Severe	9 years	0	7	Live together
Kate	Daughter	51-60	White Caucasian	None	Father	81-90	White Caucasian	None	Mild	5 years	35+	*	>100
Suzie	Daughter	31-40	White Caucasian	Christian	Mother	51-60	White Caucasian	Christian	Moderate	4 years	37.5	6	<10
Susan	Daughter	51-60	White Caucasian	None	Mother	81-90	White Caucasian	Church of England	Moderate	3 years	22	10	<10
Jack	Son	31-40	White British	Christian	Mother	61-70	White British	Christian	Severe	3 years	0	*	Live together
Lucie	Daughter	18-30	White Caucasian	None	Mother	51-60	White Caucasian	Christian	Moderate	2 years	45	10	*
Roger	Son	41-50	White Caucasian	Church of England	Mother	71-80	White Caucasian	Church of England	Severe	2 years	45	7	21-30
Patricia	Daughter	31-40	White Irish/British	Roman Catholic (lapsed)	Mother	61-70	White Irish	Roman Catholic	Moderate	4 years	50+	12	<10
Jodie	Daughter	41-50	White Caucasian	Church of England	Mother	81-90	White Caucasian	Church of England	Moderate	2 years	35	*	21-30
George	Son	51-60	White Caucasian	Quaker	Father	81-90	White Caucasian	Methodist	Severe	2 years	5	*	>100

*Asterix marks where a participant did not provide an answer

Appendix E Case studies

In line with case study approach, the following paragraphs offer descriptions of each of the adult children paying attention to context, situation, demographics, characteristics and observations from the participants' narratives. The descriptions are purposefully limited to preserve the anonymity of the participants. They serve to offer insights that are considered important in highlighting differences and similarities between the cases and as context to data analysis and findings. The cases are presented here in order of recruitment.

Mary

Mary was the only daughter-in-law to participate in the project. However, as the participants were self-selecting by responding to the study poster asking for sons and daughters of parents with dementia, she deemed herself to be appropriate for the study. She talks of her mother-in-law as 'mum' and discussed how because her parents had passed away quite young, she has always felt that her husband's parents were like a mother and father to her. This, as well as the childcare her husband's parents had provided for Mary's children when they were young, are part of the reasons Mary provides care to mum as a form of reciprocity. A further reason Mary considers that she provides care to mum is that of distance. Although her husband has siblings, they all live at longer distances from mum whereas Mary and her husband live locally. Mary provides a lot of the regular day-to-day care to mum and has employed paid care for an hour a day to support mum with personal care. Mary does however recognise the limits to her responsibility in that her husband and his brother have POA for mum's health and finances and therefore her overall care. Despite Mary's closeness to her mother-in-law and talking of her as 'mum', she reflects on her ability to remain slightly more detached than her husband because of being a daughter-in-law. Both Mary and her husband had previously worked as healthcare professionals, and when it comes to providing personal care to mum, Mary describes 'putting on her old nurse hat'. She also considers that her prior knowledge of the health and social care systems has enabled her to access appropriate sources of help and advice in providing care to mum.

Carol

Carol provides care to her father with dementia. She and her husband are self-employed and when dad was diagnosed with dementia, they decided that dad would move closer to Carol so that she would be able to look after him. Carol has a sister who, along with her husband, regularly call dad but visit infrequently. Carol considers that their involvement is not enough and telephone calls are ‘no substitute for face-to-face’. Carol believes that part of the reason she provides the most care to dad is because she is self-employed and has the flexibility in her working hours where her sister does not. She feels that she is not the ‘caregiving type’ but uses dad’s appreciation of her support as justification to continue providing care. Dad receives a telecare package and sensors on his door reduce the risk of dad leaving the house and getting lost (as has happened in the past). He also has regular visits from a lady who lives nearby and is starting up her own paid care business. Carol considers how despite having multiple systems and packages of care in place, she will always be the first point of contact should anything happen with dad which impacts on her ability to go on holidays or take breaks from providing care. At the time of participating in the study, Carol was clearly finding it difficult to make time for the interview. I therefore afforded the opportunity to withdraw from the study early, prior to interview, which Carol gratefully accepted. She had written three letters as her written accounts which I considered detailed enough to be used as her narrative within data analysis. Throughout her narratives, Carol poses multiple rhetorical questions to demonstrate how difficult she was finding risk management for her father and the majority of management strategies she employed were direct responses to risk situations rather than in preparation for potential future risks.

Ellen

Ellen provides care to her mum and previously to her dad, both of whom had dementia. Ellen’s mum lives in an annexe as part of Ellen’s home with her husband, with the support of a live-in carer. The care Ellen provides to mum now is that of care management as opposed to caregiving herself. She works with the care agency and live-in carer to ensure mum receives the care that Ellen deems to be most appropriate. Ellen has been providing care for nine years and draws on her experiences with both her mum and her dad, and the care she personally provided and management of care she now provides. The main reason Ellen describes for employing paid care was that of wanting to remain a daughter. Ellen draws on her background in social care in how she goes about managing mum’s care. She also considers herself to be financially lucky in being able to afford a large home with an annexe for mum and being able to afford professional care, which she recognises is not the case for the majority of adult children. When reflecting on the care she used to provide to her parents, prior to employing help, she considers how she perhaps provided care as the only female adult child with brothers. However, upon further discussion she reflects that her brother had offered her ‘permission’ of sorts to not provide care, as though he was telling her there was no expectation on her from her brothers that she should provide care. As the adult child providing care for the longest time and to both parents, and with her new role as care manager, Ellen produced a narrative of advice – more so than other participants in the study. This is possibly due to being more removed from the caregiving role than the other participants and because of the wealth of experience she has built over the past nine years. Ellen also draws rather clear distinctions between physical, health and safety risks and more well-being associated risks and reflects on how the nature of risks changes over the course of dementia. The example she gives is how previously she would have weighted her decisions in favour of managing physical, health and safety risks, whereas now, as long as mum is not in pain, she would avoid taking her mum for health appointments due to the distress these would cause.

Kate

Kate provides care to her dad with dementia, although her mum is still alive and physically well, she also has memory concerns and mental health problems which Kate considers would impact on her ability to provide appropriate care to dad. Kate frequently visits her parents to try to provide care and support, despite the long distance between her home and that of her parents. Kate describes attempting to put care packages in place but these are frequently ‘funnelled out the door’ by her mum, thus representing the futility Kate feels in trying to find appropriate care and support to her parents. Kate admits that her own mental health has suffered as a result of her caregiving situation. Kate has a background in healthcare research and recognises the impact of this upon the care she provides to her parents. She also recognises the challenges of having ‘pseudo-knowledge’ of medications which is enough to understand health problems, but not enough to know what to do about them. She also draws on her own research to recognise the importance of different types of risks and the differences between both physical, health and safety risks, and risks pertaining to wellbeing and quality of life. Kate’s narrative presents as a series of rhetorical questions, again representing the futility Kate experiences in attempting to provide care. She states that she has decided, with the support of her therapist, to take a step back from care provision to her parents and accept that she cannot continuously keep them safe without taking her own health seriously. She was very much looking forward to a holiday she had booked and was considering not taking her phone in order to truly take a break from caregiving duties.

Suzie

Suzie provides care to her mum with dementia alongside her dad and sisters. Unlike many of the other participants, Suzie presents a narrative of shared responsibility with her siblings and dad. This is perhaps because she and her sisters have similar working patterns and children of their own, and her dad is not yet retired. Despite presenting a united front in providing care to mum, Suzie admits that they have each acted independently of the others and hidden risky situations from the others until they have managed the risk. The example she provides is that of when mum has gotten lost and she has tried to find mum without contacting her family members in order to not worry them; her dad had similarly managed mum getting lost without informing his daughters until after she had been found. Suzie draws on her experience in studying Psychology when discussing the risks for her mum. Although Suzie had completed both the written accounts and interview, unfortunately the interview recording had become corrupted and was therefore unusable. When offering Suzie the option to redo the interview, Suzie declined as the discussions we had had had been rather upsetting and emotional. Suzie had written a long letter of continuous prose outlining her experiences of risks for her mum, this was deemed enough to be included as data alone without the interview.

Susan

Susan provides care to her mum with dementia. She had previously also provided simultaneous care to her husband who had a life-limiting illness before he passed away. She considers her experience in providing care was very challenging at the time that she was caring for two family members which has reduced now that she provides care to her mum only. Susan has some employed help for mum; two ladies who will clean and run errands for mum where necessary (for example, taking her to appointments or shopping). Susan has a brother with whom she shares POA for mum. However, her brother lives at a further distance than Susan and therefore visits mum very rarely. Susan considers how even if her brother lived closer, he would maybe take on more responsibility in terms of finances and matters pertaining to mum’s properties, but she would probably provide more day-to-day care surrounding personal care, wellbeing and health. At the time of interview, Susan was considering alternative care options for mum, whether live-in care or residential. Much of Susan’s narrative presents concerns about other people causing harm to mum and fears surrounding scams and unscrupulous carers. She draws on these fears when considering care options for mum.

Jack

Jack had recently completed his role on a project and the contract had ended. At this point he had a decision as to whether to take up an extension on the contract, take up a new contract or move in with his parents to provide support – he chose the latter. His mum has dementia and is cared for predominantly by his dad. Jack provides a narrative of attempting to find his place in his new living situation with his parents and how to provide support to both of his parents. The majority of the care Jack feels he provides is support to his dad and providing supervision to mum so that dad can complete other tasks or activities; he does not believe that he would take up providing care to mum if anything were to happen to dad. Jack has a sister who lives a long distance away with her own family including young children. He considers the differences in how his sister would provide care and support and how he provides support. He puts this down to differences in personalities between himself and his sister – describing his sister as active and wanting to enact care, whereas he tends to go along with how his dad provides care. Jack considers his responsibility is to his dad and supporting his dad to continue to provide care for mum. He reflects on how 'people' think that he is some kind of hero for moving back in with his parents due to mum's dementia diagnosis, but Jack does not feel that that is appropriate and does not consider that his role is heroic.

Lucie

Lucie is the youngest participant in the study and her mum has had symptoms of dementia since Lucie was in her teenage years. She is currently at university and therefore lives away from the family home during term-time, however frequently visits at the weekends. Lucie's mum is predominantly cared for by Lucie's step-dad, and his children from a previous relationship live with them. Lucie describes her teenage step-siblings as behaviourally quite challenging which has, and still does, caused difficulties in her mum's relationships with them. This is more apparent with the diagnosis of dementia as the step-siblings are not understanding of dementia and mum's temper has shortened. Lucie's mum and step-dad have opted for secrecy around mum's diagnosis and even some members of their wider family are unaware of her dementia. Much of Lucie's narrative draws upon the difficulties surrounding mum's young-onset dementia and the challenges Lucie faces in having a young parent with dementia which she feels many people would not be aware or understand. This is especially apparent in terms of Lucie's social circle, where some friends may have grandparents with memory problems but Lucie feels this is quite different to having a parent with dementia. A further prominent theme within Lucie's narrative is the fear of changes in relationship with her mum as the dementia progresses.

Roger

Roger provides care to his mum with dementia and supports his dad as mum's main caregiver. Roger has brothers who live at a further distance from their parents. He describes how they are a little less involved than he is and that one brother he believes was in denial for some time about mum's dementia. Roger has two young children from a previous marriage who live locally to his parents, he therefore visits most weekends to spend time with his children and his parents. He had recently moved in with his new wife and her children and admits that this has been a major change for both himself and his new step-children. Roger talks of the challenges of providing care to his mum, especially a more recent experience of helping mum dress. His mum also has diabetes which requires constant management to ensure it remains controlled mostly through diet and medications.

Appendix E

Patricia

Patricia provides care to her mum with dementia and supports her dad in his caregiving role. She has sisters who also provide care for mum, however, Patricia feels that there is an expectation that she provide more care. She considers that this is because she is self-employed and therefore has flexibility in working hours, and she has no children but her sisters do. She also talks of the challenges surrounding her dad as primary caregiver to mum, dad has recently retired during the course of mum's dementia. She draws on her parents' Irish heritage as a reason that dad struggles to take responsibility for mum's care (because of an assumption that caring is not seen as a male role in Ireland), and also dad's hobby of frequenting the local Irish bar which he can spend several days at a time visiting the local pub. These concerns add to Patricia's consideration that she must take responsibility for mum's care. Patricia describes that she has often felt 'a bit sad' during the course of providing care to her mum and that she has often considered visiting her GP to get help. She also describes the challenges surrounding young-onset dementia and that her friends often lack awareness and understanding of her situation. Despite portraying her sisters as less involved than Patricia, she also considers herself lucky to have her sisters to go through this situation with as some form of peer support and shared understanding of the challenges of caregiving to a parent with dementia.

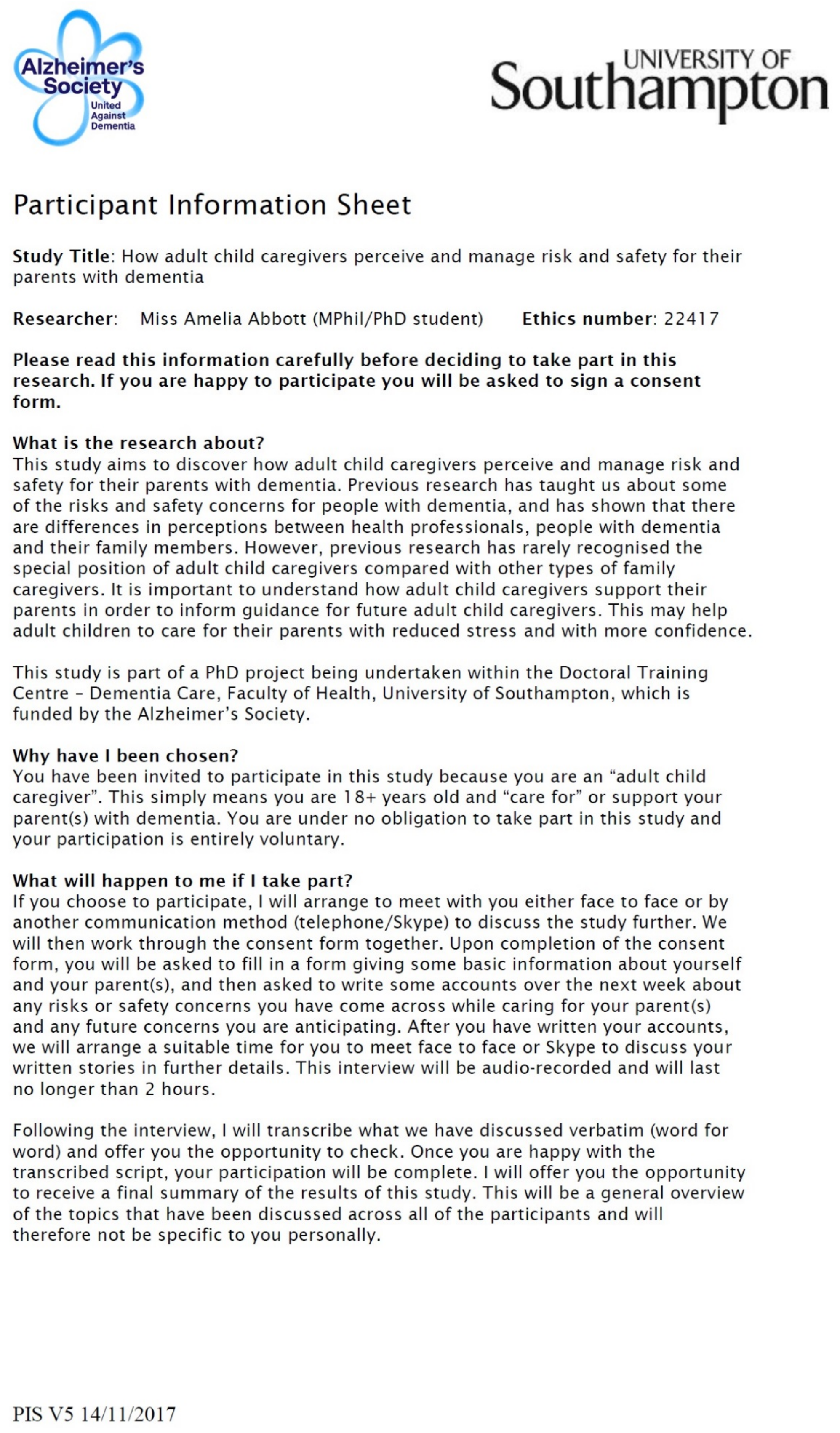
Jodie

Jodie provides care to her mum with dementia and her dad with memory problems (now diagnosed as dementia). Jodie had recently moved mum into residential care but was still providing a lot of support to her mum and dad. Jodie has a sister and a brother with whom she shares POA for her parents. Her brother had previously moved to away and therefore had less involvement with the day-to-day aspects of care for their parents. However, because they had to be in agreement when making POA decisions, Jodie feels that her brother has prevented them from being able to manage their parents' care effectively. Jodie and her sister both take equal roles in providing care to their parents; Jodie typically focusses on health and wellbeing, whereas her sister focusses on financial and legal matters. Jodie describes wanting to make sure she matches her sister in providing care to their parents. Jodie has a job which requires frequent mental health monitoring to ensure she is able to perform her role appropriately. Jodie admits that due to the challenges of providing care to her parents, her mental health has suffered and she has been unable to work too. Jodie's husband has often commented on Jodie's inability to take a break from dementia, she spends many hours researching dementia and ways to provide care. At one point, Jodie had decided to make adaptations to her family's home for her parents to move in with them. Unfortunately, these adaptations had taken too long to materialise and by the time the house was ready, Jodie's husband felt that her parents were too ill to move in with them, especially considering the disruption this would cause for their young children. Therefore, the decision was made for her parents to move to residential care.

George

George's dad has dementia and his mum is physically frail. At the time of his dad's diagnosis, the decision was made for his parents to move to near his sister's family home which she shares with her husband, children and husband's parents. This decision was in part due to his sister's capacity to provide care to their parents and the support that would be afforded also from the rest of her family (including her husband's parents). Another part of the reason their parents moved to near George's sister is because George was also in the midst of receiving a diagnosis of Parkinson's disease which they all agreed would hinder his ability to provide care to his parents. George and his sister share POA for their parents, and although George is unable to provide any of the day-to-day care, he is very active in supporting his parents with finances and legal matters. At the time of interview, the family were considering residential care for dad. This was in part because the progression of dad's dementia had reached a point where continuing care at home was proving too difficult (despite the amount of people available to provide care and support). The decision was also in part due to George's mum's condition, her lack of sleep due to dad's dementia, her physical frailty was declining and she was struggling to maintain George's dad's safety. George was taking a lead role in learning about the residential options as he was able to do this from a distance.

Appendix F Participant information sheet



Alzheimer's Society
United Against Dementia

UNIVERSITY OF
Southampton

Participant Information Sheet

Study Title: How adult child caregivers perceive and manage risk and safety for their parents with dementia

Researcher: Miss Amelia Abbott (MPhil/PhD student) **Ethics number**: 22417

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?
This study aims to discover how adult child caregivers perceive and manage risk and safety for their parents with dementia. Previous research has taught us about some of the risks and safety concerns for people with dementia, and has shown that there are differences in perceptions between health professionals, people with dementia and their family members. However, previous research has rarely recognised the special position of adult child caregivers compared with other types of family caregivers. It is important to understand how adult child caregivers support their parents in order to inform guidance for future adult child caregivers. This may help adult children to care for their parents with reduced stress and with more confidence.

This study is part of a PhD project being undertaken within the Doctoral Training Centre – Dementia Care, Faculty of Health, University of Southampton, which is funded by the Alzheimer's Society.

Why have I been chosen?
You have been invited to participate in this study because you are an "adult child caregiver". This simply means you are 18+ years old and "care for" or support your parent(s) with dementia. You are under no obligation to take part in this study and your participation is entirely voluntary.

What will happen to me if I take part?
If you choose to participate, I will arrange to meet with you either face to face or by another communication method (telephone/Skype) to discuss the study further. We will then work through the consent form together. Upon completion of the consent form, you will be asked to fill in a form giving some basic information about yourself and your parent(s), and then asked to write some accounts over the next week about any risks or safety concerns you have come across while caring for your parent(s) and any future concerns you are anticipating. After you have written your accounts, we will arrange a suitable time for you to meet face to face or Skype to discuss your written stories in further details. This interview will be audio-recorded and will last no longer than 2 hours.

Following the interview, I will transcribe what we have discussed verbatim (word for word) and offer you the opportunity to check. Once you are happy with the transcribed script, your participation will be complete. I will offer you the opportunity to receive a final summary of the results of this study. This will be a general overview of the topics that have been discussed across all of the participants and will therefore not be specific to you personally.

PIS V5 14/11/2017

Should you require any further support following the interview, please contact your GP or other healthcare professionals. Other support is available nationally from the Alzheimer's Society at: www.alzheimers.org.uk or Tel. 0330 333 0804.

Are there any benefits in my taking part?
There may be no benefits to participating in this study as all of the results will be used to provide help and support to future generations of adult child caregivers and add to the current knowledge in this area. However, some people enjoy participating in this type of research as an opportunity to discuss their experiences.

Are there any risks involved?
There are no risks in participating in this research, however, due to the nature of the topics we may discuss, some participants may find the subject sensitive and perhaps upsetting. If this is the case, the interview and recording device will be stopped and you will be offered the opportunity to continue, stop or withdraw from the study.

Will my participation be confidential?
Your participation in this study, and anything that is discussed will remain confidential. However, if anything is discussed that causes me any concern about anyone's safety or well-being, I have a duty to report this to the relevant services who would be able to provide you with help and support.
This study will comply with the Data Protection Act and University Policy. Your personal information will be stored separately to the interview recordings and transcriptions which will be coded to maintain your anonymity. All data and identifiable data will be stored in locked filing cabinets and/or password protected computers.
Some quotes may be used from your interviews to illustrate points within final reports, papers and my thesis, however, these will appear next to codenames and your personal details will not be reported alongside them. It may be possible for you to recognise what you have said during the interview within the quotes, but as they will appear alongside codenames, no one else will be able to recognise you. You may choose your own codename should you wish, or alternatively, a codename will be assigned to you.

What happens if I change my mind?
Should you choose to participate, you will be able to withdraw at any time from the study without giving a reason and without your legal rights being affected. Should you withdraw following analysis of the collected data, it may not be possible to remove your data at that point. You will be offered the opportunity to withdraw at various time points throughout the study, including: prior to the interview, following the interview and following your check of the transcribed interview.

What happens if something goes wrong?
If you have a concern or a complaint about this study you should contact the Research Governance Office Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ; Tel: +44 (0)23 8059 5058; Email: Dr. Isla Morris at rgoinfo@soton.ac.uk. If you remain unhappy and wish to complain formally the Research Governance Office can provide you with details of the University of Southampton Complaints Procedure.

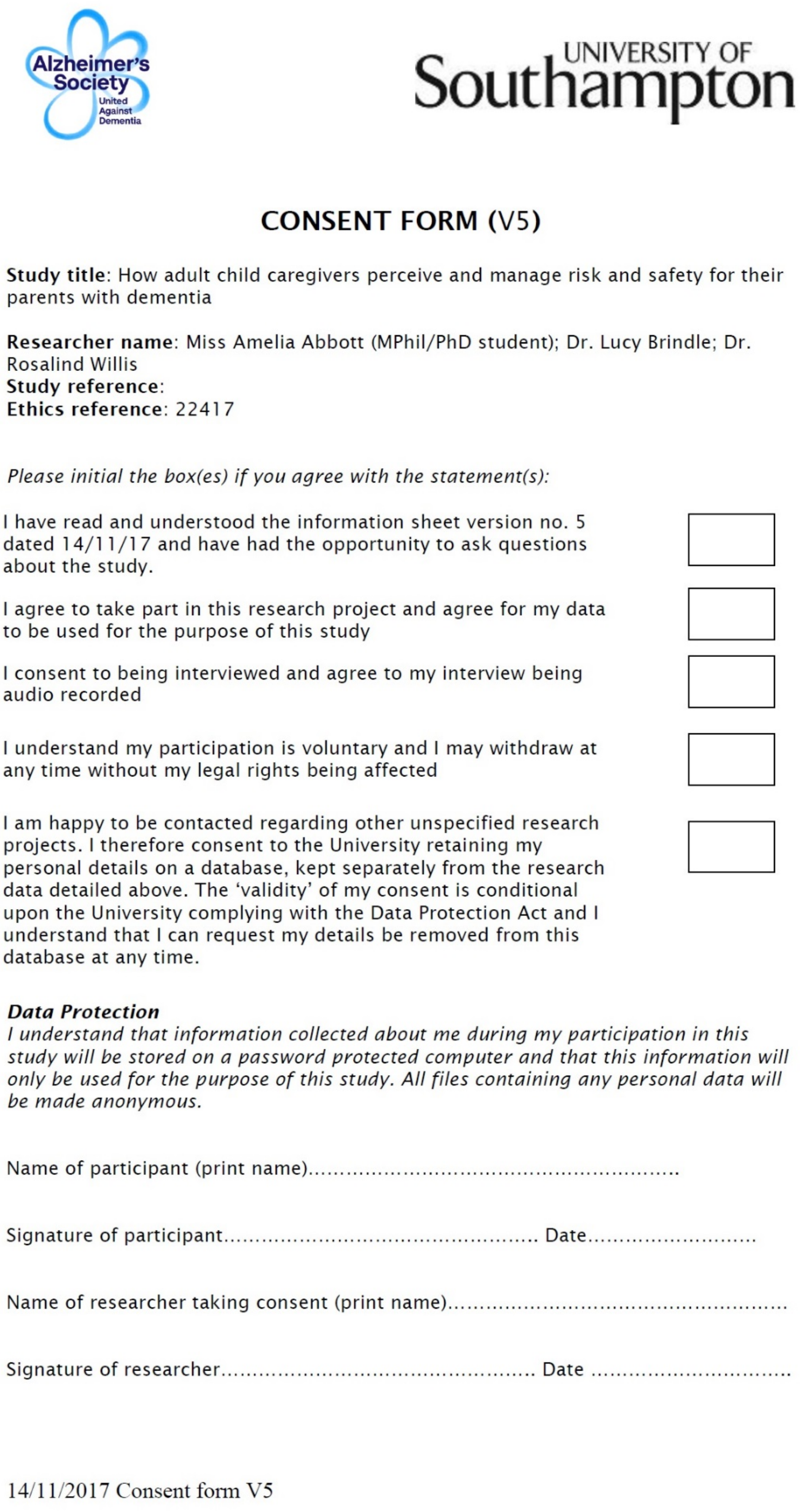
Where can I get more information?
If you would like further information, please contact:

Miss Amelia Abbott (MPhil/PhD student)
Aca1g15@soton.ac.uk
07794 304914

Supervisors: Dr. Lucy Brindle; Dr. Rosalind Willis

PIS V5 14/11/2017

Appendix G Consent Form



Alzheimer's Society
United Against Dementia

UNIVERSITY OF
Southampton

CONSENT FORM (V5)

Study title: How adult child caregivers perceive and manage risk and safety for their parents with dementia

Researcher name: Miss Amelia Abbott (MPhil/PhD student); Dr. Lucy Brindle; Dr. Rosalind Willis
Study reference:
Ethics reference: 22417

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet version no. 5 dated 14/11/17 and have had the opportunity to ask questions about the study. ☐

I agree to take part in this research project and agree for my data to be used for the purpose of this study ☐

I consent to being interviewed and agree to my interview being audio recorded ☐

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected ☐

I am happy to be contacted regarding other unspecified research projects. I therefore consent to the University retaining my personal details on a database, kept separately from the research data detailed above. The 'validity' of my consent is conditional upon the University complying with the Data Protection Act and I understand that I can request my details be removed from this database at any time. ☐

Data Protection
I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name)……………………………………………………

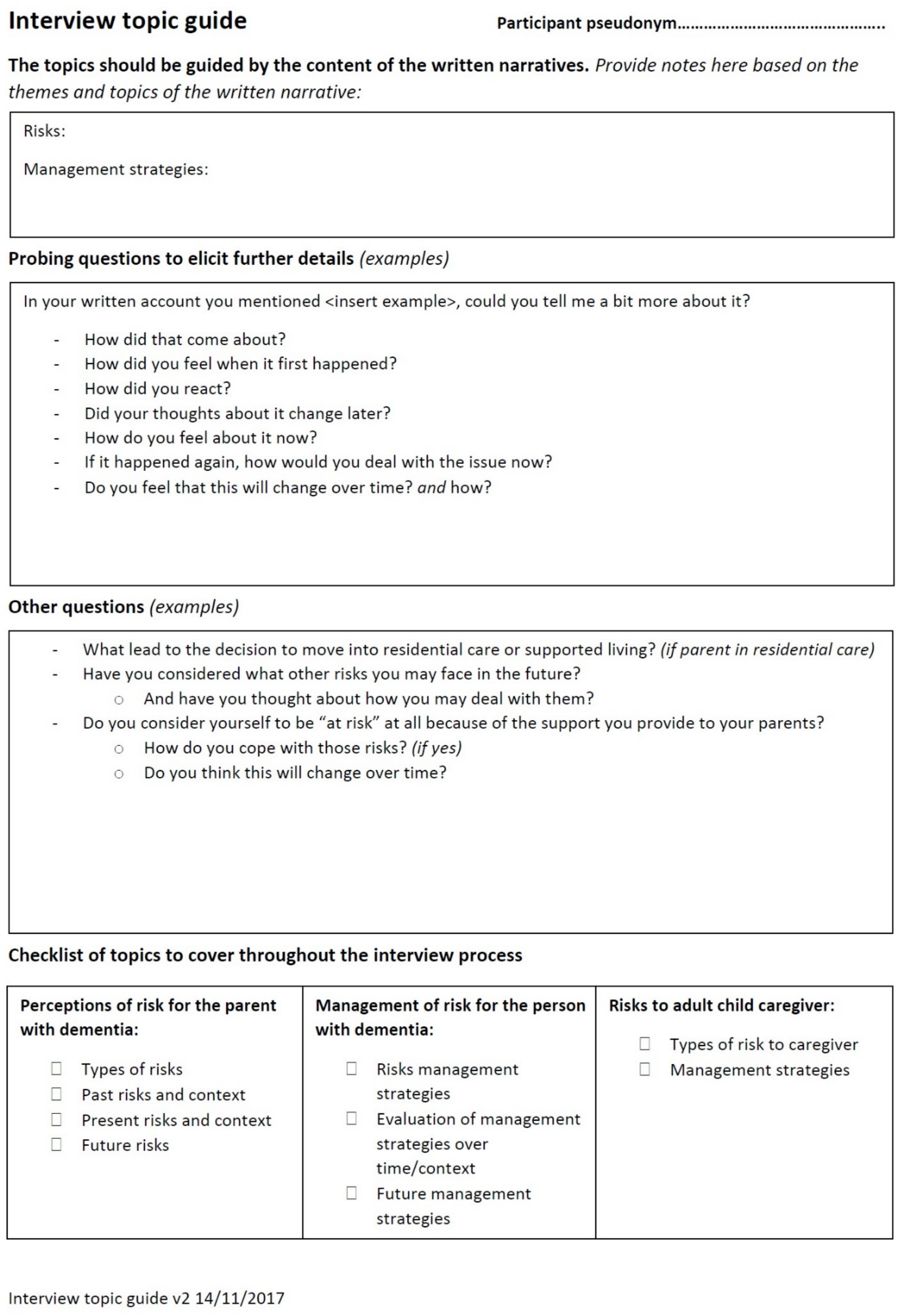
Signature of participant………………………………………… Date………………………

Name of researcher taking consent (print name)………………………………………………

Signature of researcher………………………………………… Date …………………………

14/11/2017 Consent form V5

Appendix H Interview topic guide



Interview topic guide

Participant pseudonym……………………………………….

The topics should be guided by the content of the written narratives. *Provide notes here based on the themes and topics of the written narrative:*

Risks:

Management strategies:

Probing questions to elicit further details *(examples)*

In your written account you mentioned <insert example>, could you tell me a bit more about it?

- How did that come about?
- How did you feel when it first happened?
- How did you react?
- Did your thoughts about it change later?
- How do you feel about it now?
- If it happened again, how would you deal with the issue now?
- Do you feel that this will change over time? *and* how?

Other questions *(examples)*

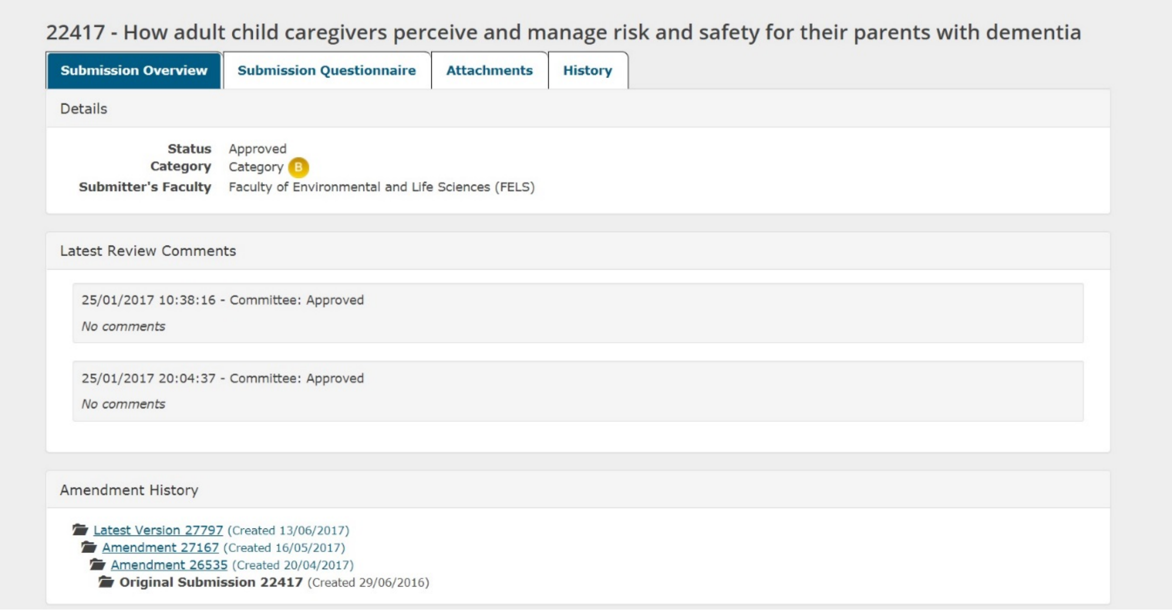
- What lead to the decision to move into residential care or supported living? *(if parent in residential care)*
- Have you considered what other risks you may face in the future?
    - And have you thought about how you may deal with them?
- Do you consider yourself to be "at risk" at all because of the support you provide to your parents?
    - How do you cope with those risks? *(if yes)*
    - Do you think this will change over time?

Checklist of topics to cover throughout the interview process

Perceptions of risk for the parent with dementia:	**Management of risk for the person with dementia:**	**Risks to adult child caregiver:**
☐ Types of risks ☐ Past risks and context ☐ Present risks and context ☐ Future risks	☐ Risks management strategies ☐ Evaluation of management strategies over time/context ☐ Future management strategies	☐ Types of risk to caregiver ☐ Management strategies

Interview topic guide v2 14/11/2017

Appendix I Ethics approval



22417 - How adult child caregivers perceive and manage risk and safety for their parents with dementia

Details

Status Approved
Category Category B
Submitter's Faculty Faculty of Environmental and Life Sciences (FELS)

Latest Review Comments

25/01/2017 10:38:16 - Committee: Approved
No comments

25/01/2017 20:04:37 - Committee: Approved
No comments

Amendment History

- Latest Version 27797 (Created 13/06/2017)
  - Amendment 27167 (Created 16/05/2017)
    - Amendment 26535 (Created 20/04/2017)
      - **Original Submission 22417** (Created 29/06/2016)

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