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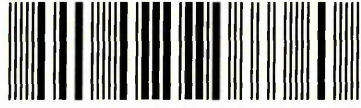
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Taking Risks with Dementia: Exploring Practitioner Accounts of Risks and Decision-Making

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ABSTRACT

Taking Risks with Dementia: Exploring practitioner accounts of risks and decision-making

In contemporary health and social care, stories of risk and risk management pervade practice discourse. This study explores practitioner accounts of risk management and decision-making in dementia care, with a particular focus on wellbeing and quality of life.

Interviews were undertaken with 11 practitioners working within NHS dementia care services in the north of England, during 2008. These were used to examine how practitioners talked about risk management, and their constructed and represented understandings of risk and decision-making.

My analysis of practitioners' stories was undertaken alongside considerations of key policy and practice guidelines.

Practitioners portrayed complex, contextual, reflexive approaches to risk management decision-making. Some discourses were so useful or strong they were represented *as if* they were the truth, whilst other discourses were questioned and reconstructed. Practitioners represented decision-making along continuums, such as subjective-objective and emotional-cognitive. Their accounts included stories of home, practice cultures, risk-taking, wellbeing, resources and discrimination. Some risk management strategies were portrayed as hazardous, in particular living 'in care', and practitioners consistently portrayed risk management decision-making as full of dilemmas and uncertainty.

Unlike some dementia care research and policy, practitioners' stories did not prioritise physical wellbeing over psychological wellbeing. Some practitioners proposed a reconsideration of risk management decision-making that takes more account of the benefits and values of risk-taking.

This research contributes to understandings of practitioners' decision-making and dilemmas in risk management with people living with a dementia. By positioning some dissemination within daily practice and discourse, I hope my study will trigger discussion, ideas, and action.

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Chapter 1: An introduction

'I'm always surprised by people especially when I'm just sitting with people ...nothing going on ... and they tell me the most amazing things' (Neil)

Introduction

This is an account of my research project. It is based on edited, fragmented and interpreted memories. There was no obvious, logical progression through the process of my research project. There is no 'real' end or beginning. It is past, present and future. However, I see no worth in being deliberately obscure and inaccessible, and have therefore attempted to provide a linear, chronological account. Although I meander and take you down some tricky paths, I provide signposts in the hope that I do not lose you on the way.

I will continue with a short, orientating statement about myself and this project, after which I provide an overview of the content and structure of this chapter and my project as a whole.

I work as an occupational therapist (OT) for older people's services within an NHS trust. Since qualifying, I have spent most of my practice in mental health teams and related training roles. I have also undertaken research and written from practice experiences (for example, Bower, 2006). In current practice, I am involved in risk management decision-making with people living with a dementia.

My motivations for undertaking this research include feelings borne out of daily practice experiences. As an OT and manager in dementia services, I continually seek to improve the quality of my practice and look for opportunities to contribute to improvements in service quality. My understandings and experiences of self as practitioner and researcher are intertwining and transactional. Influenced by my experiences and by complexity theories, I believe we can not gain meaningful understandings of daily lives by isolating and investigating separate constituent parts. However, it feels inevitable that in order to write this report, I must over-simplify my lived experience of being researcher/practitioner/writer (Blair and Robertson, 2005, Plsek and Greenhalgh, 2001, Stevens and Cox, 2008, Taylor and White, 2000 and Warren et al, 1998).

In this chapter I provide an introduction to my research project. This includes a brief introduction to the practitioners involved in the interviews and my research objectives. I continue by providing an account of why I chose to undertake this project, making links with each research objective. I then outline the structure of this report. I follow this with an account of my choices about how to write this story. In the final part of this chapter, I offer some concluding comments and links to the next chapters.

Research participants

I carried out my research within the NHS trust, where I work. I undertook interviews with 11 practitioners who worked across eight different teams in older people's services. Their professional roles included social workers, nurses, physiotherapists and occupational therapists.

Research objectives

My *Principal Research Objective* was; ***To explore practitioner accounts of decision-making in risk management with people living with a dementia*** My *Secondary Research Objectives* were;

- ***To describe and analyse assumptions and understandings influencing decisions made by health and social care practitioners***
- ***To consider this decision-making with a particular focus on psychological wellbeing and quality of life***
- ***To consider this decision-making in the context of recent legislation, policy and practice guidelines and changes in the culture of dementia care (in particular the Mental Capacity Act, 2005)***
- ***To consider ways in which discourse, narrative and reflexive analysis can contribute to understandings of practitioner decision-making in health and social care***
- ***To contribute to future work in service development, professional development, and health and social care training***

These objectives helped me to plan and keep some focus when undertaking the research and writing this report. I hope they also serve to orientate readers. Within this chapter I outline some justifications for my choice of these objectives. Throughout this report I re-visit these objectives, making

connections with some content in each chapter. In chapter 4, I examine the relationship between my research objectives and methodology, and explore how the methods I used helped me to address these objectives. In the final two chapters, I consider whether I have achieved my research objectives.

I will now outline some reasons for undertaking this project, with links to my research objectives.

Why this project?

In contemporary social and health care services, concerns for risk pervade practice discourse. In my practice experience, talk of risk dominates much of everyday discourse, but we can be talking about different things.

Throughout my years of practice, I have regularly been asked to assess people who are living at home with a dementia, but are seen by others to be 'at risk' (for example, from malnutrition, falls and getting lost). I do not wish to simplify the complex realities of living with a dementia, nor am I attempting to minimise the dangers and difficulties that can be part of everyday life for someone living with cognitive impairments. However, I often experience ethical dilemmas. Who are we protecting, and what from? Why do some people have the power to make decisions about other people's lives? Are my concerns for this person genuine, or are my decisions influenced by a fear that someone will point at me when she falls downstairs?

In my experience, much of dementia care practice continues to be founded on assumptions and judgments that are made about 'old' people; even more so when they have been labelled with 'dementia'. Once so labelled and involved with care services, it is assumed that people living with a dementia have no insight and are unable to make informed choices. Thus choices are imposed, for 'their safety' and 'in their best interests'. I wonder about daily practices that trouble me, such as chairs used as restraints, people being moved roughly, treated as objects, without compassion and without care, people being ignored, misled or 'persuaded' to do things against their will. I often feel implicated in the persuasion and coercion that goes on 'in their best interests.' Reading research by other practitioners (such as Clarke, 2000, Hill, 2004, Huxtable, 2006, and Trede, 2006), I see I am not alone in being moved by feelings about work experiences and wanting to make some

difference. Like Manthorpe (2004), I see some merit in naming and exploring *risk*;

> *'If people with dementia are seen as personifications of risk then, there is a greater likelihood that ignorance will govern assessments and risk and risk management. However, risk cannot be managed by denial: it is too ubiquitous a theme to be sidelined or swept under the carpet. Risk needs to be named and its dimensions explored through discussions...'* p148.

By listening carefully to practitioners' accounts, I hope to contribute to understandings of practitioners' risk management decision-making. In this way, I hope my research will contribute to discussions that inform ongoing dilemmas about people living with risk and dementia.

I will now provide an account of my choices written against each research objective. My principal research objective is; ***To explore practitioner accounts of decision-making in risk management with people living with a dementia*** and one secondary objective is; ***To describe and analyse assumptions and understandings influencing decisions made by health and social care practitioners.*** But why focus on *practitioner accounts* and on *decision-making?* It was never my intention to privilege practitioner perspectives in dementia care. Rather, I hope to contribute to the work of others who explore perceptions of risk with people living with dementia and their carers (such as Clarke et al 2010, 2011a, de Whitt et al, 2009, Gilmour et al 2003, Mitchell and Glendinning, 2007, Proctor, 2001, Reid et al, 2001, and Wilkinson, 2002) and by people living with dementia (such as Bryden 2005).

As a practitioner and researcher, I support arguments that we should be accountable for our practice and able to justify our decision-making. We should be aware of our assumptions, access relevant research and be open to change. As practitioners, we have to make 'professional judgements', but we do not do this in a vacuum. Healthcare discourse on evidence-based practice (EBP) rests on the assumption that 'best' evidence derives from randomised control trials (RCTs). However, such versions of decision-making and EBP are limited and the status of what counts as evidence is problematic (Hugman, 2005, Humphries, 2003, Hyde, 2004 and

Polkinghorne, 1992). I am interested in practitioners' accounts of the relationships between knowledge, evidence, practice and decision-making (Ballinger and Cheek, 2006, Blair and Robertson, 2005, Crowe and O'Malley, 2006, Duncan and Nichol, 2004, Fook and Gardner, 2007, Gordon, 1998, Hall and White, 2005, Higgs et al 2004 and Taylor and White, 2000). In this project, I have explored practitioners' assumptions about risk, risk management and living with risk and dementia.

To consider this decision-making with a particular focus on psychological wellbeing and quality of life; My choice to focus on psychological wellbeing was influenced by practice experiences and related reading. In practice, ethical dilemmas about wellbeing, autonomy and harm are complex and contested. I share Brooker's (2007) concerns;

> *'People with dementia are a vulnerable group within our society and it is wholly right that that those responsible for their care work to ensure their safety. People with dementia are, however, in danger of being kept so safe that they have no quality of life at all,'* p74.

Reflecting on my experiences of 'elder abuse' training in the 1980's, I recall dramatic stories of dreadful instances of physical assault. Although useful in raising awareness, I also felt uncomfortable with the limited acknowledgment of the pervasive, 'low level' abuse I regularly witnessed. I read about 'iatrogenesis' and political theories of mental health (Boyers and Orril 1972, Laing, 1967 and Szasz, 1974) and was heartened to read others questioning the power and legitimacy of medicine, psychiatry and mental health 'care'.

When I was writing my research proposal, a government commissioned report argued there was a lack of research focusing on dementia care and wellbeing (Wanless, 2006). When planning my project, two UK research projects were of particular interest. Both included explorations of psychological wellbeing in risk management. Edinburgh University's Centre for Research on Families and Relationships (CRFR) were undertaking a large scale project exploring constructions of risk in dementia care (Clarke, 2006 and Clarke et al, 2009, 2010 and 2011a and b). As their research has clear connections with my proposed project, I have been in correspondence with Clarke. York University's Social Policy Research Unit (SPRU) undertook a review of risk research in adult social care. They argued;

> *'...the risk of damage to psychological well-being and how it is experienced and managed has received little consideration...'*
> (Mitchell and Glendinning 2007, p98)

They suggested that future research should examine how risks of damage to psychological wellbeing are managed by practitioners. This gap in available evidence was of particular interest. Whilst writing my proposal I contacted Mitchell and Glendinning, noting our shared areas of interest. In response, they stated my proposed project was;

> *'...much needed, given the gaps I identified in the literature, especially psychological well-being'* (personal communication, 19/04/07).

To consider this decision-making in the context of recent legislation, policy and practice guidelines and changes in the culture of dementia care (in particular the Mental Capacity Act, 2005); Influenced by arguments that discourse becomes so embedded in practice that we may not be aware of its influence, I saw potential in exploring connections between the micro-narrative of interviews to the macro-narrative of practice and policy. Thus, in addition to analysing practitioners' accounts, I also examined the location of practitioner stories and situated understandings within the wider discourse and contexts of practice culture, in particular policy and guidelines. I have therefore undertaken my examination of research and policy within my literature review chapters (2 and 3) and alongside my analysis of practitioner accounts within chapters 5 to 8 (Boyes, 2006, DeBellis, 2006, Foucault, 1972, Gordon, 1998, Hill, 2009, Mason, 2006, Parker, J, 2005, Sarangi and Candlin, 2003, Watson, 2005 and Wetherell et al 2001).

There is also timeliness in my choice of research, in particular with regard to demographics, policy, legislation and a shifting discourse on rights and cultures of dementia care.

> *'There are currently about 750,000 people in the UK with a form of dementia... One in 14 people over 65 years of age and one in six people over 80 years of age has a form of dementia....It is estimated that by 2021 there will be one million people with dementia in the UK,'*
> (Alzheimer's Society 2011a, p1).

The growing number of people living with a dementia is a major demographic consideration in current health and social care policy, and a discourse of catastrophe dominates UK media and policy reports (see chapter 3). Running parallel to this have been changes in dementia care and in human rights social policy. Over the last 15 years, Kitwood (1997) has been influential in the promotion of a 'new culture' of dementia care; which prioritises relationships, communication, personhood, and physical and emotional wellbeing. Since the 1960's, disabled people and political groups have campaigned for an end to disablism (Branfield et al, 2006 and Shakespeare, 2006). Nevertheless, apart from the notable exception of Norman (1980 and 1982), these political movements marginalised the experiences of older people and people living with a dementia. However, such concepts have recently gained prominence in dementia discourse (Bartlett and O'Connor, 2007, Boyle, 2008a and b and 2010, Brannelly, 2004, Graham, 2004, Innes, 2002, Kronenberg et al, 2005, and Scholl and Sabat, 2008). The Mental Capacity Act (MCA), 2005 can be understood as part of this shift. As indicated by this research objective, the MCA is of particular interest for my research. This legislation was implemented as I was submitting my research proposal. It is intended as a legal safeguard for people who lack the capacity to make decisions. This legislation has triggered much debate and necessitates some key shifts in dementia care practice.

In addition, whilst writing this report, the Department of Health (DH) published 'Risk Guidance for people with dementia', in which they assert;

> 'Unfortunately, the research evidence base looking at risk and dementia is still limited...' (Manthorpe and Moriarty 2010, p16)

This best practice guide is of key relevance to my practice and research.

To consider ways in which discourse, narrative and reflexive analysis can contribute to understandings of practitioner decision-making in health and social care; My analysis methods are in keeping with my theoretical perspectives and practice contexts. My research is most closely aligned to relativist perspectives that language shapes our understandings, and my project draws primarily on critical, postmodern theories. From these perspectives, I am interested in 'situated' knowledge and value

contextualised, subjective experiences. However, I do not believe that interviews can give direct access to 'the truth' about practitioners' decision-making. Rather, my focus was on *'truth effects';* how some discourses in some contexts are so powerful, they influence decision-making *as if* they are common sense, natural, truths. I hoped that analysing practitioner accounts would offer some indication of how power may operate at this 'micro' level, which in turn would enable me to make some connections with wider practice and societal 'macro' discourses (Adams, 1998, Arber and Ginn, 1995, Busfield, 1996, Foucault, 1980, Polkinghorne, 1992, Stanford, 2007, Stanley and Wise, 1983, Thompson, 2006 and Warner, 2006).

In chapter 4, I provide a more detailed account of my analysis.

To contribute to future work in service development, professional development, and health and social care training; My decision to undertake a professional doctorate rather than a PhD was influenced by promotional materials that represented a professional doctorate as for *'scholarly professionals'*, rather than *'professional scholars'*. Although I feel demarcations between practitioner and academic researcher can be false and unhelpful, I felt more inclined toward the practice end of this continuum. I was drawn to the idea of learning through theory and practice, with daily connections and contributions between my work and research.

Throughout this report, I provide more details about the choices I have made about this research project. Having provided an introduction to my justifications for undertaking this research, I will now describe the structure of this report.

Report structure

Each chapter has a similar structure. I begin with an introduction, followed by the main body of chapter. At the end of each chapter I provide some reflexive considerations and concluding comments, including links to the next chapter(s).

After this introductory chapter, I review key relevant literature, in chapters 2 and 3. In chapter 2, I examine accounts of risk management and decision-making. In chapter 3, my focus is on dementia care, dementia care policy

and living with risk and dementia. In chapter 4, I provide an account of my theoretical orientations, methodology and methods.

In chapters 5 to 7, I provide my analysis of practitioner accounts. In chapter 5, I analyse accounts of the nature and assessment of risk. In chapters 6 and 7, I provide my analysis of practitioner accounts of contextual ethics. In chapter 6, I begin with an account of developing theoretical representations of practitioners' accounts. This includes a representation of key themes (Appendix I) and theoretical models (Appendices II and III). I then provide my analysis of practitioners' accounts of intrapersonal and interpersonal contexts. In chapter 7, I provided my analysis of practitioner accounts of wider contextual ethics; environmental and societal contexts.

Within chapters 5 to 7, my analysis of practitioners' accounts is alongside policy and practice guidelines. In addition, rather than write a separate 'discussion' chapter, I integrate discussions and analysis within these chapters. I resisted complete chapter separations, because I see some value in practitioners' accounts being closely connected with discussion and context, as they are in practice. I acknowledge this has the potential to confuse myself and the reader, and have been grateful for supervisors' feedback on this.

In chapter 8, I provide some project conclusions. This includes reviewing my research objectives. In my final chapter (chapter 9), I write about plans for dissemination. This includes a consideration of my final research objective. At the end of this report I provide a list of the references and 13 appendices which support and illustrate my research.

Having outlined the structure of this report, I now provide an account of some choices I made about writing.

Writing this report

I begin this section with an account of using metaphors and models. I continue with explorations terminology, being 'insider', representing practitioners' accounts and being reflexive.

Using metaphor and models; Neither my practice or project are located within any one theoretical perspective. Using metaphorical approaches helped me to explore the different, sometimes conflicting, theories within my

research. I played with multiple metaphors, such as balance, thresholds, *Cinderella*, maps and visual metaphors (Alvesson and Sköldberg, 2000, Arner and Falmange, 2007, Crowley, 2000, Hunt, 2004, Kvale, 1996, Macleod, 2002, Richardson, 2000 and Samuels and Betts, 2007).

I found visual metaphors useful, in deciding how to represent and write about the integrated structure of my analysis and concepts, particularly *kaleidoscope, mosaic* and *window. Kaleidoscope* helped me when thinking about dynamic relationships between concepts in practitioners' accounts. In attempting to represent these key concepts within layers of ever changing context, I saw parallels with *kaleidoscope;* multiple, moving lenses, reflections, small fragments grouped by colour/shape into patterns that are always open to movement, reconstruction and multiple interpretations (Jackson, 2007 and Jackson et al, 2007). In considering how to represent kaleidoscope as fixed and two dimensional within this report, my mind wondered to *mosaics;* a static picture of small fragments, with the potential of different patterns and interpretations. In keeping with my perspectives on situated knowledge, I was also attracted to the visual metaphor of *window.* By incorporating this image within my conceptual model, I hoped to portray located understandings, partial perspectives and views across boundaries and contexts. I constructed a theoretical model; *Conceptual kaleidoscope. Windows and mosaics; looking through contextual ethics in risk management decision-making (*Appendix III).

Using these representations enabled me to acknowledge complexities within and across accounts, whilst also helping me to be systematic in my analytical development from texts to themes to models. I have written more detailed accounts of creating and using theoretical models in Chapters 4 and 6.

Terminology; In Appendix IV, I provide a list of some words, terms and initials with brief explanations of their use in this report. Some words are included because of their ambiguity. The initials included are with the full version of the phrase/title they represent. I have used initials to make the report more readable, in particular when some phrases were lengthy and repeatedly used.

Some choices about terminology used within this report were to ensure confidentiality. All interview 'participants' are referred to individually by a

pseudonym or collectively as *'practitioners'* (see my justifications for this below, and in chapter 4). In addition, all transcripts and excerpts have been anonymised, and where publications indicate locality, this is indicated as XX.

Being 'insider'; In arranging and undertaking the interviews, being 'insider' did confer some legitimacy and credentials. My practice experiences equip me with some strategies that helped to open doors that for 'outsiders' may be more difficult (de Certeau, 2002, Lewis and Ridge, 2005 and Watts, 2006). We have some commonalities in identity and share some language. Throughout this report, I use *'we'* to acknowledge my belonging, my status as a practitioner. However, being insider can also get in the way of seeing and hearing. I took note of Finlay's (1998a) warning;

> *'My previous knowledge gives me insights that outsiders may not appreciate. On the other hand, I need to guard against assuming that we share the same language and meanings and see the job in the same way, so missing the point that there are differences'* p454.

Representation; I am also mindful that I was researcher, not interviewee. As such, there are differences in levels of control; I chose how to represent practitioners in this report. As I write *about* practitioners, I am talking *for* them. Therefore, in addition to 'we', I also use the more separating *'practitioner'* to refer to the 11 practitioners who were interviewed by me, the researcher. My choices about how to represent practitioners' accounts were shaped by my perspectives and experiences. Before being included in this report, I 'tidied' and anonymised practitioners' accounts. By doing so, I hoped to maintain confidentiality, whilst ensuring enough clarity for readers to make some sense of practitioners' stories. In order that excerpts from practitioners' accounts stand out from the words of others, I have used a different font to represent their voices;

Georgia 12 pt italic (indented and followed by pseudonym)

I provide a more detailed account of recording, transcription and analysis in chapter 4.

Being reflexive; As noted earlier, I resist notions of language as a neutral, transparent reflection of reality and support a more relativist perspective that language constructs our understandings. These perspectives have influenced my considerations about writing this report. Attracted to Du Bois'

(1983) description of *'passionate scholarship'*, I tried not to suppress and distance myself from 'the writer' and 'the subjects', and in keeping with my reflexive perspectives I wrote in first person narrative (Hyland, 2002 and Stephenson, 1999). I found it useful to conceptualise my reflexivity as operating at four fuzzy, inter-linking, transactional levels; *being researcher-practitioner, doing interviews, measure of quality* and *being reflexive* (Finlay 1998a and 2002 and Letherby, 2002). In *being researcher-practitioner,* I examined ways in which I influenced the research process. Throughout this doctoral programme I have written reflexive accounts, which informed my choices throughout this project. My attempts to be reflexive throughout my research rest on the argument that it is not possible to separate practitioner from researcher, nor researcher from research. Thus, I resisted dominant hierarchical binaries, such as subjective/objective and insider/outsider. Being reflexive included acknowledging ethics and power dynamics within the research process. *Doing interviews* involved examining ways in which I influenced accounts generated in interviews. This included writing reflexive notes before, during and after all interviews. In *measure of quality,* I considered how my choices influenced the ethics and quality of my project. My b*eing reflexive* is indicated by my writing style and the *'Being reflexive'* section toward the end of each chapter.

In questioning myself in this way, I hope to be transparent, accountable, and more aware of my decision-making. Like Probert (2006) I feel;

> *'The inclusion of self was important academically and personally, and I envisaged my study would lack authenticity without it'* p4.

However, I am mindful that detailed, personal, reflective accounts can feel self-absorbed and alienating. I am particularly wary of self-indulgent 'navel-gazing' that marginalised the experience of others and fails to be of any use in practice (Parker, I, 2005). I have tried to ensure that my reflexivity is not 'off-putting' for the reader.

Being reflexive, I take my research into my practice AND I take my practice into my research. Like Kitwood (1997) I had no plans to *'sit back and pretend';*

> *'My discussion is based, wherever possible, on the findings of research. I am, however, also offering a personal view, derived from*

my own particular struggle to understand the nature and context of dementia...I make no apology for this, for I would rather reveal something of my own convictions and values than stand back and pretend to be totally objective' (Kitwood 1997, p6)

I hope this report reads as a credible account with a sense of lived experience.

Having provided an account of choices I made about writing this report, I will now provide some concluding comments and links to the next chapters.

Concluding comments

In this chapter I have provided an introduction and overview of my research project. This included an introduction to my research objectives and my reasons for undertaking this project. I also outlined the structure of this report and provided an account of my decisions about how to write.

My objective is to explore practitioners' accounts of risk management decision-making in dementia care. However, it was never my intention to judge practitioners' accounts. I support arguments that there are no single, 'right' answers to inform practitioners of *the* best way of being with people who are living with risk and dementia. Clarke et al's (2009) assertion rings true to my experience;

> *'There can be few areas of practice more complex and more contended than managing risks in dementia care,'* p94.

In my research and practice, I ask questions to highlight, explore and better understand some of the assumptions and dilemmas in the changing, ambiguous, complexities of daily practice of risk management in dementia care.

In the next two chapters I review literature. In chapter 2, I focus on risk management and decision-making. In chapter 3, my focus is on dementia care literature, in particular understandings of living with risk and dementia.

Chapter 2 A review of literature; risk management decision-making

Introduction

This is the first of two chapters where I review literature. In this chapter I focus on risk, risk management and decision-making. In chapter 3, my focus is on dementia care literature, in particular understandings of living with risk and dementia, cultures of care and policy. However, my consideration of literature is not restricted to these two chapters. I also examine literature and policy alongside my analysis of practitioner accounts within chapters 5 to 8.

I begin this chapter with an account of how and where I sourced the literature. I then begin my literature review with a brief consideration of uses of the term 'risk'. I continue by examining theoretical concepts of risk and decision-making. Next, I explore the complex, contextual and ethical nature of decision-making in health and social care. I then examine literature on risk management decision-making in health and social care. In the final part of this chapter, I offer some reflexive considerations and provide some concluding comments.

Searching for literature

When reading accounts of literature reviews, my attention was drawn to Riessman and Qinney's (2005) use of fishing metaphors; *'caught in our net'* (p365). This triggered thoughts that some slipped through, some got thrown back, of dredging, trawling, line fishing and occasionally standing still and looking at what flows past.

I used terms from overlapping areas, such as dementia care practice, research epistemologies, methodologies, and theoretical perspectives. Terms used (alone and in combination) included; *risk, dementia, Alzheimer's, decisions, decision-making, wellbeing, quality of life, capacity, ethical, moral, narrative, assessment, management, politics, social policy, care, vulnerable, safety, home, safeguarding, protection, mental health, rights, older people, person-centred, culture, personhood, reflexive, deconstruction, research, analysis, social construction, qualitative, postmodern, discourse.*

Following initial searches, I excluded the term *'disease'*, as this was catching a multitude of medical texts with a focus on neurological and bio-chemical changes in brain structures. After further searching, I favoured searching using *dementia + risk* over *Alzheimer's + risk,* as using the latter dredged up less relevant literature on epidemiological studies of populations at risk from developing Alzheimer's disease.

The time frames I set for this search were publications from 1990 to present day. In this way, I planned to capture literature written at a time of structural and political change in UK health and social care, and literature that examined recent changes in understandings of the nature of dementia and risk. This time limit was also to ensure I could manage and use this literature within the practical limitations of this study. However, when my attention was drawn to particularly relevant earlier publications (such as Norman, 1980), these were also included. In addition, I also included some literature from outside of this timeframe that I was aware of through practice or my previous research (such as Elder, 1977 and Haraway, 1988).

Using the terms as 'bait', I utilised the following overlapping resources and strategies for inclusion;

- Electronic search engines and databases, such as *CINHAL, INTUTE,* and *INTEGA,* to catch articles of interest

- To catch literature that may have slipped through, I also searched within academic electronic journals. I began with journals I knew through experience had articles within my area of interest. These included professional, practice-based and research-focused journals, such as; *Ageing and Society, Ageing and Mental Health, British Medical Journal, British Journal of Social Work, British Journal of Occupational Therapy, Australian Occupational Therapy Journal, Theory, Culture and Society, Dementia, Health and Social Care in the Community, FORUM: Qualitative Social Research,* and *Risk and Society.* I also searched journals not available in academic resources, but I knew through experience may have relevant articles. These included; *Community Care, Open Mind, Red Pepper, Journal of Dementia Care* and *Signpost.* Searching through available content lists helped me to catch relevant articles missed when searching within databases

- As articles were accessed, many provided links to other literature in the references. These were used to expand the search
- I undertook physical and electronic searching using the names of some researchers who have an interest in this area. These were chosen based on my previous knowledge of their work and on advice from others, such as academic supervisors. They included Andy Alaszewski, Clive Baldwin, Chris Boyes, Geraldine Boyle, Dawn Brooker, Cary Brown, Charlotte Clarke, Murna Downs, Jan Fook, Linda Finlay, Caroline Glendinning, Tom Kitwood, Steinar Kvale, Jill Manthorpe, Jonathan Parker, Carolyn Taylor and Sue White
- I undertook electronic searches of books in university and workplace libraries using keywords in library catalogues. I also carried out physical searches of publications in university and workplace libraries. This enabled the possibility of discovering relevant publications not captured with electronic searches.
- I searched within XX trust intranet resources, in particular within practice guidance
- I explored within websites of key relevant organisations, such as; *Age Concern, Alzheimer's Societies, DH, NPSA* and *SCIE*
- I explored research organisations' and university departments' web-sites that I knew from experience undertook research in related areas. These included *Bradford Dementia Group, Mental Health Foundation, Sainsbury Centre, Joseph Rowntree Foundation* and *SPRU*. I searched within these for conference presentations, research papers and online theses.
- I explored within organisational web-sites not already covered, including links within media web-sites such as the *BBC and Guardian Society.*
- I undertook wider searches of the internet, using terms in general search engines and available e-books
- I carried out searches of literature available through OT professional membership groups, including unpublished dissertations.

As my reflexive practice and reading continued, I identified some key considerations for research, including areas where available evidence appeared to be limited. These provide a context for creating my research proposal. Once my proposal was accepted, I continued with more narrowly

focused searches. This included undertaking repeated searches focusing on terms within my research objectives. For example, as indicated in bold;

- ...**decision-*making*** in **risk management** *with people living with a* **dementia**
- *...focus on* **psychological wellbeing** *and* **quality of life**
- *...the* **culture of dementia care** *(in particular the* **Mental Capacity Act***)...*
- *...ways in which* **discourse, narrative** *and* **reflexive analysis** *....*

My searching and selection included a range of policy and practice documents. These were used to inform my planning, research objectives and my secondary level of analysis (see chapter 4). This continual, cyclical process was integrated into my re-reading of practitioner accounts, where my analysis was undertaken alongside key policy and practice documents (Boyes, 2006, DeBellis, 2006, Foucault, 1972, Gordon, 1998, Hill, 2009, Parker, J, 2005, Sarangi and Candlin, 2003, Watson, 2005 and Wetherell et al, 2001).

I am aware that a particular limitation of my literature search was that it only caught publications written in English. Throughout my project I have continued to cast the net, sort, group, reject, use, think and write.

A review of literature on risk management and decision-making

I begin this review by considering uses of the term 'risk'. I continue with an examination of theoretical concepts of risk and decision-making. Next, I explore decision-making in health and social care. I then focus on risk management decision-making in health and social care practice.

'Risk'

> '*Risk is a calculation. Risk is a commodity. Risk is a capital. Risk is a technique of government. Risk is objective and scientifically knowable. Risk is subjective and socially constructed. Risk is a problem, a threat, a source of insecurity. Risk is a pleasure, a thrill, a source of profit and freedom. Risk is the means whereby we colonize and control the future,*' (Garland 2003, p49)

In academic and practice literature there are multiple representations and understandings of *'risk'*. In practice we can be talking about and trying to manage different practice realities.

Historically, *'risk'* was used neutrally to denote chance, destiny, fate, god's will, something we cannot control. It was used by insurers to denote hazards and benefits. With modernism came developments in science and statistical calculations of population 'norms', and *'risk'* became associated with predictions of negative, hazardous events. Definitions have since included some notion of uncertainties and probabilities. Alaszewski et al (1998) suggested that *'risk'* is used as both noun (a consequence, usually emphasising negative) and verb (actions with high probability of loss or harm).

Theoretical concepts of risk and decision-making

A key concept for my research is that understandings of risk influence risk management decision-making. As with much research literature, theories of risk and decision-making are written different perspectives, based on particular assumptions located within different ontological and epistemological perspectives. Such perspectives are often portrayed as hierarchical oppositional binaries where one 'side' is supported by the dominant discourse.

My reading of this literature was influenced by researchers who used Derrida's (1978) notions of constructions and binaries to explore discourse in health and social care. This literature explores and questions dualisms, such as real/constructed, cognition/emotion, objective/subjective and abstract/contextual (Arner and Falmange, 2007, Crowley, 2000, Janks, 2005, Kikuchi, 2006, Macleod, 2002, Oakley, 2000, Paley, 2002 and Stanford, 2007). In my analysis I examine such binaries within practitioner accounts

I will now explore some realist perspectives of risk and decision-making, and continue with a consideration of social, structuralist and post-structuralist perspectives. Along this continuum accounts differ in relation to how much value is given to concepts such as objectivity, construction, context, interpretation, power and relationships.

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Literature from realist perspectives mostly represent risks as objective hazards that exist independent of context and interpretation, and can be measured and controlled;

> *'Realist ontologies of risk accord to the view that risks are real – they exist independently of interpretative processes. On the basis of this viewpoint, various people, events and experiences can be regarded as independently comprising a risk in and of themselves'* (Stanford 2007, p30).

Much of this literature argues that risk can and should be reduced to separate components to be measured, predicted, controlled and managed in the natural world <u>and</u> social world. This 'modern' approach was a move away from hazards being determined by gods (fate), to being controlled by people and their science.

This literature is particularly influenced by psychological cognitive information processing theories, and by statistical probability theories popular in economic risk calculations. Decision-making is represented as logical, rational, objective, linear stages. People are likened to computers –retrieving and acting on stored information (like 'evidence'). From this perspective, decisions are analysed by examining each of stage of the process, and decision-making is portrayed as undertaking individual cost-benefit analysis (weighing up 'risks' and 'benefits'). It is assumed that people make rational decisions to minimise the probability of harm from objective hazards.

However, such perspectives often fail to take account of 'errors' in cognition and perception that can occur when making complex, contextual decisions. Although useful in some technical aspects of healthcare, the most reductionist approaches can be based on over-simplistic, de-contextualised notions of health, and the myth that there is a scientific solution for everything. They can fail to acknowledge the influence of daily complexities, such as emotions, socio-cultural assumptions and contexts. Such approaches can therefore be inadequate in complex, chaotic, uncertain and highly contextualised health and social care practice (Brown et al, 2008 and Taylor and White, 2000). Other concepts of risk and decision-making pay more attention to emotions and contextual complexities.

Some psychological literature considers subjectivity, emotions and social factors. Based on my experience, some 'post-war' psychological theories remain influential in discourse and practice. Festinger (1957) introduced the notion of *'cognitive dissonance'*, arguing that we modify our interpretations and behaviour in an attempt to avoid cognitive conflict. He suggested we reduce such dissonance by being selective in our attention, perceptions and interpretations. The concept of a closed cognitive loop was used to represent how we pay more attention to information that is consistent with our assumptions. From this cognitive-social-learning perspective we are seen as information processors, who select and simplify complex, contextual, subjective experiences using *schemata;* cognitive frameworks for organising, interpreting and recalling information. It is argued that *schemata* influence our interpretations and assumptions in decision-making. Such concepts informed influential social-psychological concepts of labelling and stereotyping. Goffman (1956) argued that cognitive dissonance is an adaptation to social contexts. He introduced the notion of presentation of the self, to explain how we manage our social self to ensure acceptance. Heider (1958) attempted to explain behaviour using the concept of attribution, proposing that we seek causes for events, in order to maintain some control. Such causes are seen to reside either within the person (internal) or be contextual/environmental (external). These concepts continue to be influential in health and social care literature (Dawson, 2006, Innes et al 2004 and Scholl and Sabat, 2008).

Some literature is more focused on subconscious decision-making. For example, psychological defence mechanisms, such as withdrawal and denial are understood as protecting us from emotional pain/conflict. These perspectives overlap with humanistic psychology, which rejects behaviourist generalisations from animal behaviour, and Newtonian, cognitive inferences to humans as machines. Influenced by existential phenomenology, humanistic perspectives maintain that behaviour is associated with norms of acceptability within dominant ideologies (Rogers, 1961 and Kitwood, 1997).

Other perspectives on risk and decision-making include sociological, post-modern and critical perspectives. This literature examines interpretative, contextual, subjective notions of risk as socially constructed and constructing

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(Henwood et al, 2008, Heyman et al, 2010, Kemshall, 2002, Lupton,1999, Lupton and Tulloch, 2002 and Taylor-Gooby and Zinn, 2005). Recent literature from these perspectives continues to cite Douglas, Beck and Giddens as influential theorists. Douglas (1990) examined the influence of underlying structural, historical, political and cultural contexts on concepts of risk and decision-making. Risks are understood as contextual constructions;

> '...risk operates as a political construct that actively and materially constitutes the living conditions of people...defining and recognising 'what is a risk' cannot be separated from the operations of power, in various social, political or cultural contexts,' (Stanford 2007, p57).

From post-structural perspectives, Beck and Giddens argue that contemporary society is organised according to concepts of risk. This global/macro theory represents risk as endemic, incalculable, uncertainty. Beck (1992) proposed that risk is an unintended consequence/side-effect of industrialisation and fragmented identities. He also suggested a lack of trust or faith in 'experts'. Giddens (1994) portrayed a political shift from focusing on need, to focusing on risks, with a corresponding shift in responsibilities from social to individual. We each become individually responsible for protecting ourselves or putting self at risk (for example taking measures to stay healthy). These perspectives can be seen within recent governments' *modernisation* strategies (DH, 1998a, 1998b).

Foucault's (1972, 1980 and 1989) post-structural writings on *governmentality* explore relationships between power, knowledge and decision-making. Foucault (1980) challenged critical theorists' concepts of power residing with individuals or groups. Whilst acknowledging that certain institutions are powerful (such as education or psychiatry), he focused on social relationships and micro-dynamics of power. Rather than the institutional dynamics of Goffman (1961), he proposed that 'truths' are created and maintained, and power is embodied, by micro, local, diffuse, daily and 'discursive' practices (such as risk assessments and training). He developed the notion of *governmentality* to explain how institutions organise and exert power. He argued that complex and intersecting structures and institutions (for example universities, DH and clinical governance) control/govern people and their perceptions, interpretations and decision-making from a distance.

In this way, they shape decision-making and practice, towards 'norms' and 'common sense' understandings (dominant discourse) (Candlin and Candlin, 2002, Petersen and Bunton, 1997, Rose et al, 2006 and Stanford, 2007). From this perspective, dominant discourses influence understandings and decisions. For example the nature of risk is constructed through talk and social processes, and controlled through risk management policies, procedures and practice. Foucault also suggested there is a possibility of resistance, which can lead to some changes. However, such changes can be superficial with dominant ideologies, discourse and power dynamics remaining (Pollard, personal communication, 2011).

Post-structural literature considers how risk is constructed within 'self', and within relationships between people and wider society; along a micro, meso and macro continuum. In daily practice, I am reminded that ideas about risk (such as who is at risk, why and what from) can be constructed. However, I am also regularly confronted with examples of how the dangers and hazards of living with a dementia can be very real (for example being moved out of your home against your will, being ignored and falling downstairs).

These concepts are examined further alongside my analysis of practitioner accounts of decision-making.

Having considered some accounts of risk and decision-making in general, I will now continue with an examination of some literature on decision-making in health and social care.

Decision-making in health and social care

My research and practice are influenced by literature on complex, contextual, ethical decision-making in health and social care practice. It is my experience that practice can be chaotic, is forever changing, and practitioners do not simply act as objective processors or followers of rules. Influenced by socio-cultural, structural and post-structural perspectives, some practice-focused literature argues for a need to consider underlying structural, historical, ethical, political and cultural contexts. I am particularly influenced by literature that examines the influence of ideology and dominant discourses in government policy and decision-making in mental health, social work and OT practice (Bracken and Thomas, 2005, Brown et al, 2008, Hammell, 2009,

Higgs et al 2004, Humphries, 2003, Jenkins, 2001, Stanford, 2007 and Taylor and White, 2000). Like Brown et al (2008), I see some merit in attempts to;

> '...scrutinise prevalent modernist assumptions that guide clinical decision-making and problem-solving,' p1.

Influenced by Foucault's notion of *governmentality*, it is my understanding that policies and practice guidelines 'govern' practitioners' risk management decision-making. In this way, policies form part of the discourse <u>and</u> the contextual realities and restrictions on decision-making in practice. For example, policy and practice discourse instructs practitioners that their practice should be evidence-based. In healthcare, dominant perspectives on decision-making are based on probability and cognitive theories. Healthcare discourse on evidence-based practice (EBP) rests on the assumption that 'best' evidence derives from randomised control trials (RCTs). However, such versions of decision-making and EBP are limited and the status of what counts as evidence is contested. I am persuaded by health and social care literature that questions and challenges dominant healthcare discourse on EBP (Ballinger and Cheek, 2006, Blair and Robertson, 2005, Crowe and O'Malley, 2006, Duncan and Nichol, 2004, Fook and Gardner, 2007, Gordon, 1998, Hall and White, 2005, Higgs et al 2004, Hugman, 2005, Humphries, 2003, Polkinghorne, 1992 and Taylor and White, 2000).

In examining literature on decision-making, I am also mindful of hierarchical dichotomies such as skills/knowledge, art/science and cognitive/emotional. Based on my experience, I support literature that asserts the importance of emotions and subconscious on decision-making in uncertain, daily, practice. In health and social care literature, such perspectives are attributed to the work of Benner (1984), Schon (1987) and Mattingly and Fleming (1994). Literature from this perspective resists reductionist objective, scientific, cognitive perspectives, and explores differences in decision-making between 'novice' and experienced practitioners, and use of 'intuition' in decision-making. Similarly, Bourdieu (1990) argued that decision-making in practice is not always a rational choice. He suggested decision-making is contextual, and as we become more experienced it becomes less rule-based and less conscious. In this way decision-making in practice can be more reflexive,

improvised, practical, implicit, with a *'fuzzy logic'* (Bourdieu 1990, p87) (Hancock and Durham, 2007, Stalker, 2003, Thompson and Dowding, 2001, and Thompson et al, 2002).

With an interest in philosophy, psychology, neurology and mental health, I am also drawn to the writings of neuroscientist Damasio (1994 and1999), who argues that emotions are essential to rationality and decision-making. Influenced by Damasio, Taylor and White (2001) argue that emotions and ethical judgements have a central role in complex, reflexive decision-making in social work practice;

> *'Emotions are not the messy and recalcitrant enemies of rationality, but are absolutely integral to the process of decision making ...By placing feelings in their proper role, Damasio and others force us to confront the moral nature of our professional practices'* p52.

Zinn (2008) argued there may be no 'right' way to undertake decision-making in the uncertainty of complex practice, and proposed the usefulness of *'in-between strategies'* (p442); risk management decision-making that is between rational and irrational.

I am influenced by arguments that decision-making is guided by what feels right, based on reflexivity, intuition, embodied knowledge, emotions and social relationships. When making decisions we have 'feelings about', 'feelings for' and we can 'feel as though'. In my analysis, I explore non-dichotomous representations that enable understandings of risk and decision-making along a continuum of different perspectives, such as real-constructed, individual-social, objective-subjective, rational-emotional (Alaszewski and Coxon, 2009, Bourdieu, 1990, Crawshaw and Bunton, 2009, Taylor and White, 2000, Williams, 1995 and Zinn, 2004, 2007, 2008).

This literature also includes explorations of ethics and ethical dilemmas;

> *'Ethics is, simply put, the study of what is good and bad, right and wrong, and of moral duty and obligation. It also includes the values and principles of conduct governing an individual or a group,'* (Clark et al 2007, p591)

Dominant discourses in healthcare literature on ethical decision-making include dichotomous portrayals of outcomes (*utilitarianism*) as opposed to duties (*deontology*). Utilitarianism is attributed to the 18th century writings of

Bentham, developed by John Stuart Mill, in the early 19th century (Beauchamp and Childress, 2009). From utilitarian perspectives moral judgements are about maximisation; the greatest good for 'the majority'. This approach may include economic theories, for example focusing on resources, using cost-benefit analysis. This perspective is also known as consequentialism, as decisions about what is best are based on the consequences of actions;

> '… the best action in a specific situation is the one most able to reach the value goal in question, and is therefore the right one to be chosen' (Bolmsjo et al 2006, p342).

It is easy to see the appeal of this approach, in particular attempts to make best/efficient use of scarce resources and choose support/services that have the best results. Examples of utilitarianism are evident in dominant discourses supporting EBP, and in literature on economic decision-making in dementia care (Alzheimer's Society, 2007a and NIHCE, 2011).

However, in risk management decision-making there are ethical dilemmas about how to choose, prioritise and predict outcomes. For example, how can we accurately predict the future? Is utilitarianism about 'majority' or most powerful/valued? What about 'the minority'? How do we know what is best? I explore these questions in more detail in later chapters, in particular when analysing practitioner accounts against policy guidance.

Deontological perspectives are attributed to Kant, an 18th century philosopher who advocated unconditional respect and universal moral judgements. Deontology focuses on actions and process, in particular the person taking action and their sense of duty. From this perspective decision-making is about practitioners doing the right thing by following universal rules and principles, not dependent on individual or contextual differences. Such rules include professional duties and codes, religions, legislation and cultures. However, in practice there can be dilemmas if we are unsure how to choose between consequences and duty, or when principles conflict. As an alternative to Kantian ethics of principle, some health and social care literature supports an argument for an ethics of care (Banks, 2001, Gilligan, 1982, Jaeger, 2001, Kitwood, 1998a, Sevenhuijsen, 2000 and Tronto, 1993).

Throughout this report I examine ethical perspectives within health and social care discourse. In chapter 3, I review literature on ethics, with a particular focus on dementia care. I also examine ethical decision-making alongside my analysis of practitioner accounts, in chapters 5 to 8.

Having reviewed some literature on decision-making, I will now explore literature on risk management.

Risk management decision-making in health and social care

Risk management decision-making in health and social care literature, includes practice guidance, policies and legislation. This literature is dominated by epidemiological accounts of the biomedical and economic risks of disease and legal perspectives, such as 'health and safety'.

The prevailing discourse in literature and practice upholds realist perspectives. Risk assessments are presented as part of a logical process, consisting of assessment, management, intervention, evaluation and reassessment. Practitioners can discover objective truths, as long as we assess in the correct way (using the 'right' tools or following the 'right' guidelines). However, risk management policy and guidelines are written from different perspectives. They can be ambiguous, inconsistent, conflicting and contradictory. Risk management is portrayed as both a technical and a social process. Within healthcare discourse, accounts that support more constructionist, subjective, critical, political, perspectives of risk management are present but marginalised (Currie et al 2008, Heyman et al 2010, Mitchell and Glendinning, 2007, Thompson, 2006 and Titterton, 2005).

In 2001, in response to media publicity about high profile *'adverse events'*, the government created the National Patient Safety Agency (NPSA). They have responsibility for the development of national policy, regulation and training on *'patient safety'* and *'adverse incidents'* in the NHS. Their publications support objectivist, realist and logical perspectives of risk and are influential in strategic, 'trust' level risk management (Cornish, 2005, Currie et al, 2008, Macrea, 2008 and XX Trust, 2008). In my experience, a key aspect of NPSA's strategy is how we respond to *adverse incidents* in practice. Alaszewski and Coxon (2008) argue that practitioners see this practice as protecting the organisation and looking for someone to blame. I

feel more ambivalent. However, I am mindful that NPSA's objectives include the management of financial risks to the NHS;

> *'It is essential that risks can be rated in a common currency within NHS trusts, allowing financial, operational and clinical risks to be compared against each other and prioritised'* (NPSA 2008, p12).

Their risk assessment guidance states;

> *'Calculate the risk score by multiplying the consequence by the likelihood: C (consequence) × L (likelihood) = R (risk score)'* (NPSA 2008, p10).

I can see the appeal of such approaches, for practitioners and managers. Statistical calculations portray clear, scientific-looking decision-making. The complexities, uncertainties and dilemmas of practice can appear less complex and more certain. It is as though we can control and manage risks;

> *'Objectifying risk as a calculable entity renders it governable and controllable. Accordingly, those who become associated with risk (such as welfare clients) are similarly rendered calculable, governable and controllable'* (Stanford 2007, p47).

However, based on my experience, I support literature that questions NPSA discourse;

> *'...the meaning of terms such as ... 'serious untoward incident'...were quite fluid, and frequently contested. This suggests that...'patient safety incidents' are not stable realities. They are constructed and interpreted within specific organisational and professional contexts...'* (Cornish 2005, p42).

Practitioners are not information processors or automatons. Narrow, statistical approaches in risk management guidance can act as a barrier to the skilled, interpersonal communications that are essential for risk management decision-making in the complexities of practice (Bessant, 2004). I support literature from more subjective, contextual perspectives, where the nature of risk is contested and practitioner subjectivity is considered as part of the decision-making process (Alaszewski and Coxon, 2008 and Shaw, 2010).

Some health and social care literature examines 'risk averse' decision-making and 'blame cultures' in health and social care (Alaszewski et al 1998

and 2000, Cornish, 2005, Department of Health, 2000, Douglas, 1990, Heyman et al 2010, Kemshall, 2002, Manthorpe, 2004, Nicholls et al, 2006, Stamp, 2000 and Titterton, 2005). This literature explores practitioners' fears of blame, defensive practice and organisational risks (such as reputation and financial). Titterton (2005) argued that risk assessments undertaken by health and social care practitioners are located in two theoretical perspectives;

> '...the risk-taking model (risk is normal and positive and assessment focuses on mental wellbeing, rights, abilities, choice and participation); and the risk minimisation model (which targets those most at risk and assessment focuses on physical health, danger, control and incapacity)' p82.

This dichotomous perspective continues to be represented, although other literature also represents practice as located within a continuum from risk-taking to risk-minimisation.

Some literature explores practitioners' use of risk assessment 'tools'. Douglas (1990) and Kemshall (2002) suggested that anxieties about blame and individual accountability have led practitioners to rely less on their decision-making skills and more on prescriptive risk management tools to justify their practice. However, Stanley (2005) argued that such a reliance on risk assessment tools can move the emphasis and liability from the organisation to the practitioner. Godin (2004), Mitchell and Glendinning (2007) and Reich et al (1998) reported that practitioners had some knowledge of formal risk assessment tools, but also used other approaches to risk management decision-making. They also reported that practitioners talked about being influenced by previous experiences, and acting on intuition and gut feelings. Unlike NPSA, some recent practice guidelines in dementia care (in particular Manthorpe and Moriarty, 2010 and Nuffield Council on Bioethics (NCB), 2009) consider ethics, psychological wellbeing and the positive opportunities of risk-taking within risk management decision-making. I explore these policy documents throughout this report.

Some health and social care literature examines the governments' *modernisation* of the welfare state, in particular the shifting focus of assessments from *need* to *risk*. Some literature represents these changes as

attempts to limit state expenditure and involvement in care provision. Concerned with increasing expenditure in community care, New Labour introduced guidance on assessing for eligibility (DH, 2002a, updated in 2010a). Within this guidance, DH represented risks in a framework of four bands: *Critical, Substantial, Moderate* and *Low.* Following this guidance, people previously assessed to be 'in need' of services, were reassessed and found to be no longer eligible. This utilitarian approach to rationing care provision resulted in a gradual tightening of criteria, which has increasingly involved practitioners in ethical dilemmas based on the rationing of state services. In his review of social care provision for older people in England, Wanless (2006) described resources that were not adequate to respond to the changing demographics. I support Lloyd's (2006) argument that stricter eligibility criteria left practitioners *'with little room for manoeuvre'* (p1173). (Cestari et al, 2006, Dunning, 2010, Green, 2007, Graham, 2004, Griffiths, 2001, Hudson and Henwood, 2008, Jaeger, 2001, Kemshall, 2002, Lymbery, 2010, Scourfield, 2006, Stanford, 2007, Waterson, 1999 and Wilks, 2005).

During the 1990's other developments, such as 'Public Private Partnerships' and 'foundation trusts', strengthened the outcomes focussed culture and increased private investment and ownership of the public sector (McMaster, 2002b). With an eye on financial outcomes as a measure of 'performance', I was saddened but not surprised by the report on poor quality of care provided by Mid Staffordshire NHS Foundation Trusts;

> *'Its strategic focus was on financial and business matters at a time when the quality of care of its patients…was well below acceptable standards…'* (Healthcare Commission 2009, p134).

I agree with the Commission's argument that trusts need to;

> *'…ensure that a preoccupation with finances and strategic objectives does not cause insufficient focus on the quality of patients' care…'* (Healthcare Commission 2009, p136).

…but I am not convinced this is possible without a shift in the current ideology of health and social care policy.

Having provided a literature review of risk management and decision-making in health and social care, I now offer some reflexive considerations and concluding comments.

Being reflexive

As stated in chapter 1, a key motivation for embarking on this project was my practice experiences, which prompted me to read around and consider research. My explorations of literature began before this project and will continue after it. In undertaking these literature reviews, I have tried to cast my net wide enough to develop my knowledge and inform my research, without wandering too far from my research objectives. I have questioned my assumptions and assumptions within the literature. I have tried to be open about and mindful of my *'theoretical baggage'* (Mason 2002, p6).

Concluding comments

This is the first of two literature review chapters.

I began this chapter with an account of how I carried out my literature review. The focus of my literature review in this chapter has been on risk management decision-making in health and social care. This included an examination of theoretical concepts of risk and decision-making. I also explored literature on complex, contextual and ethical understandings of decision-making and risk management in health and social care practice.

In chapter 3, my review is focused on dementia care literature, in particular understandings of living with risk and dementia, cultures of care and policy.

I also integrate some of my explorations of literature and policy within the analysis chapters, so they can be examined alongside my analysis of practitioner accounts.

Chapter 3 A review of literature; living with risk and dementia

Introduction

This is the second of two literature review chapters. In chapter 2, I provided an account of sourcing literature and examined some literature on risk management and decision-making in health and social care. In this chapter my focus is on dementia care, dementia care policy and living with risk and dementia.

I begin this chapter with an exploration of research literature on practitioner accounts of risk management in dementia care. I then review some literature on policy and dementia care. Next, I explore literature on assessments, ethical decision-making and risk policy in dementia care. I follow this with a review of some key concepts within this literate that are related to my research; *vulnerability, quality of life* (QoL) and *psychological wellbeing.* In the final part of this chapter, I offer some reflexive considerations and provide some concluding comments.

Practitioner accounts of risk management and dementia care

In 2002, Alaszewski and Horlick-Jones reported that since the late 1990's, there had been an increase in literature exploring risk management in health and social care. However, relatively little of this literature had explored *practitioner accounts* of risk, and most did not focus on dementia care. Only two studies in their review explored practitioner accounts of risk management decision-making in dementia care (Stamp, 2000 and Clarke, 2000). Stamp (2000) proposed several reasons why practitioners may be risk-averse when working with people living with dementia. These included pressure from family, practice cultures and concerns for safety (often over-riding the wishes of the person living with a dementia). Clarke (2000) portrayed important differences between the perceptions of practitioners, family carers and people living with a dementia;

> *'...practitioners may emphasise the physical domains of risk identification, such as risk of self harm or the risk of falling. People with dementia, however, may emphasise biographical domains of risk such as loss of self identity...'* p84.

Since 2000, a few more researchers have examined practitioner accounts of risk management in dementia care. Karlsson et al (2000) investigated nurses' justifications for using physical restraints when working with people living with a dementia. They suggested a need for further research to explore practitioners' ethical dilemmas in dementia care risk management. Gilmour et al (2003) undertook a study with 10 people living alone with dementia, family carers and practitioners. They reported that practitioners perceived key areas of risk as hazards relating to heating, cooking, falling and getting lost. Although these were similar to the 'physical domains' indicated by Clarke (2000), Gilmour et al (2003) did not present any difference between family carers' and practitioners' perceptions of risks. They concluded there was a lack of research exploring how practitioners understand and assess risk with people living with a dementia. Based on interviews with 17 practitioners, Corner (2003) recommended;

> *'Future research needs to examine the ways that risks are perceived during the care and support of people with dementia and how risk assessments by care givers and professionals impact on their quality of life,'* p107.

Although published too late to inform my research proposal, some more recent literature exploring practitioners accounts of risk management informed my project (Clarke et al, 2009, 2010, 2011a, Mitchell and Glendinning, 2007, Robinson et al, 2007 and Waugh, 2009). Whilst I have been undertaking my project, Clarke and colleagues have published several related articles. Initially Clarke et al (2009) undertook a survey of perceptions of risk with people living with a dementia, their carers and practitioners. They stated that practitioners reported different understandings of risk management, including attempts to avoid physical harm and risk-taking. Next, they undertook collaborative learning groups with 20 practitioners. They argued that practitioners' risk management decision-making is influenced by conflicting aspects within care systems. They concluded that practitioners' assessments prioritise certainty and physical risks over psychological wellbeing.

Mitchell and Glendinning (2007) reviewed risk research in adult social care. As noted in chapter 1, they suggested a need for future research to examine how practitioners managed risks of damage to psychological wellbeing.

Robinson et al (2007) undertook two focus groups with ten health and social care practitioners. They suggested that key factors influencing practitioners' risk management decision-making include fear of litigation and attempts to balance a duty to minimise harm with a persons' right to autonomy.

Waugh (2009) undertook research with five practitioners who worked in community care in Australia with people living with a dementia. She argued that ethical considerations are important to practitioners' decision-making, and that practitioners' main focus was not always risk.

I explore this literature further in later chapters, in particular alongside my analysis of practitioner accounts.

I will now review some literature on key policy changes in dementia care.

Government policy and dementia care

Since the 1970's, governments have been increasingly concerned with how to 'square the welfare circle'. In 1983, the Health Advisory Service warned of the *'rising tide'* of people with dementia, who would *'overwhelm the entire healthcare system'* (Health Advisory Service, 1983). Alongside such catastrophic predictions, reports were commissioned to investigate public funding in community care. Recommendations included plans to reduce spending on residential care for older people, and resulted in the *NHS and Community Care Act*, 1990. Health and social care has since been dominated by the 'quasi' market economy as *the* way of reducing expenditure. Successive governments have developed this notion, with *modernisations* of state services (DH, 1998a, 1998b) and *liberation* of the NHS (DH, 2010c). A key strategy within *modernisation* has been *personalisation* of adult social care. In 1990s, the government introduced *Direct Payments*, portraying these as increasing opportunities for choice and control (DH, 2005). In 2006, consumerism was developed through *Individual Budgets* (DH, 2006, 2007a). This allows Local Authorities to calculate 'need' as an amount of money, which people can use to buy services, such as personal care (Manthorpe et al, 2009 and MHNE, 2010). These policies mark

a shift away from a comprehensive Welfare State, to a belief in individualism and business ideologies (Bracken and Thomas, 2005, Carey, 2008, Harrison and Smith, 2004, Humphries, 2003, Jones-Devitt and Smith, 2007 and Stanford, 2007).

Given this emphasis, it's hardly surprising that managers have increasingly demonstrated quality through use of economic performance statistics. Old people are an obvious target in this consumerist ideology. Changes in government ideology and discourse have redefined ageing as an expensive medical condition. Health has become an economic judgement, and 'positive', 'successful' ageing are economic directives (Ahmad and Broussine, 2003, Cowen, 1999, Estes et al, 2003, Jenkins, 2001, May and Buck, 1998 and McMaster, 2002a and b). Based on my experience, I support Higgs' (1997) suggestion that consumerism does not work for some people, because exercising choice can be difficult or impossible.

Like Seymor (2006) and Pollard et al (2009) I see my practice as critical and political. From critical perspectives, 'Western' medicine and policies construct ageing people/bodies as a problem, and marginalise social and contextual factors, such as poverty and isolation. Estes and Binney (1989) named this construction the *'biomedicalization of ageing'*. Kitwood (1997) argued that dementia is also bio-medicalised, and this *'alzheimerization of dementia'* shapes dominant 'Western' perceptions. In addition, Bourdieu's concept of *symbolic cultural capital* rings true to my experience (Calhoun et al 1993). Contemporary 'Western' society privileges cognitive abilities, objective knowledge and abstract rationality over subjective knowledge embedded in a specific situation. From such societal perspectives, people living with a cognitive impairment have less capital (value) and are disempowered. Some literature examines the potential of Bourdieu and critical theories for exploring dementia care (Angus et al, 2005, Bartlett and O'Connor, 2007, Bond et al, 2004, Brannelly, 2004, Brijnath and Manderson, 2008, Graham, 2004, Kontos, 2005, Parker, 2007, Post 1995, Rhynas, 2005 and Scholl and Sabat, 2008). These critical perspectives influence my understanding of political decision-making and resource allocation in dementia care.

Discourse on demographic changes (see chapter 1) continues to create and maintain a 'truth' that people living with dementia are an economic burden of little value;

'NHS facing dementia time bomb' (Roberts 2007, p9).

Although Alzheimer's Society publishes demographic statistics that contribute to such discourse, they are critical of such representations;

'Many people talk about the 'demographic time bomb' or 'tidal wave' of older people which the state cannot afford to cater for. The Society believes that this is misleading,' (Alzheimer's Society 2011b, p6).

However, the disaster discourse of dementia continues;

'...in the future, the risk of dementia increases as people live longer, and the emotional, social and economic burden we all will face if this threat is left unchecked will be catastrophic...' (Windsor 2009, p3).

The growth in the number and proportion of older people living with a dementia is clearly a major demographic and economic consideration (Alzheimer's Society, 2007b and 2011a). Nevertheless, there are alternative economic and values-based discourses. For example the Alzheimer's Society (2007b) estimate that unpaid carers of people living with a dementia 'save' the state £6 billion a year. There is also much discourse that values people who live with a dementia (see Brooker, 2007, Downs and Bowers, 2008, Hughes and Baldwin, 2006, Hughes et al, 2006, Innes et al, 2004, Marshall and Allan, 2006, NCB, 2009, O'Connor and Purves, 2009, Parker, 2001 and Perrin et al 2008).

I resist consumerist interpretations of care and worth. However, there is only so much resistance possible when care is being *modernised* and *liberated*. Whilst increasing the rationing of social care (DH, 2002a) the government also introduced *'payment by results'* into healthcare. This involved developing national codes, care pathways and costings within the NHS (DH, 2002b). Six years later they began to implement this policy in mental health services (DH, 2008 and Jacques, 2008). Some NHS trusts (including where this project was undertaken) are currently part of a national *Care Pathways and Packages Project* (CPPP) to develop systems that use 'tariffs' for commissioning mental health services. Practitioners are instructed to 'group'

people who use mental health services into medicalised 'clusters' using the *'Mental Health Clustering Tool'* for guidance;

> *'Use the decision tree ...to decide if the presenting needs are non-psychotic, psychotic or organic in origin, then which of the next level of headings is most accurate. This will have narrowed down the list of possible clusters,'* (CPPP 2010, p3).

CPPP trusts are generating this information in preparation for developing agreed cost of 'treatment' for a particular unit (*cluster* group). The government plans to have nationally agreed 'tariffs' for mental health care by 2014. The dominant discourse used by CPPP and DH in *payment by results* publications, is from rational, instrumental, technical, cognitive, realist, medicalised perspectives of decision-making (see Self et al, 2008). The practice guide has a clear focus on labelling and costing;

> *'PbR is a different way of funding providers in order to provide the right care to service users. A PbR funding system has 4 basic elements/steps:*
>
> *1. Capturing the number of service users treated.*
>
> *2. Allocating each patient to a classification system.*
>
> *3. Agreeing what should be provided for people in each cluster.*
>
> *4. Agreeing a price for each group/cluster in the classification system that means providers can afford to deliver the agreed care,'* (CPPP 2010, p6).

Influenced by practice experiences and Foucault's (1980) *governmentality*, I see this tool as a strategic way in which government institutions organise and exert power in practice. This guidance creates, promotes and maintains a 'truth' of living with risk and dementia, through this daily, discursive practice.

Having explored some literature on policy, I will now review some literature and policy on assessments and dementia care.

Assessments and dementia care

Dementia care literature and policy on how, why, who, when and what to assess, reflect different theoretical perspectives. Practitioners' assessments are guided by numerous overlapping and sometimes conflicting considerations, such as professional roles, previous experiences, the person

they are assessing, the objectives of the assessments, training, research literature, assumptions, emotions, policy, procedures and legislation (Adams and Manthorpe, 2003, Downs and Bowers, 2008, Long and Cronin-Davis, 2006, Marshall and Tibbs, 2006, Parker and Penhale, 1998 and Perrin et al 2008).

In 1990, the NHS and Community Care Act introduced a legal right to assessment. Within this policy, government discourse presented needs-led assessment and care management as the 'cornerstone' of good quality community care. Since this legislation, there have been several government policies that have influenced assessments in dementia care, including *National Service Frameworks* (DH, 1999 and 2001), the Mental Capacity Act, 2005, *Mental Health Clustering Tool* (CPPP, 2010) and eligibility guidance (DH, 2002a and 2010a). As already noted, some policies shifted the focus of assessments away from *needs* toward *risks* and/or costs.

Also during the 1990's, dominant 'Western' bio-medical/neurological discourse on dementia was increasingly criticised for privileging individual neuropathology, and discounting socio-cultural contexts. Kitwood (1997) developed theories of dementia into more complex trans-disciplinary understandings and argued for changes in dementia care. The 'old culture' of dementia care was portrayed as being too narrow, focusing on neurological changes, and technical assessments and treatments that attempt to measure/slow down/stop/prevent these changes. He proposed 'new culture' perspectives, advocating more complex, contextual and person-centred understandings, which prioritise personhood and wellbeing. 'New culture' assessments go beyond neurological/cognitive/biological impairments to consider how contexts (such as inter-personal communications, relationships, social, spiritual and cultural) influence a person's experience of living with a dementia (Kitwood and Bredin 1992, and Kitwood and Benson, 1997). Kitwood (1997) explored the use of *'access routes'* (p73) in assessments, such as using life stories and focused observations. He argued that such assessments enable greater understandings of *the person* living with dementia, rather than assessments of *dementia* (hence my continued reference to *'person living with dementia'*).

Since Kitwood's death in 1998, the Bradford Dementia Group has continued to question, develop and reconstruct understandings of dementia and good practice in dementia care, through training, research, and practice guidance. Much research and practice literature has since examined the importance of relationships, communication, ethics and contexts in assessments with people living with a dementia. From this perspective, a key 'outcome' of dementia care (including risk management) is to maintain and enhance relationships, personhood, QoL and wellbeing (see Baldwin and Capstick, 2007, Bartlett and O'Connor, 2007, Boyle, 2008a, Brooker, 2007, Clarke et al 2010, Downs and Bowers, 2008, Godfrey at al, 2005, Hoe et al, 2009, Hughes and Baldwin, 2006, Innes et al, 2004, Manthorpe and Moriarty, 2010, NCB, 2009, Nicholls et al, 2006, O'Connor and Purves, 2009, Parker, 2001, Perrin et al 2008 and Ryan et al, 2008).

Both 'old' and 'new' culture perspectives are evident in assessments in contemporary dementia care. Advances in technology continue to promote 'scientific' understandings of dementia, focusing on neurology and genetics. For example computerised tomography scans measure brain atrophy and post-mortems explore changes in neurotransmitters. In addition, cognitive performance tests are widely used to estimate cognitive abilities and impairments. In practice, I regularly witness the misuse and over-interpretation of standardised, cognitive assessment tools, in attempts to fit people into cognitive-neuro-medicalised constructions of dementia (see *Mini-Mental State Examination*, Folstein, et al 1975). These assessments may provide a rough estimate of de-contextualised cognitive functioning, but they are routinely and mistakenly assumed to indicate levels of functional skills and lived experiences. The scores created by these assessments are attributable to more than medical and neurological damage. They can also indicate wider psychological, social, contextual factors, such as anxiety in 'performance', communication and literacy skills, context of assessment and assessors' subjective interpretations (Downs, 2000, Downs and Bowers, 2008, Estes and Binney, 1989, Hughes and Baldwin, 2006, Kitwood, 1997, Perrin et al 2008 and Scholl and Sabat, 2008).

Having reviewed some accounts of assessments, I will now explore some literature on ethics and decision-making in dementia care.

Ethics and decision-making in dementia care

As noted in chapter 2, from utilitarian perspectives, ethical decision-making is based on predicting best outcomes for most people. From deontological perspectives, decision-making is about doing the right thing by following rules (such as cultural, legislation and professional codes). In healthcare, Beauchamp and Childress' (2009) ethical framework has been particularly influential. It has been incorporated into the *Code of Ethics* of several professions and is evident in much of the literature on ethical decision-making in dementia care. Beauchamp and Childress (2009) argue that healthcare practitioners should practice in accordance with four principles; *beneficence, non- maleficence, autonomy* and *justice*, following the strongest if principles conflict. *Beneficence* is about trying to do good and be helpful to others, and *non-maleficence* is about trying to ensure that we do not harm others. In practice both are inextricably entangled with *autonomy, justice* and wellbeing. *Autonomy* is a key feature in explorations of ethics in dementia care literature and policy. According to NCB (2009);

> *'Autonomy is often defined as 'self-rule', 'making your own choices', 'ability to live independently' or 'right to self determination'* p26

Ethical dilemmas explored in dementia care literature include how to make decisions that respect autonomy, whilst also considering best interests, for example;

> *'Many of the ethical tensions that arise in looking after people with dementia do so because of, on the one hand, the requirement that autonomy ought to be respected and, on the other, the realities of increasing dependency, where this entails loss of personal freedom,'* (NICE/SCIE 2006a, p99).

Rather than attempting to resolve ethical dilemmas by making either/or choices between conflicting ethical principles, some literature represents principles along continuums from universal to contextual perspectives. For example from individual autonomy to autonomy that is negotiated, with a focus on inter-personal relationships, interdependence and contexts. Some feminist ethics literature questions 'Western' notions of autonomous individuals and argues for more relational understandings of autonomy that

acknowledge the influence of emotions on ethical decision-making (Benhabib, 1986, Gilligan, 1982 and Jaeger, 2001).

Influenced by Kitwood (1997 and 1998a), much of the literature on autonomy in dementia care considers relationships and psychological wellbeing. McCormac (2001) made a useful distinction between decisional autonomy (ability and freedom to make choices) and executional autonomy (able to carry out choices). He also advocated negotiated autonomy, asserting the importance of interpersonal relationships in considerations of autonomy. This literature does not argue against choice and autonomy in dementia care, rather such perspectives question the privileging of individual autonomy over other considerations in decision-making, such as relationships (Boyle, 2008a and 2010, Darzins, 2010, Durocher and Gibson, 2010, Moats and Doble, 2006, and O'Connor and Donnelly, 2009).

Such perspectives on autonomy and ethical dilemmas are also evident in recent dementia care policy and practice guides. Some argue that enhanced autonomy enables a sense of wellbeing, and reduced autonomy damages wellbeing;

> *'People with dementia emphasise that being able to make small decisions on a day to day basis adds to their wellbeing and quality of life,'* (Manthorpe and Moriarty 2010, p10).

Introducing *'Risk Guidance for People with Dementia'*, Alistair Burns (National Clinical Director for Dementia) was explicit about risk, and ethical dilemmas in dementia care, in particular regarding non-maleficence and autonomy;

> *'It is a challenge to tread the line between being overprotective (in an attempt to eliminate risk altogether) while respecting individual freedoms'* (Manthorpe and Moriarty 2010, p2).

NCB (2009) also support an understanding of autonomy that acknowledges relational and emotional aspects. However, they warn that understandings of autonomy as a right to make choices can lead to neglectful practice, and thus be in conflict with other principles, such as *beneficence* and *non-maleficence.*

The overlapping principle of *justice* is about people's legal entitlements and rights. As noted in chapter 1, rights and justice have been increasing

explored in dementia care research literature (Barnes and Brannelly, 2008, Bartlett and O'Connor, 2007, Boyle, 2008a and b and 2010, Brannelly, 2004, Graham, 2004, Innes et al, 2004, Kitwood, 1997, Kronenberg et al, 2005, Post, 2006, Robinson et al 2007 and Scholl and Sabat, 2008).

Some government policy and good practice documents also include a *rights* discourse, for example in social care;

> *'By denying people the opportunity to take risks for fear of them being unsafe, over-protection can present risks to people's human rights,'* (Commission for Social Care Inspection (CSCI) 2006, p20).

> *'A good approach to risk in social care bases itself on human rights,'* (DH 2007b, p11).

Dementia care policy documents with a rights discourse include the *'Inquiry into the prescription of antipsychotic drugs to people with dementia living in care homes'*;

> *'The widespread inappropriate prescribing of antipsychotic drugs is an unacceptable abuse of the human rights of people with dementia, robbing thousands of people of their quality of life,'* (All-Party Parliamentary Group on Dementia 2008, p2).

and the *Deprivation of Liberty Safeguards;*

> *'...extra safeguards have been introduced, in law, to protect their rights and ensure that the care or treatment they receive is in their best interests,'* (Ministry of Justice 2008, p1).

As noted in Chapter 1, Mental Capacity Act (2005) was introduced as a legal safeguard for people who lack mental capacity. A key principle of this act is the right to autonomy. Early indications of implementing these legal rights were not promising;

> *'...people with dementia and carers are being excluded from decision-making, despite this being a requirement of the Mental Capacity Act...'* (All-Party Parliamentary Group 2008, p15).

I consider this legislation in the next section of this chapter.

Other perspectives in ethical decision-making within dementia care literature are *virtue ethics* and *ethics of care*. Virtue ethics literature argues that ethical decision-making develops in communities, such as practice contexts. The focus is on the practitioner, for example whether communications and

decision-making are honest, fair and compassionate (Gardiner, 2003, and McCormac, 2001). Ethics of care perspectives were developed within feminist theories of gender and care (Arber and Ginn, 1995, Jamieson et al 1997, Twigg, 2000 and Wilkinson and Kitzinger, 1994). Whilst some of this literature focused on the division of labour and 'burden of care', others explored relationships, context, emotions and justice in health and social care decision-making. Gilligan (1982) focused on moral sensitivity, context, interdependence, relationships and responsibilities. Tronto (1993) and Sevenhuijsen (2003) examined relationships within care, and wider contextual contexts, such as government policies and political ethics. Two researchers (Bolmsjo et al, 2006 and Brannelly, 2006) have since developed Tronto's (1993) ethics of care model into models that attempt to address the complexities of ethical decision-making in dementia care. There are clear links between these perspectives and person-centred perspectives on dementia care. For example, Kitwood emphasised the importance of ethics, interpersonal communication, relationships, interdependence, compassion and contextual understandings;

> '...an "ethic of context" does, of course, apply to every kind of social setting. It simply has a particular poignancy in the case of the care of people who have dementia, because they are extremely vulnerable, and their wellbeing is crucially dependent on the interactions that are generated by others' (Kitwood 1998a, p30).

Contrary to dominant contemporary discourses on living with a dementia, Kitwood argued that self is not lost, but damaged through interaction with others. His theories on personhood present practitioners with an 'ethical task' of trying to enable people living with a dementia to maintain a sense of self and identity. Such understandings of being attentive go beyond empathy. Kitwood developed this argument using the concept of 'malignant social psychology' (MSP) and 'positive social psychology' in dementia care (Kitwood, 1990, 1997, and 1998a). He theorised that MSP-type practice (such as stigmatisation, invalidation and disempowerment) results in practitioners and care services ignoring people's psychological, emotional and social needs. In this way, MSP acts as a barrier to positive self-regard and emotional wellbeing for people living with a dementia. Alternatively,

decision-making and practice from *positive social psychology* perspectives (such as *warmth, validation* and *empowerment*) are understood as maintaining personhood and enhancing wellbeing. Influenced by Kitwood, other researchers have since developed these concepts (Allan and Killick, 2008, Baldwin, 2008, Brooker, 2007, Ellis, 2007, Hoe et al, 2009, Hughes and Baldwin, 2006, Lloyd, 2006 and Ryan et al, 2008). This literature asserts the importance of communication and relationships when making ethical decisions with people living with a dementia. My practice and research are influenced by this literature, and I support related arguments that practitioners' undertaking ethical decision-making in dementia care need high levels of reflexive, communication, interpersonal and negotiation skills.

Much of the literature exploring dilemmas in dementia care uses the concepts of balance and principlism in decision-making. However, as already noted, principles intended to steer practitioners through these dilemmas may conflict. In addition to ethical principles conflicting with each other (such as autonomy and beneficence), professional codes of conduct can conflict with practice priorities, and priorities of people living with a dementia can conflict with those of carers, practitioners, care agencies and government policies. Practitioners therefore need to feel able to work with conflict and uncertainties (Alaszewski et al, 1998, Alaszewski and Manthorpe, 2000, Alzheimer's Society, 2008a, Clarke et al 2011a and b, DH, 2007b, 2007c, Hughes and Baldwin, 2006, Kitwood, 1998a, Robinson et al 2007, Taylor, BJ, 2006 and Waugh, 2009).

Having reviewed some literature on ethics and decision-making, I will now explore some literature on risk policy and dementia care.

Risk policy and dementia care

This section is directly linked to my research objective; *To consider this decision-making in the context of recent legislation, policy and practice guidelines and changes in the culture of dementia care (in particular the Mental Capacity Act, 2005).* I will now provide a brief chronological overview of some key policy documents relating to risk management in dementia care over the last 15 years. However, as already noted, my exploration of policy

literature is also integrated throughout this report, in particular alongside my analysis of practitioners' accounts.

Despite the Health Advisory Service's (1983) dramatic warnings of a *'rising tide',* recommendations for dementia services have been marginalised, mostly added on to other policies. In the 1980's and 1990's several tragedies, where people with severe mental health difficulties harmed/ killed themselves or others, received much media coverage. In response, the government produced mental health policy (DH, 1998a and 1999) where they made explicit links between risky people and the 'failures' of community mental health services in the1980's;

> *"Care in the community has failed because, while it improved the treatment of many people who were mentally ill, it left far too many walking the streets, often at risk to themselves and a nuisance to others. A small but significant minority have been a threat to others and themselves"* (DH 1998a, p2).

The Joseph Rowntree Foundation (2002) argued that policy developments in mental health were excluding older people. Since then, there have been several investigations and government policies relating to dementia care. In contrast to other mental health policies, the dominant discourse within policies relating to older people is about older people being at risk.

The Commission for Health Improvement's investigation into complaints about older people's mental health services at 'Rowan' ward described numerous examples of poor practice (CHI, 2003). The minutes of a contemporary parliamentary meeting argued;

> *'...CHI's findings would provide a "wake-up call" to the NHS to improve services for the most vulnerable people'* (DH 2004, p1).

Following this, the government commissioned a review of all older people's mental health services (Age Concern and Mental Health Foundation, 2006 and Lingard and Milne, 2004). In 2005, the Royal College of Psychiatrists published two reports (RCP, 2005a and 2005b) which made recommendations for good practice for practitioners working with people living with a dementia, for example developing liaison work with general hospitals.

Also in 2005, SCIE published their best practice guide for social care practitioners involved in assessing the mental health needs of older people (Moriarty, 2005). This included recommendations for good practice, including communication skills and risk-taking in risk management. This was soon developed into more detailed guidance (Nicholls et al, 2006). This has recently developed into comprehensive on-line practitioner guidance, including training in risk management and dementia care.

In contrast, NICE/SCIE (2006a) *Dementia Clinical Guideline's* perspective on risk management is predominately individualistic, medical, psychological, economic or institutional. Guidance within this policy focuses on eligibility for medical and cognitive treatments, *'adverse events,'* managing *'behaviour that challenges'* and the impact of building design.

Based on my experience, I can identify with Hird and Cash's (2000) assertion;

> *'A key concept in risk assessment is whether or not the service user's judgement about their risk taking or dangerousness is to be taken as valid. This is based on the idea that some groups of people do not have the capacity to make such judgements for themselves."* p12.

Manthorpe's account also echoes my experience;

> *'People with dementia are often considered to have enhanced vulnerability to risk as danger and to have diminishing capacity to deal with risks rationally. This leads to a protective approach in their own best interests which is the dominant theme in discussions about professional accountability and duties of care.'* (Manthorpe 2004, p146)

For years 'experts' have assumed that people living with a dementia lack the mental capacity to make decisions. The MCA (2005) was implemented throughout 2007, as a legal safeguard for people who lack the capacity and as guidance for people who make decisions on their behalf. A key principle of the act is *'presumption of capacity'*, which guides practitioners to presume a person has capacity to make their own decisions, despite their diagnosis, unless a formal assessment indicates otherwise. Practitioners are advised to refer to the practice guidance (DCA, 2007), which includes some guidance on risk management;

'Information about decisions the person has made based on a lack of understanding of risks or inability to weigh up the information can form part of a capacity assessment – particularly if someone repeatedly makes decisions that put them at risk or result in harm to them or someone else,' p50.

'...care planning should include risk assessments and set out appropriate actions to try to prevent possible risks. But it is impossible to remove all risk, and a proportionate response is needed when the risk of harm does arise,' p108.

The Act also promotes the rights of people living with a dementia to have support to enable their remaining capacity for decisional and executional autonomy. However, I agree with Boyle (2008a, 2008b and 2010) and NCB (2009) that for people living with a dementia autonomy is a 'restricted right'. Restricted by what others (such as practitioners and family) judge to be 'in their best interests';

'...if they are assessed as lacking capacity their wishes may be over-ruled by others in the hope of protecting their best interests,' (NCB 2009, pxxii).

The *Dementia Strategy* (DH, 2009a) recommended assistive technology as good practice in risk management, from financial and QoL perspectives. However, such approaches are not without ethical dilemmas (Manthorpe and Moriarty, 2010 and Robinson et al 2007). Referring to reports by All-Party Parliamentary Group (2008) and Alzheimer's Society (2007c), the *Dementia Strategy* also included a damning account of the risks of misusing anti-psychotic drugs;

'It appears that there are particular risks that are serious and negative in the use of anti-psychotic medications for people with dementia. These include increased mortality and stroke,' (DH 2009a, p54).

The DH commissioned an investigation into the use of antipsychotic medication with people living with a dementia. The subsequent report was published later that year (Banerjee, 2009), and informed the updated *Dementia Strategy* (DH, 2010c).

Three recent DH *Good Practice Guidelines* on managing risk are particularly relevant to my project. Two were published as I submitted my research

proposal; *Best Practice in Managing Risk* (DH, 2007c), with a focus on mental health services, and *Independence, choice and risk* (DH, 2007b) which focuses on social care. The third and most relevant was published as I was writing this report; *Nothing ventured, nothing gained: risk guidance for people with dementia* (Manthorpe and Moriarty, 2010). As noted earlier, this policy has a clear focus on ethics and psychological wellbeing in risk management decision-making. Although these recent policy documents were published too late to inform my research plans, they have informed and updated my project as I have undertaken it. They are examined alongside my analysis of practitioner accounts and have informed my plans for disseminations (chapter 9).

Having reviewed some literature on practitioner accounts, government policy, assessments, ethical decision-making and risk policy in dementia care, I will now provide an account of some key theoretical concepts that are present throughout this literature and are related to my research; *vulnerability,* QoL and *psychological wellbeing.*

Vulnerability, QoL and psychological wellbeing

In mental health literature and practice discourse people living with dementia are constructed as **vulnerable**; in need of protection from themselves/others/the environment. Literature on risk management in dementia care regularly refers to risks such as financial abuse, falls, malnutrition, and getting lost. Thus, dementia care practice becomes 'safeguarding' vulnerable people from risk/harm/abuse/neglect. In 2000, practice guidance on safeguarding older people was updated (DH, 2000) and later developed into *Safeguarding Adults* (Association of Directors of Social Services, 2005) and *Safeguarding Vulnerable Adults* (CSCI, 2007a). Such accounts of vulnerability represent the 'location of risk' (Warner, 2006 and 2008) as being within particular groups of people, for example;

> *'People with dementia are known to be an 'at risk' group in terms of abuse, particularly (although not exclusively) through financial exploitation, fraud and theft.'* (DH 2009a, p49)

QoL and *psychological wellbeing* are concepts directly linked to my research objective; *To consider this decision-making with a particular focus*

on psychological wellbeing and quality of life. Understandings of QoL in health and social care discourse vary, and include 'normative', 'economic' and 'subjective' perspectives. Normative approaches are dominated by medical discourse and based on objective measurements, population statistics and assumptions that increased levels of disability are reflected in a decreased QoL (for example, HRQoL). Economic approaches are used in conjunction with normative approaches, to ration resources by determining eligibility and access to services (for example DALY and QALY). Some literature questions these measurements of QoL and advocates more subjective and contextual approaches from the perspective of the person living with disability (Bond 1998, 1999, Metts, 2001, Patrick and Erickson 1993, Smith, 2000 and Walker and Rosser, 1993). In 1997, the World Health Organisation (WHO) adopted a subjective, contextual definition of QoL;

> *'...individuals perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment'* (WHO 1997, p1).

In dementia care literature and practice, concepts of QoL differ with regard to 'domains'. Which areas of life to include in QoL, and how to prioritise these areas, is contested (Hughes and Baldwin, 2006). Until the 1990's (with the notable exception of Norman, 1980, 1982, 1988 and Robb, 1967) healthcare discourse on QoL and people living with a dementia was dominated by normative, biomedical perspectives, with a focus on neurological/cognitive deficits or environments. Measures focusing on subjective experiences, self, personhood and emotion wellbeing have been less common. However, Kitwood (1997) was influential in inspiring others to question this dominance. Bond (1998) proposed that changes in understandings of dementia necessitated different ways of measuring QoL, quality of care, and 'outcomes' for dementia care. Corner (2003) advocated a shift in dementia research, to enable a more meaningful understanding of the impact of dementia care on wellbeing. Wider definitions of QoL in dementia care

literature now include subjective and objective considerations, including physical, psychological, individual and social domains. Aspects of life include health status, physical environment, social environment, relative economic wealth, autonomy, self-concept, coping strategies, spirituality and physical and psychological wellbeing. It is no longer unusual to hear arguments for subjective perspectives of QoL in dementia care literature;

> *'For the person with dementia, it is their experience rather than their disability that most influences their QoL...although aspects of health are important in assessing the impact of the disease process, it is the individual's subjective interpretation of the objective experience that truly defines QoL,'* (Hoe et al 2009, p288).

Some dementia care research explores ways of overcoming barriers to communication, in order to take account of subjective understandings of dementia and QoL (Cahill et al, 2004, Clarke et al 2010, Downs and Bowers, 2008, Fukushima et al 2005, Goldsmith, 1996, Katsuno, 2005, Manthorpe et al 2010, Moyle, 2010, NCB, 2009 and Venturato, 2010).

Concepts of **psychological wellbeing** focus on the nature of relationships with self, environment and others. This includes subjective experiences and emotions. From critical, cultural perspectives, some literature explores less dominant concepts of wellbeing. For example Ingersoll-Dayton et al (2001) represented Thai elders' concepts of psychological wellbeing as focussing on the key dimensions of *harmony, enjoyment, acceptance, respect and interdependence.* From such perspectives, increased independence is <u>not</u> necessarily linked to greater wellbeing. The notion of independence promoting wellbeing is understood as an individualistic, 'Western' construction. From collectivist, non-'Western' perspectives, concepts of wellbeing are more focused on interdependence, including an interest in the wellbeing and expectation of others (Baldwin and Capstick, 2007, Bognar, 2008, Brooker and Surr, 2005, NCB, 2009, Smith, 2000, Tiberius, 2004 and Veenhoven, 2000).

Kitwood and Bredin (1992) argued that 'damaging' interactions with a person living with dementia can be more detrimental to a person's wellbeing than neurological damage (see my earlier explorations of MSP). Kitwood (1997) argued that, as cognition is only one aspect of our personhood, other

aspects of personhood (such as feelings and relationships) can remain intact. Thus, he proposed that people with a dementia can live in a relative state of wellbeing, and that levels of wellbeing/ill being are influenced by the quality of their interactions and relationships. Dementia care literature and policy continues to support the argument that the nature of inter-personal communications and relationships influence psychological wellbeing (Allen, 2008, Alzheimer's Society, 2007c, 2007d, 2008b, Alzheimer's Society and Mental Health Foundation, 2008, Brooker and Woolley, 2006, Manthorpe and Moriarty, 2010, Owens and NCHRDF, 2006, NICE/SCIE, 2006b and NCB, 2009). For example;

> 'There is broad consensus that the principles of person-centred care underpin good practice in the field of dementia care and they are reflected in many of the recommendations made in the guideline. The principles assert...the importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being' (NICE/SCIE 2006b, p6)

and

> 'A person-centred framework to risk starts with understanding what is important to the person with dementia. Wellbeing is promoted by meeting psychological needs for love, comfort, identity, occupation, inclusion and attachment...' (Manthorpe and Moriarty 2010, p46).

However, perspectives and practice guidelines on risk, QoL, wellbeing and dementia care continue to conflict and pose complex ethical dilemmas. Based on public consultations in England in 2007 and 2008, NCB (2009) explored opposing views of QoL and dementia. From one perspective, there was a view that with the right support and care, people living with a dementia can have a positive QoL. However, others held the view that living with dementia is so bad that death is preferable.

Although some government policies and practice guidelines have suggested broadening understandings of 'healthy old age', to include experiences of wellbeing, this conflicts with other individualistic, economic concepts of 'healthy old age', as represented in the government's *liberation* strategy (DH, 2010b and 2011).

Having explored accounts of *vulnerability,* QoL and *psychological wellbeing,*

I now offer some reflexive considerations and concluding comments.

Being reflexive

In undertaking this review and constructing this report, I question why, when I challenge so many assumptions of dominant ideologies and discourse, do I continue to accept the *'conventions of academic writing'* (Middleton, 2002, p3), by constantly seeking the words of others/'experts'? Maybe to make my voice more convincing and credible? In part, I see myself as yielding to the gate-keeping power of the academic approval processes (Johnson, 2001). When undertaking this review, I identified with Kaufman's (2005) description of the integrated practice of reading and writing;

> *"...every text I read is interpreted and rewritten through my own biography and my own biography is rewritten as I read it through alternate texts, a reciprocal writing and rewriting'* p577.

As I write, read, work, think and write, so content grows and changes.

Concluding comments

This is the second of two literature review chapters. In chapter 2 my focus was on risk management and decision-making in health and social care. In this chapter, my review was more focused on risk management decision-making in dementia care. I began this chapter with an exploration of literature on practitioner accounts of risk management in dementia care. Then I reviewed some literature on policy and dementia care. I also explored literature on assessments, ethical decision-making and risk policy in dementia care. Toward the end of this chapter, I considered some key concepts within this literate that are related to my research; *vulnerability, quality of life* (QoL) and *psychological wellbeing.*

Based on my literature search, I only identified 5 researchers who focused their studies on *practitioner perspectives* of risk management in UK dementia care (Clarke et al, 2009, 2010, 2011a, Corner, 2003, Gilmour et al, 2003, Robinson et al, 2007 and Stamp 2000). I hope my study will contribute to their work.

In the next chapter I provide an account of my theoretical perspectives and methodology, and the methods I used to generate, organise and analyse the research information.

Chapter 4 Theoretical orientation and methodology

Introduction

In previous chapters I provided some justifications for undertaking this project and reviewed some key relevant literature. In this chapter, I provide an account of my theoretical orientations, methodology, and methods.

I begin with a brief overview of my choices. Next, I consider philosophical perspectives, and follow this with an account of my theoretical choices and methodological implications. In the main body of this chapter, I examine the methods I used to generate, organise and analyse the research information. I follow this with an exploration of ethical and quality issues.

Toward the end of this chapter, I offer some reflexive considerations and concluding comments.

Choices

Choices I have made throughout this project reflect the complex, chaotic and ambiguous world of risk management in dementia care practice. As a practitioner-researcher, I believe there is no one right answer that can instruct practitioners in the best way to assess and manage risk with people who are living with a dementia. Within my research I asked questions in an attempt to highlight, explore and challenge assumptions that underlie our decision-making in contemporary dementia care.

I see some value in learning from practitioners' accounts of everyday practice, in particular stories of decision-making (Banks and Williams, 2005, Boyes, 2006, Brooker, 2007, Brown et al 2008, De Bellis, 2006, Hammell, 2009, Higgs et al 2004, Pollard et al 2009, Stanley, 2005, Stanford, 2007, Taylor and White, 2000, White et al, 2006 and Wilson, 2001).

My choices were also influenced by a belief that practitioners' accounts are embedded in and influenced by contextual complexities. Therefore, I also considered wider contexts (Alvesson and Sköldberg, 2000, Carey 2008, Griffiths, 2001, Harrison and Smith, 2004, Hui and Stickley, 2007, Mason, 2006, Opie, 1997, Parker, 2007, Sarangi and Candlin, 2003 and Wetherell et al 2001).

Research literature often presents research paradigms as the foundation of, and justification for, choices within the research process. Paradigms are

portrayed as dichotomous, according to the underpinning philosophy, theory, and methodology. Reading Crotty (1998), I found it useful to conceptualise research on four levels - *epistemology, theoretical perspectives, methodology* and *method.* From this perspective, epistemology underlies my theoretical perspectives and methodology, which in turn influence my choice of methods.

Philosophical considerations

The concept of binary opposition dominates much of contemporary 'Western' philosophy. Philosophical foundations of research are often represented within an ontological oppositional binary of 'realism' versus 'relativism'. Realist, objectivist perspectives argue that a stable, independent reality exists outside of our interpretations and consciousness. There are objective truths to be discovered through research, as long as we go about it in the correct way. Alternatively, constructionists argue there is no objective reality; realities are relative, multiple and socially constructed. We interpret. Our understandings develop through engaging with the world, through subjective, lived experiences.

My research proposal is most closely aligned to a constructionist perspective. I acknowledge complexity, contexts and ambiguity in practice. However, I am mindful of criticisms of 'nihilistic relativism', where all truth claims are portrayed as equally valid. Like, Taylor and White (2000), I resist relativist/realist polemics and am critical of *'universal constructionism'*;

> *'There are things whose existence 'can not be denied' ...and things which 'ought not to be denied'...From any perspective, to argue against the existence of this material reality is nonsense'* p25.

In resisting a practice/theory dichotomy, I am also influenced by Schon's (1983) proposal that we build on theories ('know-how') by using them in practice, becoming contextually informed and constructing specialist knowledge ('know-that'). I also see some value in Polkinghorne's (1992) pragmatic, partial, subtle version of realism; *practitioner epistemology* (Dausien et al, 2008, Duncan and Nichol, 2004, Fook, 2001, Gordon, 1998, Hammersley, 1992 and 2005, Hill, 2009, Hollway and Jefferson, 2000,

Parton, 1999, Polkinghorne, 1992, Rossiter, 2001, Seymour, 2006 and Taylor and White, 2000).

Theoretical pathways and methodological implications

Theoretical perspectives are often represented in an oppositional binary; *positivism/anti-positivisms.* Since the seventeenth century, 'Western' science has been based on the 'Enlightenment' vision of an objective truth, with a search for universal truths and absolute knowledge. In the 1840's, Comte argued that 'positive' scientific methods should be the same for all sciences. Therefore, when studying people and social situations we use the same methods as natural sciences (methodological monism). The aim of positivist science is to systematically collect observed facts and create laws of 'cause and effect' relationships. There is a belief in universal laws and objective truth/reality, which 'good' scientific investigation can discover, by examining component parts. 'Anti-positivist' theories argue that the purpose of human science is to try to understand or interpret, rather than offer causal explanations. Interpretive theories view human behaviour as meaningful and emphasise the contribution of contexts and subjective interpretations to understandings (Crotty, 1998, Oakley, 2000, and Seale, 2004).

My practice involves knowledge <u>and</u> skills, procedure <u>and</u> chaos, health <u>and</u> social, community <u>and</u> hospital, physical <u>and</u> psychological, science <u>and</u> art, 'care' <u>and</u> 'therapy'. As with my practice, I did not restrict my research to one particular approach or perspective. I am influenced by notions of *situated knowledge, partial perspectives* and *fractured objectivities;* understandings as incomplete and located in particular contexts. In response to complexities in practice, and influenced by feminist and complexity theorists, I advocate trans-disciplinary, 'multi-dimensional' approaches to research (Arner and Falmange, 2007, Haraway, 1988, Oakley, 2000, Mason, 2006, Middleton, 2002 and Westmarland, 2001);

> *'...lived realities are multi-dimensional ... our understandings are impoverished and may be inadequate if we view these phenomena only along a single dimension,'* (Mason 2006, p10).

I will now examine theories that have most influenced my approaches to this research project. This includes some practice related sociology and

psychology, phenomenology, critical theories and postmodernist theories. I also consider use of methodological metaphors.

Some psychology and sociology; Since starting work in mental health services in the 1970's I have been influenced by practice related sociology and psychology, such as Szasz (1974), Laing (1967) and other 'anti-psychiatry' writers (Boyers and Orril 1972). In the 1980's, I was also influenced humanistic psychology, in particular rejections of narrow Newtonian inferences to humans as machines (Rogers, 1961). My reflexive analysis is influenced by Gestalt psychological theories of perception, in particular the notion of 'figure' and 'ground'. From this perspective, I was mindful that 'figures' of interest to me in practitioners' accounts may 'stand out' from other concepts/stories, which merge into the background. I have also soaked up sociological writings on institutionalisation (Goffman, 1961) and labelling (Becker, 1963 and Denzin 1995), which have helped me make some sense of practice experiences.

As outlined in chapter 3, my practice has also been influenced by psychological and sociological theories on dementia and dementia care. My choices in research are in keeping with 'new cultures' in dementia care, which favour qualitative, interpretive, trans-disciplinary, contextual understandings (Bartlett and O'Connor, 2007, Boyle, 2008a, Brooker, 2007, Downs and Bowers, 2008, Godfrey at al, 2005 Hughes and Baldwin, 2006, Kitwood, 1997, Kitwood and Benson, 1997 and Perrin et al 2008).

Phenomenology; Since Benner's (1984) explorations of decision-making in nursing, phenomenology has been a popular choice in healthcare research (Brocki and Wearden, 2006, Diekelmann and Ironside, 1998, Edwards and Titchen, 2003, Evans and Hallett, 2007, Gurbutt, 2006, Hantikainen and Kappeli, 2000, Hughes et al, 2006, Johnson, 2000, Leith, 2006, Paterson and Higgs, 2005, Thomas, 2005, Todres and Galvin, 2008 and Wilding and Whiteford, 2005). Interpretative, hermeneutical phenomenology was developed by Heidegger, who proposed that all experiences involve interpretations, and that things (phenomena) become meaningful to people 'in the context of'. To understand we interpret, and our interpretations are based on contexts and experiences. Thus, the world is what we perceive/ experience it to be, with the possibility of multiple realities. The notion of

'hermeneutic circle' is used to explain how we understand the world through continually moving back and forth between 'pre-understandings' and new experiences; questioning assumptions and pre-judgements, examining and re-examining knowledge. 'My' profession (OT) is rooted in notions of understanding through being and doing, and relationships between wellbeing and occupational being (Mattingly, 1991 and Perrin et al, 2008). Indeed, Nygard (1999) described OT as *'applied phenomenology'*. From this perspective, I question taken for granted assumptions about complex phenomena, acknowledge the importance of contextual understandings, and work with the possibility of multiple realities.

Critical theories; Influenced by the work of Marx, Freire and Gramsci, critical theory attempts to understand interactions between the person and societal structures. Gramsci (1971) proposed the concept of 'hegemony', to examine how dominant cultures saturate our consciousness and shape our interpretation of the world. Not content with phenomenological descriptions and apolitical postmodernisms, critical research challenges assumptions and attempts to reduce injustice. However, there are similarities with critical phenomenology and postmodernisms, in attempts to expose dominant ideologies and explore relationships between power and language. Critical theorists' notion of *resistance* is in keeping with being reflexive; exploring interactions between personal and structural, considering assumptions in practice and avoiding uncritical reproduction of dominant ideologies (Alvesson and Sköldberg, 2000, Eagleton,1994, Freire,1972, Houston, 2001, Jones-Devitt and Smith, 2007 and Schwartz McCotter, 2001). I am also influenced by critical gerontology. In particular, I resist reductionist constructions of ageing and dementia, and challenge discrimination in dementia care (Angus et al, 2005, Brijnath and Manderson, 2008, Estes and Binney, 1989, Jamieson et al, 1997, Katz, 1996, Kontos, 2005, Parker, 2007, Rhynas, 2005 and Walker, 1981). In addition, I am influenced by critical feminist theory. From this perspective I value contextualised, subjective experiences, resist 'Western' hegemony and question the masculinisation of experience and science (Arber and Ginn, 1995, Busfield, 1996, Ramazanoglu, 1992, Oakley, 2000, Stanley and Wise, 1983 and Wilkinson, 2004).

My choices have also been influenced by critical complexity theories. In particular, I question traditional 'Western' linear scientific theories. I agree with Bloor (2000) that, although trans-disciplinary approaches can be complex and confusing, they also hold the potential for creative and relevant research in complex practice. In my research I have tried not to over-simplify the lived experience of being a practitioner-researcher, or over-generalise the complex realities of working with people who are living with a dementia. Rather than attempting to demarcate risk management into discrete variables, and make predictions based on calculable percentages, I acknowledged diversity, complexities and un-predictabilities. In undertaking this approach to research, I support Derrida's (1988) argument;

> *'One shouldn't complicate things for the pleasure of complicating, but one should also never simplify or pretend to be sure of such simplicity where there is none'* p119.

(Hall and White, 2005, Hammersley, 2005, Hill, 2009, Kincheloe, 2005, Kincheloe and Berry, 2004, Moats and Doble, 2006, O'Connor et al, 2007, Parker, 2001, Plsek and Greenhalgh, 2001, Stalker, 2003, Stevens and Cox, 2008, Taylor and White, 2000 and 2006 and Warren et al, 1998).

Postmodernisms; Postmodernist theories emphasise the role of language and propose new ways of understanding power, knowledge and self. Derrida (1978) argued that texts structure our interpretation of the world. Foucault was critical of positivistic knowledge being privileged over knowledge embedded in specific situations/contexts. In advocating a history of the present (genealogy), Foucault (1972) challenged modernist assumptions about progression and continuity. He proposed that we investigate the present by exploring and questioning the history of the 'taken for granted' (such as psychiatry). Foucault (1980) also challenged critical theorists' concepts of power residing with an individual or groups. As noted earlier, he developed the notion of *governmentality* to account for ways in which institutions organise and exert power, through controlling individuals and their practice. Influenced by *Queer Theory*, I reject false universals, for example what it is to be old, or be a woman. I am influenced, but not totally convinced, by Butler's (1990) argument that there is no pre-existing self; we are only real in 'performance' and our identities are the result of how we

present ourselves rather than the other way round. Influenced by postmodernisms, I question concepts of essential self and am interested in micro-narratives, difference and the micro-dynamics of power relations (Beckett, 2001, Benhabib, 1994, Bloor, 2000, Docherty, 1993, Hughes and Sharrock, 1997, Mitchell, 1996, Mohr, 1999, Nicholson, 1990 and Seidman, 1996).

There are some similarities between Foucault's (1980) explorations of power and Bourdieu's (1990) concept of *habitus*. Bourdieu uses *habitus* to explore how what we say and do in daily practice can be influenced by assumptions, power relationships and 'internalizations' of contextual social interactions. Both perspectives also have some connections with reflexivity.

I am mindful of pragmatic, political critiques that postmodernists may disregard the power and influences of oppressive structures. Relativist perspectives are potentially oppressive in arguing that all knowledge claims have equal standing. As stated earlier, I reject nihilistic understandings of relativism, in favour of more pragmatic situated, partial perspectives of material realities (Nussbaum, 1999, Oakley, 2000, Phillipson and Biggs, 1998, Polkinghorne, 1992 and Taylor and White, 2000).

Methodological metaphors; Using a metaphorical approach enabled me to explore different, sometimes conflicting, theories within my research process. As a metaphor for my work and research, I was drawn to Levi-Strauss' notion of *'bricoleur'* (Denzin and Lincoln 2000, p4). As bricoleur, I improvise, adapt and work creatively with resources and complexities.

I also found Schwarz McCotter's (2001) maps metaphor helpful in thinking about my theoretical choices, and less constraining than paradigms. Cartographers and researchers choose what to emphasise and omit. Maps are created to include different emphases (relief, political, road), scope (local, global, universe) and scale/detail. Maps help travellers to avoid loosing direction, without over-simplification to one route. Alternative routes offer different experiences in the same locality. I explore my use of metaphors in more detail alongside my analysis of practitioner accounts (Banks and Williams, 2005, Bartlett and O'Connor, 2007, Blair and Robertson, 2005, Clark et al, 2007, Duncan and Nichol, 2004, Gobbi, 2005 and Richardson, 2000).

Having explored my epistemological, theoretical and methodological considerations, I now examine my research methods.

Methods

My choice of methods was guided by three key considerations; my theoretical perspectives, working towards my research objectives, and the practical and ethical considerations of undertaking this research in practice. I will now provide an account of methods I used to generate, organise and analyse.

Generating information

I chose three main methods to generate information; *interviews, literature reviews* and *reflexive accounts*.

Interviews; My primary method was to undertake interviews with health and social care practitioners. My plan was to generate rich, contextual accounts by undertaking lightly structured interviews. In keeping with my perspectives, I did not intend to make inferences about a wider population, and did not attempt to recruit a random, statistically representative sample. Recommended numbers of participants suggested in methodologically comparable studies vary from 5 to 15 (Bergan-Gander and van Kurthy, 2006, Hall, 2004, and Kvale, 1996). I therefore planned to undertake interviews with approximately 10 practitioners who worked with people living with a dementia. I decided to only interview qualified professionals, as I was aware they were most likely to have experience of risk management decision-making.

I undertook this project within an NHS trust, where I work as practitioner. The choice of authority was purposive as it has teams working within older people's mental health services (Silverman, 2006). I was also mindful of constructing a research plan that was realistic in terms of my time, expenses, travel, and access. After consultations with my principle academic supervisor and the trust's research governance manager, I approached practitioners in localities within the trust furthest from my work base, where I had no management or supervisory responsibilities. In this way, I hoped to minimise the possibility of practitioners feeling obliged to take part, and reduce the complex dynamics within interviews (Watts, 2006). However, I agree with

Thompson (2006) that such dynamics are *'messy'*, not under my control, and thus I can never fully know how they influenced practitioners' accounts.

I made initial contact with managers by email, as this offered an efficient way of cascading information, and enabled me to keep a record of this process. In the email I introduced myself and the project, and attached the *Research Participant Information Document* (Appendix V) for their information and distribution. Most managers responded by email to inform me they would share this information through team meetings. Over the next few weeks I had steady email contacts from practitioners who were interested in taking part. After 3 months I had arranged interviews with 11 practitioners. Due to work commitments, I undertook interviews one day per week over five months. To comply with insurance cover, all interviews took place within trust buildings.

The 11 practitioners worked across 8 different teams in older people's services. These included community services and in-patient units that were located in towns and more rural locations. They included men and women who had worked in older people's mental health services for a range of 5 to 30 years. Their professional roles included social workers, nurses, physiotherapists and occupational therapists. I have not disclosed any further details about the practitioners who took part, as this would increase the risks of identification. I explore my approaches to confidentiality in the ethics section later in this chapter.

I acknowledge this is only a small subgroup of practitioners who are involved in risk management decision-making with people living with a dementia. In particular, I noted that no psychiatrists expressed an interest in being involved in the interviews. This may be a reflection of their different professional and managerial communication networks within the trust. In addition, my recruitment strategy excluded the majority of practitioners who are involved in risk management decision-making with people living with a dementia outside of this trust, for example those who work in residential care, district nurses, general practitioners and those working in different geographical locations.

My theoretical perspectives have informed and influenced the status I accord research 'data'. I acknowledge my role in the interaction, construction, shaping of stories and performance of interview. I also acknowledge the

complex relationship between the conscious and subconscious, and between perceptions, feelings, cognitions, and behaviours. However, I see access to practitioners' 'inner world' as neither desirable nor possible. I understand the relationship between interview accounts and practitioners' decision-making in practice as complex; within the interviews, we engaged in story telling, not a declaration of truth about inner feelings or practice behaviours (Boyes, 2006, Denzin, 2001, Gardner, 2001, Holloway and Freshwater, 2007, Holstein and Gubrium, 2003, Kvale, 1996, Parker, I, 2005, Seidman, 1998, Silverman, 2001 and Williams, 1995). Having said that, I am also mindful critiques of *universal constructionism'* (Taylor and White, 2001) and influenced by practitioner epistemology (Polkinghorne, 1992). From this perspective, I see some value in treating practitioners' accounts as having something to say about realities outside the interview. Whilst understanding language as constructing realities, this is limited by the 'real', material world.

In consultation with the local research ethics committee (LREC), the trust's research and governance manager and my academic supervisors, I developed an *Interview Guide* (Appendix VI) as a flexible prompt, to ensure topics covered related to my research objectives. I was also influenced by Seidman's (1998) 'three phase interviews' (life history, reconstructing experiences, reflections). I also noted Hollway and Jefferson's (2000) argument that the 'best' questions to elicit stories ask about specific events, but are broad enough not to limit responses to researchers' interests and expectations. In addition, I considered types of questions, such as 'probing' and 'clarification' (Kvale, 1996 and Rapley, 2001).

Once I had gained informed, written consent (see Appendix VII), I arranged interviews. I began each interview with an open introductory question like; *'Can you tell me about your experiences of working with people who are living with a dementia?* My follow up questions were prompted by the guide and dependent on the practitioners' account.

I recorded all interviews, using 2 recorders (one as 'back-up'). This enabled me to focus on the interview, rather than being distracted by trying to capture content (Boyes, 2006 and Watts, 2006). I also wrote brief notes, which served as a reminder of things practitioners mentioned in passing that I may

want to return to later in the interview, for clarification or probing. I also used these notes after interviews to trigger reflexive notes.

In preparation for the interviews, I undertook one 'pilot' interview to test my skills, methods and tasks. The practitioner did not fall into the selection criteria (he was unqualified and worked with me). He was interested in taking part because he was undertaking an undergraduate research project and felt this may help his understanding of research. In this way, I trialled my interview skills, 'Research Participant Consent Form' (Appendix VII), 'Research Participant Information Document' (Appendix V), Interview Guide (Appendix VI) and recorders.

I reconsidered the Interview Guide after a 'pilot' interview and after the second interview. As the questions used had generated numerous accounts of risk management and decision-making in dementia care, I did not make any amendments for future interviews.

Based on my reading of similar research, previous experience and advice from academic supervisors, I planned to undertake one interview of one hour, and offer a second interview if the practitioner felt they needed or wanted more time. The interviews lasted between 55 and 70 minutes. No practitioners requested further time and I did not feel a need to ask for more.

Having examined my primary method, I will now provide an account of the secondary methods I used to generate further research information; *policy and practice literature* and *reflexive accounts*.

Policy and practice literature; My literature review and analysis included key policies and practice guidelines. By including some of these 'ready made' texts, I was able to undertake analysis of practitioners' accounts alongside wider contexts of risk management in dementia care. My choice to extend my analysis beyond interview texts was influenced by my postmodern theories on the influence of language and texts in practice (Boyes, 2006, Mason, 2006 and Parker, I, 2005).

I also accessed anonymised risk management documents from case records for 7 people who were living with a dementia and using trust services. In doing so, I hoped to add to my resources of practitioner accounts of risk management decision-making. Mindful of issues of confidentiality and consent, I took guidance on access to records from LREC and the trust

research governance manager. It was my intention that these resources would be analysed in the same way as interview transcripts. However, as I began to analyse interview transcripts, I realised I had too much material for my project. I therefore chose not to use these records.

Reflexive accounts; My third method was to generate information though writing reflexive accounts of my experience of being researcher. This method was integral to my project. As part of the doctoral seminar scheme, whilst undertaking my analysis, I wrote a *reflexive account of learning.* I also wrote *interviews notes* before, during and after interviews; thinking and writing about my observations, feelings, theoretical and methodological considerations, and wider practice contexts (Fook and Gardner, 2007, Potter and Wetherell, 1987 and Richardson, 1994). The notes served as useful reminders about my thoughts, feelings, initial impressions and experiences around the time of each interview. I also added to these notes when transcribing each interview, and as I began analysis. In this way, I tried to get a sense of the whole of each account before analysing content in more detail (Crossley, 2000, Kvale, 1996, Nygren and Blom, 2001, Schwarz McCotter, 2001, Stanford, 2007 and Wetherell et al 2001).

Having provided an account of generating research information, I will now outline how I organised this information, in preparations for analysis.

Organising information

Interviews; I created texts by transcribing from interview recordings. Influenced by previous experience and other practice researchers, I did my own transcribing. Although time consuming, this meant I 'lived with' the interviews for several months (doing interviews, listening, transcribing, thinking about and making reflexive notes), before focusing on analysis (Bazely, 2007, Boyes, 2006, Parker, I, 2005, Schwarz McCotter, 2001 and Watson, 2006).

Transcribing is not an objective, technical task. Before transcribing, I had to decide how detailed to make the translation from sound to text. Some transcriptions are written with repetitions, pauses and detailed coding to indicate non-verbal communication, whilst others are 'tidied up' to be more readable (Kvale, 1996 and Wetherell et al 2001). My choice was influenced

by my theoretical perspectives, approaches to analysis, different intended 'audiences' and academic advisors. As I was not undertaking conversational analysis or sociolinguistics, I transcribed at 'intermediate' level (Appendices VIII and IX). My transcriptions followed a simplified version of the Jefferson (2004) system, which preserves some rhythm, and structure, but leaves out some of the details and tricky symbols commonly used in conversational analysis. I also acted on academic supervisors' advice to *'punctuate', 'tidy'* and;

> *'...ensure they read appropriately without taking anything away from the narrator'*, academic supervisor feedback, April, 2010.

I consulted more research literature, and gradually included less repetitions and sounds of listening, such as *'mmm'*, *'yeah'* (Boyes, 2006, Elliot, 2005, Parker, I, 2005, Poland, 2003 and Watson, 2006);

> *'...render the speech into as 'fluid' a format as possible trying to capture something of the rhythm and performativity...but inserting grammar where it seems appropriate to aid understanding and readability'* (Watson 2006, p373).

I offered to provide an anonymised transcript to each of the practitioners who took part, as an extension of their ongoing, informed consent (Watts, 2006). In response, four asked for a copy. No further interest in my analysis was expressed by the practitioners, apart from brief general enquiries when I met some by chance. I used available time in-between interviews to transcribe and write reflexive notes. As each anonymised transcript was completed, I printed out a paper copy and saved it within my software project.

Policy and practice literature; Once selected from my literature review, I included these documents within the software project for ease of access. However, these documents were for secondary levels of analysis and so I did not organise them in the same manner as interview transcripts.

Reflexive notes; Using these notes, I constructed *reflexive memos* (Appendix X) for inclusion into the software project. My decision to use these memos within software analysis was influenced by reading about others who have used this approach in practice-based research (Ajjawi, 2006, Banks and Williams, 2005, Hill, 2009, Leith, 2006, Stanford, 2007 and Stanley,

2005) and by referring to software guidance (Bazeley, 2007 and Richards, 2009).

I will now continue with an account of my methods of analysis. However, these demarcations are constructed to enable clarity for readers. In practice my generating, organising and analysis were overlapping and transactional.

Analysing information

I begin this section with an overview of my analysis. Next, I provide my account of undertaking narrative analysis, discourse analysis, reflexive analysis and analysis across accounts. I then consider my secondary analysis and my use of theoretical models.

Analysis overview; My primary analysis was of practitioners' accounts in interview. My choice of analysis methods was based on narrative, discourse and reflexive perspectives. My secondary analysis was of contextual texts from policy and practice guidance. I created an *Analysis Guide* (Appendix XI) to help me with directions though my research analysis. This plan was informed by my reflexive consideration of literature by researchers with an interest in narrative and discourse analysis in health and social care. I used the following structure;

1. Create texts (interview transcriptions and reflexive memos)
2. Collate, listen and read texts
3. Continue reading and listening. Make notes. Prepare for use in software
4. Narrative analysis
5. Discourse analysis
6. Reflexive analysis
7. Continue across all transcripts. Collate open codes into categories
8. [Secondary level] Continue analysis of practitioner accounts against and across policy and practice documents.
9. Organise, represent and analyse information using conceptual modelling

Although represented as nine discrete linear steps, in practice my analysis was more cyclical. I moved between reading, listening, thinking, coding, analysis and writing.

Once I had transcribed an interview, I read and re-read the transcript and listened to the recording. Initially this involved 'naïve' reading and listening, to

familiarise myself with stories and get some sense of the whole. I made brief notes on content and things that caught my attention, such as persuasive stories, contradictions and use of metaphors. I also made reflexive notes of my involvement. I undertook further readings of each transcript, making reflexive, analytical notes on paper. Before moving to software, I re-read and re-listened to each interview as a whole narrative, making brief notes and marking initial codes on paper transcripts. I used these codes to manage, organise and label the content of practitioners' accounts. I began by coding as inclusively as possible, using broad, open, overlapping codes. Some codes were 'a-priori', focusing on my research objectives, such as; *decision-making, risk management; living with a dementia, psychological wellbeing and QoL* and *legislation/policy/guidelines.* Bazeley (2007) supports this approach to coding;

> *'Those working from a background of extensive reading in the literature, who have a lot of a priori experience ... will come to their data already with a list of concepts they are interested in exploring...'* p76.

I acknowledge that in undertaking such 'top down' processing, my perception was influenced by prior experience. I was wary of assuming shared understandings (Finlay, 1998a). I therefore tried to ensure that I was open to difference and change, and I amended these conceptual codes as I worked through my analysis. I also generated other *'in-vivo'* codes as I explored the content of transcripts. Initially these codes were 'meaning units'; grouped and labelled, even if content was borderline and connections were vague. This helped me to manage information and identify patterns, in preparation for further analysis. By this stage, I was using paper less and software more. Still guided by my plan, I then focused on narrative analysis, discourse and reflexive analysis. I gradually moved beyond individual transcripts. Undertaking coding and analysis, I collated codes into categories and networks across all transcripts. At this stage, I included secondary levels of analysis. This involved revisiting and exploring policy and practice documents against my analysis of practitioner accounts. Toward the end of my analysis, I organised my analysis through use of reflexive framing, networks and models of core conceptual themes.

I will now provide a more detailed account of my analysis.

Narrative analysis; My interest in narrative was triggered by Mattingly and Fleming's (1994) study of OT's use of narrative decision-making in practice. I remain interested in how we develop stories to make sense of practice, how we use stories to explain and perform 'self' to others, and how stories involve transactions with wider social narratives;

> *' Not all the interviewee's responses take the form of a narrative, but my justification for the approach is the central position occupied by narrative in terms of how we understand, we attempt explanations, in general, how we account for things in terms of stories,'* (Boyes 2006, p29).

Much of the health and social care literature on narrative research refers to Mishler, Lieblich, and/or Riessman. Mishler (1995) proposed that approaches to narrative analysis differ in the emphasis they place on content, structure and/or performance. Lieblich et al (1998), described approaches to narrative analysis along two dimensions; holistic/categorical and content/form. Riessman (1993 and 2003) explored narrative as performance of identity.

In trying to ensure my project has some usefulness in practice, my analysis focused on context and content over linguistic structures. In addition, rather than questioning 'truth', I was interested in *functions* of accounts. I examined accounts for patterns, functions and performance of self. Exploring patterns, I noted the use of metaphors, alliteration and repetition, and made reflexive notes of some triggered images. Exploring functions, I noted if a story was particularly persuasive and engaging and if it portrayed particular perspectives, for example ethical values. I made links with wider patterns, contexts and institutional discourses. Exploring performance of self, I noted how practitioners' constructed identities and represent their practice and that of others, for example whether practitioners' situated self, 'owned' experiences, and/or told stories of abstract events that distanced self. I considered whether narratives appeared vague and 'disconnected' and/or particularly descriptive, articulate or emotional (Boyes, 2006, Bradby and Hargreaves, 2009, Crossley, 2000, Czarniawska, 2004, Frost, 2009, Greenhalgh and Collard, 2003, Hall and White, 2005, Holloway and Freshwater, 2007, Hurwitz et al, 2004, Jordens and Little, 2004, Lawler,

2002, Lucius-Hoene, 2000, Mancini and Rogers, 2007, Mensinga, 2005, Nygren and Blom, 2001, Parker, I, 2005, Phoenix et al 2010, Riessman, 2003, Riessman and Quinney 2005, Roulston, 2010, Taylor, C, 2006 and Watson, 2006). I used Gee's (2004) guidance on use of 'I-statements', to examine whether some words/phrases were intensified, whether practitioners' used the direct speech of others, and whether they addressed me as interviewer/practitioner.

In acknowledging that narratives are contextual and cultural, it was important to pay attention to wider contextual and structures;

> *'Understanding the discourses embedded in these texts is the link between the local and the global, since texts and social practices are mutually constructive and serve to relate local contexts to the wider culture. This approach sought to illuminate the parts played by both the individual and the institution in the creation of local 'reality'. Neither should be completely dominated by the other'* (Boyes 2006, p27).

Discourse analysis is an umbrella term referring to ways of studying language. In Foucault's (1980) explorations of power and knowledge, he argued that power pervades social relations and relies on 'truths' being reproduced through discourse. His notion of the capillary nature of power describes how the internalisation of such 'truths' by individuals and groups produces a particular subjectivity. Discourse can become so much a part of daily practice that we may not be aware of its influence. Foucault advocated the use of discourse analysis at 'the interface' of person and institution. Thus, my analysis examines *'truth effects'*; how certain discourses in certain contexts are so powerful they are understood and acted upon as if they are a truth. In using discourse analysis, I was trying to explore how certain 'truths' are taken for granted/assumed, and how discourse represents, constructs and maintains understandings of risk management and dementia care. In particular, I made notes when I felt practitioners' accounts supported or challenged dominant discourses.

My use of discourse analysis was particularly influenced by researchers who use this approach in analysing health and social care practice (Adams, 1998, 2001a, 2001b, Alldred and Burman, 2005, Allen and Hardin, 2001, Ballinger and Cheek, 2006, Boyes, 2004, 2006, Breheny and Stephens, 2007, Brown

et al 2008, Crowe and Carlyle, 2003, Crowe and O'Malley, 2006, De Bellis, 2006, Freshwater and Rolfe, 2004, Gordon, 1998, Hall and White, 2005, Hamilton and Manias, 2006, Hammell, 2009, Henderson and Henderson , 2002, Ikels, 2002, Kontos, 2004, Lean, 2007, Mackey, 2007, Mitchell, 1996, Opie, 1997, Parker, I, 2005, Parker, J, 2005 and 2007, Polkinghorne,1992, Rolfe, 2005, Rossiter, 2005, Rouveyrol et al 2005, Sarangi and Candlin, 2003, Sims–Schouten, 2007, Stanford, 2007, Stanley, 2005, Stevens and Harper, 2007, Taylor and White, 2006, Thorne, 2001, Thornton, 2006, Traynor, 2006, Urek, 2005, Warner, 2006 and Wetherell et al, 2001).

My analysis was also influenced by Derrida (1978), who argued that texts structure our interpretation of the world. He advocated the deconstruction, and reconstruction of binaries in texts. From this perspective, the division of complex daily practice into two opposing, hierarchical concepts is an over-simplification. However, I was also mindful of Kikuchi's (2006) argument that problem is not the binary but the misuse of binaries. In analysis, I noted if practitioners used binaries to construct hierarchies (such as safe/risky, mind/body, cognition/emotion) and questioned whether their stories implied that one is more important /desirable/ worthy than 'other'. I also considered practitioners' resistance and reconstruction. For example, I noted whether practitioners represented possible alternatives and differences as 'both-and' continuums, rather than relying on the 'either/or' of dominant dualisms. This included considering practitioners' use of metaphors (Arner and Falmagne, 2007, Bevir, 1999, Crowe and O'Malley, 2006, Crowley, 2000, Freshwater and Rolfe, 2004, Hepburn, 1999, Humphries, 1997, Janks, 2005, Koro-Ljungberg, 2004, Mackey, 2007, Macleod, 2002, McCabe and Holmes, 2009, Opie, 1997, Rolfe, 2004, Samuels and Betts, 2007 and Seymour, 2006).

Reflexive analysis; My reflexive analysis included ongoing, critical, and systematic considerations of my methodological choices throughout the research process. Schon (1987) distinguished between retrospective *reflection-on-action*, and *reflection-in-action* where thinking and doing happen together as we adapt in context. Influenced by Schon, Finlay (1998a, 1998b) suggested that *reflection* denotes thinking about something after it has happened, whereas *reflexivity* and *reflexive analysis* attempt to develop

these understandings. Likewise, Letherby (2002) distinguishes between *descriptive reflexivity* (reflection) and *analytical reflexivity.*

In my reflexive analysis, I explored and questioned my assumptions, power relations and representations. I have tried to identify dominant constructions that may influence my research and practice. I agree with Pels (2000);

> '...reflexivity presupposes that, while saying something about the 'real world', one is simultaneously disclosing something about oneself,' p2.

and Taylor and White (2000);

> 'If we are going to stand by our assertions that knowledge is socially constructed then we need to recognise that this must also apply to our own work,' p35.

However, I believe we can never fully know self or others, and see limitations in *introspective* reflexivity (Thompson, 2006).

In undertaking reflexive analysis for this project, I referred to my *reflexive notes*, and questioned ways in which I may have shaped practitioners' stories in interview. I noted where I moved from being active listener to co-constructor. I made notes on how I was being a listener; whether I was active, passive and/or intrusive. I noted instances when I felt I stood back/ distanced myself. I questioned whether I had gone along with assumptions and/or agreed with assumptions I do not share. I noted ways in which I attempted to control the content of what was said and how long we spoke for. I noted my use of questions, and particular subjects that I returned to. I noted ways in which I identified with practitioners, and considered possible influences of my assumptions. My reflexive analysis was particularly influenced by writers who have used these approaches in practice research (Bannigan and Moores, 2009, Boyes, 2006, Bracken and Thomas 2005, Brown et al, 2008, Crowe and O'Malley, 2006, D'Cruz et al, 2007, Finlay 1998b and 2002, Fook and Gardner, 2007, Hill, 2009, Hughes et al 2006, Huxtable, 2006, Kidd, 2008, Kinsella, 2009, Letherby, 2002, McCabe and Holmes, 2009, Randall et al 2006, Rhynas, 2005, Rossiter, 2005, Schwarz McCotter, 2001, Taylor, C, 2006 and 2008, Taylor and White, 2000, 2001and 2006, Vincent et al, 2007 Watson, 2005, Watt, 2007, Watts, 2006, Wetherell et al, 2001, White, 1997, White et al 2006 and Wiesenfeld 2000).

Analysis across accounts;

> *'The task of the analysis is then to show how the story of this single subject can not be understood without connecting it with the stories of others'* (Parker, I 2005, p82).

In order to help me manage texts for analysis, I created a 'virtual' project using *'NVIVO'*. This software enabled me to save, organise, explore, track, manage and link information in ways that would have been impractical if this information had remained on paper, or in different locations and word documents within the computer. I could take 'closer' looks in and across transcripts, without loosing track or being overwhelmed by information, connections and overlaps (Ajjawi, 2006, Bazeley, 2007, Stanford, 2007, and Stanley, 2005).

I began by transferring the initial coding from paper transcripts into the software. I then 'imported' my reflexive memos. I used the facilities available to link a reflexive memo with each transcript, and then coded these memos. I also 'imported' policy and practice documents, so they were readily accessible to review as I was undertaking my analysis of practitioner accounts.

The software facilities enabled me to view the amount and location of my coding as I was undertaking it, for example regularly reviewing coding density and use of particular codes. In this way, I 'took stock' of my coding as I undertook analysis within <u>and</u> across documents. As I moved from searching, coding, and grouping, I referred to my analysis guide (Appendix XI). I also used the 'annotations' facility to create reflexive footnotes and reminders linked to my analytical decisions. When initially using the software, I organised codes in an open, broad, inclusive, non-hierarchical system. I also considered some key words that were of interest and/or repeatedly used (such as *'home'* and *'Sainsbury'*). These codes began as descriptive labels, but I gradually created more thematic, analytical codes. From narrative discourse perspectives, I generated groupings such as *metaphors, ownership*, *binaries*, *dilemmas* and *complexities*. I then used software facilities to connect, categorise and arrange analytical codes into groupings. I organised these based on conceptual relationships, for example; *'Risk management decisions'*, which included *assessments, emotions, intuition,*

thresholds and complexity and *policy.* A particular advantage over paper and less interactive e-systems was this facility to reflexively view potentially related and linked accounts across documents in manageable formats (Ajjawi, 2006, Banks and Williams, 2005, Bazeley, 2007, Bringer et al, 2004, Furner and Steadman, 2004, Gibbs, 2002, Hill, 2009, Johnston, 2006, Stanford, 2007, Stanley, 2005, and Waugh, 2009).

I also used the software to generate reports, which helped me track my grouping and analysis across and within texts (see Appendix XII). However, I continued to create paper reflexive notes, as moving away from my computer helped me to free-up my thoughts, take a break and play with ideas. I explored patterns and relationships between concepts and considered theoretical groupings, themes and models. In this way, I decided how to represent analytical information using networks and conceptual models. Finding software models restrictive, I used paper then 'word' documents to develop these representations. I used these conceptual representations to complete my analysis (see below).

Secondary analysis; I explored practitioners' accounts alongside wider practice discourses, in particular policy and guidelines. This secondary level of analysis was influenced by Foucaults' (1980) notion of the capillary nature of power and Bourdieu's (1990) concepts of *'habitus'*. Although represented as a stage in my analysis, my searching and reviewing of these documents was a continual, cyclical process. I used these documents to inform my discourse analysis of practitioners' accounts (Boyes, 2006, DeBellis, 2006, Foucault, 1972, Gordon,1998, Hill, 2009, Parker, J, 2005, Sarangi and Candlin, 2003, Watson, 2005 and Wetherell et al 2001).

Networks and models; In constructing analytical representations, I was particularly influenced by the work of Ajjawi, 2006, Attride–Stirling, 2001 and Jackson et al, 2007. Guided by my analysis plan, I worked with conceptual groupings. I began with a *linear representation of key themes* (Appendix I) with the following outline structure;

- *Becoming and Being at Risk; Practitioner accounts of the nature and assessment of risk* (see chapter 5)
- *Contextual Ethics in Risk Management Decision-Making; Intrapersonal and interpersonal contexts* (see chapter 6)

- *Contextual Ethics in Risk Management Decision-Making; Environmental and societal contexts* (see chapter 7)

I developed this *linear representation* into a *network representation* (Appendix II) on three levels; core themes, organising themes and elements. In creating this network, I selected, organised and represented concepts as connected and overlapping. I represented relationships between concepts using shape, pattern, shading, colour, pictures and words. Looking at patterns and difference in the network representation, my attention was drawn to the pervasiveness of contextual ethics and a notion that these connections influenced the whole picture. Thus, I constructed a *conceptual kaleidoscope*; contextual ethics in risk management decision-making (Appendix III). Using these representations enabled me to acknowledge complexities within and across accounts, helped me to be systematic in my analytical development from texts to themes to models, and ensured some clarity and openness about my analysis. I examine these representations further in chapters 6 to 8.

Having provided you with an account of my research methods, I will now explore my considerations of ethics and quality in the research process.

Considerations of ethics and quality

I have made decisions about ethics and quality throughout my project. My choices about quality have been guided by ethical and theoretical considerations. I begin this section with an examination of ethical processes in my research. I then explore ethics of interviews. I also acknowledge other measures of research quality, in particular reflexivity, validity and transferability.

My research proposal was scrutinised and approved by several research ethics organisation and procedures;

- Sheffield Hallam University; 'Independent Scientific Review', research degree sub-committee and academic supervisory team
- Local service user and carer research group
- Local NHS Research Ethics Committee (LREC)
- Local NHS 'Mental Health Research and Development Consortium'

As practitioner-researcher, I was also guided by COT (2003) research ethics guidelines. This outlines key ethical principles against which my research can be judged. These include minimising potential for harm, maximising potential benefits, working in partnership (including avoiding exploitation of power imbalances), openness, accuracy, confidentiality, informed consent and choice.

In order to obtain ethical approval for research with NHS practitioners, I followed the trust's research governance procedures, agreed actions with the trust's research governance board of ethics and LREC, and obtained permission from the trust's director of older peoples' services. In consultation with LREC, the service user and carer research group, and the trust research governance manager, I developed the *'Research Participant Information Document'* (Appendix V) and *'Research Participant Consent Form'* (Appendix VII). I tried to ensure these were written in an accessible way and acted on advice and feedback provided in consultations.

When considering ethics in interviews, I was aware that interviews would involve practitioners reflecting on practice, and this could trigger uncomfortable feelings and cause some distress. In advance of the interview, I provided practitioners with the *'Research Participant Information Document'* (Appendix V), which included a statement relating to consent and confidentiality. I provided university contact details for practitioners who had queries or concerns about my research. Although I offered to provide each practitioner with a copy of an anonymised transcript of 'their' interview, I was mindful that reading this could also raise ethical dilemmas for the practitioner. Indeed two practitioners have since been in contact and spoken with me about how they felt reading through their transcript.

In parallel with my practice ethics, as interviewer I needed to be competent in reflexive inter-personal skills, such as being able to establish meaningful, informed and ongoing consent (Ramcharan and Cutliffe, 2001). As practitioner and researcher there is the added complexity (and impossibility) of attempting to keep these roles separate. For example, there may be a duty to respond in becoming aware of 'unsafe' practice. As in practice, the complex notion of confidentiality needs to be understood and agreed. Therefore, I sought guidance when designing the *'Research Participant*

Information Document', in particular regarding my statement on *'the limits of confidentiality'*, which begins;

> *'It is important to note there is a limit to confidentiality and anonymity. As a health professional, I have a professional duty that overrides the principle of confidentiality,'* Appendix V, p 3.

I was unsettled by advice from some academics that my professional responsibilities regarding safeguarding procedures did not apply, and I had no responsibility to act. As this did not fit with my professional ethics, this was an ethical dilemma. However, on consulting the trust's research governance manager and service user and carer research group, they expressed particular interest in my inclusion of *'limits of confidentiality'*, and were unequivocal in their stance. Although they acknowledged that including this statement may influence who consented to take part in interviews, they judged that I *did* have responsibilities, and therefore it was important for this statement to remain and be acted on if necessary. I followed their advice.

Another ethical consideration was the anonymity of practitioners who took part in the interviews and the confidentiality of interview recordings, notes and transcripts. Throughout the project, my reflexive notes were anonymised as they were written. All interviews took place in staff areas within trust buildings. I anonymised each interview recording as I transcribed it. I addressed issues of confidentiality in the *'Research Participant Consent Form'* (Appendix VII) and *'Research Participant Information Document'* (Appendix V). I also reminded all practitioners of the nature and practice of confidentiality for this research just before each interview. Once I had received a signed *Research Participant Consent Form'*, I assigned that person a number and pseudonym, which I used from that point onwards in all my audit trace notes. There is only one list of participant names linked with their assigned number and pseudonym, which I saved in a password protected document behind a 'firewall', in an NHS computer. This will be deleted on completion of my project.

I also removed any other potentially identifying details (such as peoples' names and locations) as I transcribed. I did not undertake any analysis or import any document into *NVIVO* software until I had double-checked the transcript was anonymous. Therefore, when I use direct quotes from

practitioner accounts, these are not attributable to any person. I also included a request for permission to direct quotes, in the *Research Participant Consent Form*'. Although this concern for anonymity resulted in some de-personalisation and de-contextualisation of practitioners' accounts, and thus has implications for my analysis, I feel this compromise is justifiable from an ethical perspective (Adams, 2008 and Watts, 2006).

When consulting the trust's research governance board of ethics and LREC, I also took guidance from and acted on their recommendations regarding access to case records. All these records (17 documents, from 7 people's case notes) were accessed by one administrative assistant, who was already accessing these notes as part of his daily practice. In agreement with his manager, he was given time to access and anonymise the documents I requested. Before I saw these records he removed all personal, identifiable information, relating to service users, staff members and carers. This involved removing names, dates of birth, addresses, NHS numbers and names of service providers and places. However as already mentioned, after collating these notes and consulting academic advisors, I decided it was beyond the scope of this project to include this information for analysis. These copies have since been destroyed.

I also judged my project quality by considering reflexivity, validity and transferability throughout the research process. As already explored, from a reflexive perspective I acknowledged and examined my theoretical assumptions, and considered ethical issues relating to myself as insider practitioner-researcher. Validity is about whether my arguments are justified and credible to others, such as the reader. Thus, I attempted to make this report detailed and transparent enough to enable readers to judge. Another measure of worth for my project is about usefulness and transferability to similar situations. I have tried to work towards worthwhile and achievable objectives. I also tried to ensure enough detail in my report to enable comparison with similar practice situations (Boyes, 2006, Cho and Trent, 2006 and Lincoln and Guba, 2000).

I provide a more detailed account of ethics and quality in chapter 8, and consider the usefulness of this project in chapter 9.

Having considered ethics and quality in my research, I now offer some reflexive considerations and concluding comments.

Being Reflexive

In my draft research proposal I wrote;

> *"For the purpose of my research, I will not be confined to a particular perspective, but will move amongst several ..."*

Feedback from supervisors warned of possible resistance from academic reviews and ethics committees. My choice was to narrow down my perspectives or risk having my proposal rejected. Although wary, I decided to risk rejection (irony not lost, given my chosen subject area). As stated at the beginning of this chapter, I felt my choices should reflect the complex, chaotic and ambiguous world of risk management in dementia care. I did not intend to privilege one single authority. At work, I resist the evangelical way of being OT. Likewise, I do not subscribe to a belief in one 'pure' way of being researcher. Like Schwarz McCotter (2001);

> *'I want theory to help me understand, not to help me to pretend to understand, or to strike a pose,'* p3.

In an attempt to address my concern over possible rejection, I read more and reflected. I was mindful of possible tensions between my political, critical, perspectives and some approaches to phenomenology and postmodernisms. There was also potential for tensions in my undertaking narrative and discourse analysis. I am indebted for timely supervisory guidance (Boyes, 2006). I also found some reassurance and was amused by Middleton's (2002) account of her *'theoretical promiscuity'* p1.

I am also grateful for other supervisory advice, in particular to create my Analysis Guide (Appendix XI), without which I may well have been lost and still finding my way out. In planning and undertaking my analysis, I took some comfort from Richards' (2009) suggestion that feeling overwhelmed is a *'common and necessary'* (p196) when undertaking and writing about the complexities of qualitative analysis.

During the time I was interviewing, I met one practitioner by chance in a meeting. He had been given the *Participant Information Document* (Appendix V) by his manager and wanted to explain why he had declined to be

interviewed. Our brief discussion reminded me of the messy dynamics of interviews. I wondered how many of the practitioners who did take part had somehow felt obligated. I acknowledge that I can never fully know how choices about taking part influenced practitioners' accounts and my project (Schwarz McCotter, 2001, Thompson, 2006 and Watts, 2006).

Concluding comments

In this chapter I have provided an account of the theoretical orientation and methodology of my research. I began with a brief overview of my choices. Next, I outlined my philosophical perspectives, theoretical choices and methodological implications. In the main body of this chapter, I examined the methods I used to generate, organise and analyse the research information. In the last section, I explored some ethical and quality issues in my research. In chapters 5 to 8, I provide my analysis of practitioner accounts. In chapter 5, I analyse accounts of the nature and assessment of risk. In chapters 6 and 7, I provide my analysis of practitioner accounts of contextual ethics. In chapter 6, I focus on practitioner accounts of intrapersonal and interpersonal contexts. In chapter 7, I focus on practitioner accounts of wider contextual ethics; environmental and societal contexts. In Chapter 8, I provide some project conclusions alongside my research objectives.

Chapter 5 Becoming and Being at Risk; Practitioner accounts of the nature and assessment of risk

Introduction

This is the first of three chapters where I analyse practitioner accounts of risk management with people who are living with a dementia. In this chapter I focus on practitioner accounts of the nature and assessment of risk. In chapters 6 and 7, I examine practitioners' accounts of risk management.

I begin this chapter with an overview of the nature and assessment of risk in dementia care practice. I continue with my analysis of practitioners' accounts of the nature of risk and risk assessment. Towards the end of this chapter, I offer some reflexive considerations and concluding comments.

The nature and assessment of risk

In my daily practice assessing risk is a key priority. For over 30 years researchers have also represented risk assessment as a central feature in health and social care policy and practice (Alaszewski et al, 1998, Alaszewski and Horlick-Jones, 2002, Clarke et al, 2011a, Cornish, 2005, Heyman et al 2010, Kemshall, 2002, Manthorpe, 2004, Mitchell and Glendinning, 2007, Moriarty, 2005, Norman, 1980, Taylor, BJ, 2006 and Warner, 2008). In common with some of these researchers, I too am interested in examining assumptions and concepts that underlie risk assessments.

As explored in chapters 2 and 3, there are different understandings of the nature of risk and assessment, and this is reflected in literature, policy and practice. Most contemporary policy and practice guidelines include negative concepts of risk, with a focus on hazards, probability and consequences of harm;

> 'A risk is the likelihood of the hazard occurring, its potential severity and the type of harm that could be caused' (Alzheimer's Society 2003, p45).

> 'Risk relates to a negative event (i.e. violence, self-harm/suicide or self-neglect) and covers a number of aspects.

> • How likely it is that the event will occur.

> • *How soon it is expected to occur.*
>
> • *How severe the outcome will be if it does occur'* (DH 2007c, p13)

However, practice guidelines do not consistently promote negative perspectives of risk. Some acknowledge ambiguities, and guide practitioners toward the consideration of positive risk management and risk enablement (DH 2007b, 2007c, Manthorpe and Moriarty, 2010, NCB, 2009 and Morgan, 2000a). For example the risk management tool used where this project was undertaken begins;

> *'Risk (in mental health);The likelihood of an event happening with potentially harmful or beneficial outcomes for self and others,'* (Morgan 2000a, p1).

Titterton (2005) proposed two models of risk assessment; *'safety first'* and *'risk-taking'.* Safety first assessments construct practitioners as experts and focus on physical health, dangers, control and disabilities. Risk-taking assessments consider subjective, lived experiences and communication, and include psychological wellbeing, rights, abilities and inclusion.

I will now provide my analysis of practitioners' accounts of the nature of risk.

Practitioner accounts of risk

In their accounts of risk assessments, practitioners used different terms. In addition to talking about *'risk',* they also spoke of *'safety', 'danger', 'harm', 'protection', 'vulnerability', 'wellbeing'* and provided examples of particular hazards. These are similar to terms used in Alaszewski's (1998) metaphor of a 'risk iceberg'. In my analysis, I examined how these words were used to describe, explain, influence and construct experiences and understandings of risk assessment and risk management decision-making (Boyes, 2006 and Heyman et al, 2010). As with practice guidance and policy, practitioners presented negative *and* positive concepts of risks;

> *Some things are worth taking a risk for* (Neil)
>
> *I think we owe a duty of care to our patients to make sure they are safe* (Teena)

All practitioners told stories of realist, individualistic notions of risks, and provided examples of particular risks as objective phenomena and possible hazards that need to be assessed and controlled.

Practitioners' stories also supported complex, subjective, negotiated, constructed, political and contextual concepts of risk, such as;

> ... *to keep somebody safe at home is more expensive than 24 hour care...and that doesn't always go down well...* (Hannah)
>
> *I think possibly myself and the social worker were more active in positive risk taking and possibly some of the nursing staff were very cautious* (Sue)
>
> *So if her daughter's brought her in for an appointment with a psychiatrist straight away her risk assessment's not going to be what I see when I go and see her at home* ...(Rachel)

I support Warner's (2006 and 2008) suggestion that examining where practitioners' 'locate' risk is helpful in understanding their contrasting, complex constructions of risk;

> *'Focusing on the sites in which practitioners (and others) locate risk can therefore be a helpful conceptual tool in terms of understanding the fluid and unstable nature of constructions of risk in general, and may serve to clarify sources of conflict in relation to multidisciplinary working in particular,'* (Warner 2006, p9).

However, I have some reservations about Warner's reference to conflicts in multidisciplinary working. Her research was uni-disciplinary, with conclusions based on stories told by mental health social workers. Although my project was undertaken with four different professions, it was not my aim to compare and contrast by profession, or indeed any other 'subject variable', such as work-base, age or gender of practitioner. The complex constructions of risk explored in my project may be contradictory and conflicting, but I did not assume that such differences are a product of professional identities.

Differences portrayed were both *between* practitioners, and *within* the account of each practitioner. Unlike some uni-disciplinary risk management research, differences in practitioners' stories and perspectives were not represented as contradictions, or in conflict or opposition, but as part of the complex nature of everyday life and professional practice.

Influenced by Warner's (2006 and 2008) writings on the *location* of risk, and similar groupings in trust risk assessment guidance (XX trust, 2008), I have represented practitioners' accounts of risk in three conceptual areas that are

loosely related and overlapping. These are stories of people living with a dementia becoming and being;

- at risk of harm from hazards and self
- at risk from others
- a risk/danger to others

At risk from hazards and self; Practitioners' accounts included stories which 'located' risk in daily life; in environments and situations that were presented as potentially hazardous for people living with a dementia. These included ordinary activities, such as walking, eating and using gas.

In keeping with some government risk discourse (such as DH, 2007b, 2007c and Manthorpe and Moriarty, 2010), practitioners' stories of risk were not limited to static, objective phenomena. Practitioners' accounts included historical, subjective and contextual factors. Their stories implied concepts of risk as negotiated, complex and not always conscious. They spoke of risks as multiple and changing with time, place, situation and person. Some accounts supported a probabilities discourse, for example practitioners' stories included attempts to identify hazards, make predictions and control the likelihood and / or severity of harm.

All practitioners told stories of the difficulties of making predictions, such as;

> *The risks were x y and z, so if b c and d happens we couldn't have foreseen that ...So that's not necessarily a failure* (Orla)

> *I don't know what's gonna happen in the future ...Neither does the client or the carer* (Karl)

This included exploring the notion that risks can be calculated based on past events;

> *It's looking for the early warning signs* (Naomi)

> *It's a not just one thing ...It's always the accumulation ... it's never just that there's a huge risk* (Naomi)

> *There's a fair risk that she could trip and fall or her knee could give way. She's got a history of falls* (Daniel)

> *You think 'oh no wait a minute, she's had a fall in the last year'* (Teena)

All accounts included stories that portrayed dominant individual, medicalised discourses of dementia, in particular that living with dementia inevitably

means living with the progressive loss of daily living skills and cognitive abilities. Alongside these stories, practitioners constructed living with dementia as increasing the probability of harm associated with ordinary, everyday living. Hazards we all face in life were portrayed as acquiring different proportions, priorities and potentials;

> *A lot of referrals that come to me are for home safety assessments and risk assessments to do with kitchen ... whether someone's safe to still make their own meals* (Isobel)

> *She's got a dementia and lives on her own and she ... doesn't touch the fire, she doesn't do any cooking ... but if she did, if she tried, if she thought that she could, we wouldn't be able to leave her in the house on her own* (Rachel)

> *It's not just a consequence of them falling and not being found, but falling and then not actually knowing what to do* (Rachel)

> *People with dementia they don't always realise the risks that they're in* (Teena)

However, in contrast with some research undertaken with practitioners in 'adult' mental health (Stanford, 2007 and Warner, 2006 and 2008), practitioners constructions of risk to self did not include stories of suicide or 'deliberate' self harm. The only explicit inclusion was by Tariq, who portrayed risk of *'suicide'* as discrete and separable from *dementia* in risk management decision-making;

> *It starts off with what the referral is...if it is to do with depression and sort of risk of suicide, then you'll be aiming at that. Whereas if it's for a dementia, you'll be looking at those aspects* (Tariq)

Some stories implied that people place themselves in danger because they are not passive recipients of 'expert' medical advice and treatment;

> *The risk is of non compliance with treatment...I think there's a great worry that ... the person with dementia won't allow the homecare team in...and that's a risk* (Orla)

> *Compliance with medication... Because a lot of people will tell you they take their medication and they don't* (Teena)

> *It's just some people just will not accept some services* (Teena)

> *People don't recognise their own risks, do they?* (Rachel)

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Practitioners' accounts of hazards and being *at risk* included stories of home and contextual risks, such as;

> *She was going out of the house on a night ...walking round the streets with no clothes on ... She didn't have any family. She didn't have any neighbours that looked out for her ... She would have cigarettes and throw them straight on to the floor ... The carpet was completely burnt. She was extremely, extremely incontinent* (Isobel)

In these stories practitioners' portrayed 'locations' of risks to self as multiple; in environmental hazards, behaviour, bodily 'functions' and 'symptoms' of a dementia. Many stories supported complex discourses on contextual, ethical and political understandings of risk in dementia care. These are explored in later chapters.

At risk from others; Practitioners' accounts of becoming and being *at* risk from *others* included stories of risk from 'strangers' and services. In keeping some policy (see chapter 3), some practitioners portrayed people living with a dementia as being particularly *vulnerable* to harm from others;

> *So they're quite vulnerable in that sense and I think people do prey on them* (Tariq)

Some stories of vulnerability were within accounts of 'wandering' and home;

> *Wandering the streets at 2 or 3 o'clock in the morning... She'd be very vulnerable ...You don't know who she would bump into* (Teena)
>
> *When someone is so vulnerable that they're allowing access into their home* (Sue)

Such accounts imply a dichotomy of dangerous streets and strangers, in opposition to safer home and family. However this dichotomy contrasts with other accounts of home as hazardous.

Whilst some stories presented service provision and care as a way of reducing unacceptable levels of risks, other stories were of people being at risk from services and care. For example Naomi's account of moving to live 'in care';

> *There isn't the risk of wandering out the door ...and getting lost, but there are the other risks the effect on mood when they suddenly get bereaved of everything that makes them, them* (Naomi)

I explore accounts of being at risk from 'care' in more detail within my analysis of practitioner accounts of environmental contexts, in chapter 7.

Being a risk to others; Practitioners' accounts of people living with dementia being _risky people_ were less common than those of people living with dementia being _at_ risk. Such accounts were usually implied within stories of unintentional, dangerous behaviour towards anonymous others/neighbours (in particular gas explosions and fires). For example, I interpret Teena's story as implying risks to self _and_ others, through dangerous behaviour;

> _...that's a big danger if they smoke_ (Teena)

Tariq was one of only two practitioners who spoke of practitioners being at risk of harm from people living with a dementia;

> _If there's considered to be a high risk and an uncertainty about what someone's going into then it would be expected that 2 people would go on that initial visit_ (Tariq)

Accounts of people living with dementia being a risk to others were also implied in stories of blame cultures and risks to the agency. I examine such accounts in more detail in chapter 7.

Having explored practitioner accounts of the nature of risk, I will now provide my analysis of practitioner accounts of risk assessment.

Practitioner accounts of risk assessment

I will now provide my analysis of practitioner accounts of _what_ is assessed and _how_ risk assessments are undertaken. I write this analysis alongside related literature.

**What** **is assessed;** Some practitioner stories supported medical discourses;

> _We're looking at it from the psychiatric point of view_ (Teena)

Some relied on realist notions of true/false and right /wrong;

> _So we're getting a true picture ... so that we would know that we are doing the right thing for the person_ (Teena)

Rachel's story of difference in assessments was based on a mental/physical dichotomy;

> _I've done 2 and a half years in an acute trust seeing acute illnesses so when I see somebody and they're looking a bit ... a bit low and they're head's down I'm thinking oh I wonder if they're not very well whereas a mental health nurse will be thinking I wonder if their_

> *mood's low ....So it's a very different perspective of seeing the same*
> *thing* (Rachel)

Practitioners' accounts supported *and* resisted the dominant constructions of risk-led assessments.

Naomi, Sue and Neil resisted a narrow focus on risk;

> *You engage, gather information, see what their goals and wishes are.*
> *See what the other things that impact on them are* (Naomi)
>
> *It's not just a risk assessment I do, no, no...I think a big part of it is*
> *looking at ...the persons self perception and what their own hopes*
> *and aspirations are* (Sue)
>
> *I think you can focus too much on the risk ...You know the risk to*
> *whom, for what* (Neil)
>
> *I always talk about increased needs rather than increased risks*
> (Neil)

Isobel portrayed risk assessments as subjective interpretations;

> *I do really believe that it differs whoever's the assessor ...and the level*
> *I think the level of risk as well ... to what degree and what severity*
> *the risk is I think whoever's doing it it differs as well* (Isobel)

Neil was explicit about complexity and values in assessment;

> *It's a very complex situation really and people do make value*
> *judgments rather than risk assessments* (Neil)

Practitioners' stories of complexity, context and ethics in risk assessments and decision-making stood out both in the passionate and reflexive ways in which many were narrated, and the extent to which they challenged dominant discourses. I examine these accounts in more detail within my analysis of practitioner accounts of risk management decision-making, in chapters 6 and 7.

How **risks are assessed;** As explored in chapter 3, guidance on how to assess and manage risk in contemporary health and social care is plentiful, and can be contradictory. Guidance that forms part of the context of my daily practice includes the *MCA Code of Practice* (DCA, 2007), *Mental Health Clustering Tool,* (CPPP, 2010) and 'tools' that attempt to score risk of falls (Nandy et al, 2004). Guidelines recommend numerous 'tools', for example practice guidance *'Best practice in managing risk'* (DH, 2007c) provides 18 examples of risk assessment 'tools'. However, they suggest that such tools

should only be used as part of an assessment process, to guide decision-making, and warn;

'Risk assessment tools must be used with caution' (DH 2007c, p30).

Likewise, whilst *'formally approving'* the *Sainsbury* tool (Morgan, 2000a), XX trust (2008) argues;

'A tool can only contribute one part of an overall view of the risk presented by a particular individual at a point in time. The results of the tool-based assessment must always be combined with other information on many aspects of the service user's life and current situation,' p15.

Given the practice context, I was not surprised that all accounts included stories of using risk assessment tools, in particular the *'Sainsbury'*;

When we initially go out and see somebody we'd always do the Sainsbury's risk assessment. That <u>has</u> to be done (Isobel)

We do the Sainsbury's risk ....everybody does the Sainsbury's risk... that is the base risk assessment (Naomi)

Sue portrayed this tool as structuring her preparation and focus for risk assessments. She also included a more contextual representation of assessment. In addition, she portrayed her *'natural'* and *'obvious'* starting points as being attributable to her professional role, implying professional differences;

I look at the Sainsbury's risk assessment and get a better picture of that person ... it might ring alarm bells ...it might say to me there are certain areas I really need to double check...but there are still things that I would naturally look at because of the general concern I would have about somebody perhaps living on their own with memory impairment ...and the possible risks they would have ... because historically OTs have always, no matter what area they have worked in, have always looked at home environments ... that's obviously where I would start ... (Sue)

Practitioners also referred to other assessment tools;

It depends where you're coming from. In my head I guess there is the community care assessment (Hannah)

Karl's metaphorical story represented the MCA as a *'tool'* at hand to guide assessments;

> *Now I've got the Mental Capacity Act under my belt well as much as I think anybody can ....I find it a very useful tool* (Karl)

Teena's stories can be interpreted as portraying faith in medical models and the reliability and validity of tools to support her judgements. She represented tools as categorisation devices and supported discourses of control (*'my patients'*) and scientific certainty through numbers;

> *If I went and saw someone to do the mini-mental, but I thought they looked a bit tearful, not eating very well, not sleeping, I would have a HAD scale ...for the anxiety and depression...and sometimes you'll do it and it will show the person's got a mild depression* (Teena)

> *We'd do the assessments ...the mini-mental... the Bristol activities of daily living... the Sainsbury risk assessment...so that would highlight ... different areas where there were problems ...and we'd also do a 'HONAS' ...and we'd put them in the category where most of my patients are like ... 14, 15, 16 ... That's the bracket they sort of fall into people with dementias ... so we need to look at the tools that are available* (Teena)

In contrast, Rachel portrayed a more sceptical understanding of the usefulness of scores in risk assessments;

> *What's a score?... It's just a number isn't it?* (Rachel)

Karl portrayed trust policy and procedure as a memory aid and guide for his assessments. His use of *'package'* portrayed a tidying-up of assessment findings into neat bundles, to be passed on;

> *Once I've come back to the office and I've done all the computer stuff with HONAS and the Sainsbury's risks, which also is another prompt to make sure that I've considered risk assessments in relation to suicide, in relation to whether they're eating, whether they're drinking. So they're all extra prompts to make sure that, before I package this up and give it to the consultant, that I've covered as many aspects of risk as possible. Then once it goes to the consultant, well then really that's it for me* (Karl)

Like Karl, Daniel also portrayed tools as useful prompts, whilst implying that decisions and practice are not constrained by them. However, he also positioned himself within a defensive 'blame culture' discourse, presenting documents as *'protection'* for practitioners;

The risk assessment, the record keeping and documentation, is all proof that clinical people and NHS people have done everything they can so if there's something wrong, as does happen, they can show that they tried everything. So in a way it is your protection against that ... Of course that makes some people go through the motions and perhaps without that prompt they might cut a few corners ... I see it as that protection, as that back up ... You still make your decisions, you still do your clinical things, but then you record it all and make sure it's all up to standard (Daniel)

Sue and Hannah's accounts of assessment tools included hierarchical stories of feeling/facts, verbal/written. They portrayed written records of 'facts' as most valued in practice;

The staff perceptions ... that they possibly couldn't write down because it's just a feeling they might have about somebody ...and so... it's not factual. So it's not written down (Sue)

Putting it to paper makes it more real (Hannah)

In some stories practitioners portrayed uncertainties about the use of assessment tools, and most practitioners performed multiple subject positions.

In contrast with his earlier account of *'Sainsbury'* as guidance, Karl also represented documentation as restricting assessments

How we document the information how it's ... handed down from on high also impacts upon how ... how I function (Karl)

Influenced by Foucault's (1980) *governmentality*, I see such stories as indicating institutions exerting power.

In contrast with her other stories of assessment tools, Teena questioned the validity of the *'mini-mental'* (Folstein et al, 1975) and resisted government guidance;

Some people might be great in the mini-mental because you'll find people that's very highly intelligent ... They do very well in the mini-mental...Whereas someone else that never had much schooling might do very poorly in the mini mental...So you've got to look at other things, you cant just go by that (Teena)

As the NICE guidelines state I'm expected to visit these patients every 6 months to do the mini-mental state examination, just to

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> *show benefit. But also you've got to take a holistic approach and look at the functioning and their activities of daily living and other things. You can't just base it on the mini-mental* (Teena)

Other practitioners also resisted dominant practice discourse on the desirability of uniform, standardised risk assessment;

> *I haven't got a standard way of approaching it...It's case by case. Everyone's different and that's how I do it. There probably is somewhere some standardised assessment, but for me, I don't know if I'm old fashioned, but I always think there's no two people the same* (Daniel)

> *I don't always think ... they're that much use in dementia clients... because either they won't be able to follow the instruction- and its only standardised if you do it in a standardised way- so that's definitely an issue ... as well as ... what's that relate to in their environment?* (Rachel)

In this metaphorical account, Daniel portrayed risk assessment as needing appropriate tools, approach and timing;

> *Sometimes ... the fruit isn't ready to be plucked straight away and you've got to wait a while and wait for it to ripen and get a ladder big enough to climb up to get it. They're not always there to grab straight away* (Daniel)

Like Sue, Daniel also implied that his risk assessments are different to some others;

> *I've looked at various sorts of risk management tools and obviously those that the trust use, but to be honest they're not the sort of risks ... They don't fulfil what I think of in my job as the risks that I take ... That makes it sound like I'm doing all dodgy things all day every day. It's not ...* (Daniel)

Isobel's account of not using standardised assessments was more tentative. I interpret her story as portraying some doubts about whether she is at fault/ lacking knowledge;

> *We don't have any, as far as I'm aware, a standard risk assessment for home assessments ...but no, not that I'm aware, not that we use here ... there's nothing standardised ... as far as I'm aware* (Isobel)

Naomi challenged the focus on *'deficit'* and the dominant hierarchical binary of standardised / observational assessments;

> *I love the observational assessment ...I know that's very difficult to put down in any standardised way <u>but</u> you're seeing. You're not just ticking little boxes. I don't like ticky boxes* (Naomi)
>
> *Formal assessments, mini-mentals, MEAMS ...are threatening ...It highlights deficit ... Observational assessments perhaps see them function as something they're confident in. You see skill, you see positive interaction...or you're looking for positive interaction. You might not get it, but you are not just looking for what they can't do ...* (Naomi)
>
> *... Can you say a little bit more about that?* (Me)
>
> ((laughs)) *I'm digging myself into a big hole, aren't I?* (Naomi)

In response to my probing question, I interpret her laughter and use of metaphor as her portrayal that, in going against dominant discourse, she is putting herself at risk. Naomi continued her challenge. Whilst acknowledging the attraction of simplified versions of risk assessment (*'ticky boxes'*), she presented such tools as inadequate and indicating false certainties about risk (*'yes or no'*). She portrayed her risk assessments as an interactional, contextual process that should not be reduced to standardised forms;

> *It's very much an interaction and it's different for everyone ...There is no set little ticky box ...Of course people <u>want</u> a little ticky box, because it tells them are they at risk at home... well, maybe ... They haven't got a 'maybe', it's 'yes' or 'no' ...* (Naomi)

Such resistance to *'ticky boxes'* has since been supported by guidance;

> *'Risk enablement is not consistent with 'tick box' risk assessments,'* (Manthorpe and Moriarty 2010, p10).

Like Naomi, Neil resisted a subjective/objective dichotomy in his account of using 'the Sainsbury'. In praising the tool, he also challenged other hierarchical dichotomies such as qualitative/quantitative. His use of *'flesh on the bones'* triggered my consideration of numerous continuums, such as soft-hard, flexible-rigid, outer-inner. Similarly, his use of *'colours in a paint box'* represented this tool as having the potential to be structured <u>and</u> creative, art <u>and</u> science;

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> *You know the flesh on the bones really and it qualifies and quantifies what you're ticking ... So I like the Sainsbury's ....You paint a different picture it's like the colours in a paint box isn't it and then you can fill in the details then....It's not just 'yes, no, don't know'... ...I just wish I had more time to really give do justice to the forms, but this is where its rapport its communication with the people who know that information* (Neil)

His account also supported arguments that risk assessments should go beyond the collection of information, to interpersonal communication and relationships. I examine such accounts in more detail in chapter 6.

Orla also challenged the dominant hierarchical binaries of standardised/none-standardised, objective/subjective risk assessments. Although she supported using tools, she also presented other information, such as *'emotional stuff'* and ways of enabling risk-taking, as being more *'valuable'* information in risk assessments;

> *Use the Sainsbury's and the HONAS and other risk assessment tools almost as an underpinning thing ... but valuable stuff, the real valuable information about supporting risk for me is quite often difficult to measure ... its more about experiential ...* (Orla)
>
> *I find it very frustrating ...because I think the staff are conditioned into having to tick boxes and ... sending the Sainsbury's risk assessment the HONAS etc etc ticks a box on discharge ... but I think it's that emotional stuff that we need to get over. That is very difficult to quantify and write down* (Orla)

Like Neil, Karl also used colour as metaphor. I interpret Karl's *'black and white'* as like Naomi's *'maybe';* resisting the false certainties of risky/safe binaries in assessment tools;

> *We fill in the forms... but the thing is that its not a definition in black and white...it's a definition in grey... like this couple I went to see earlier this week ... a lot of the risks were automated. It would flash up in my mind* (Karl)

In addition, I interpret being *'automated'* as portraying tacit, experienced-based, embodied, subconscious decision-making. In resisting false certainty and telling stories of risk assessment as cognitive <u>and</u> embodied, rational

<u>and</u> non-rational, practitioners portrayed *in-between strategies* (Zinn 2008, p442).

In keeping with their multiple, complex concepts of risk, practitioners' accounts went beyond stories of tools. Some stories portrayed assessments as contextual, flexible observations of people doing ordinary, practical, daily activities;

> *There's a lot from what you can see, isn't there and both from the house and the physical person themselves. Their ... body language...their appearance* (Hannah)

> *..they may not be able to use the switch on the gas cooker...or they may not be able to turn the heating on in the living room...or they're having difficulty with locking the door* (Isobel)

> *Getting in and out of the bath, on and off the toilet. Those sort of more practical things* (Karl)

> *The way I do look at the risk is by observation, probably going to somebody's home and actually looking at how they are managing ... are they able to actually put a fire safely on and off? I'd also be talking to the person themselves about how they are living and the routines that they have in their daily life, and a big part of it would be actually talking to the carer* (Sue)

I interpreted Isobel's account as challenging assessments that do not include practical observations;

> *All they did was speak to them and the family... They never saw them doing an activity* (Isobel)

After my probing question, Isobel portrayed her practice as resistant to requests for narrow risk assessments;

> *There's been times when I've gone to assess people and I've ...only done what is asked for on the assessment* (Isobel)

> *You mean you don't usually do just what's asked for?* (Me)

> *No ...Never ((laughs)).....say, for example the referral says oh 'can you do a bathing assessment'...I tend not to do that because I still ask them to give me a tour of the house...so I can go through ...are they orientated , are they good at problem solving ...all that* (Isobel)

Both Karl and Sue portrayed themselves as *'gathering'* and *'scanning'* for *evidence, proof* and *clues.* This supports a realist discourse that if experts

look hard enough they can find the real, objective 'truth'. However, both also portrayed their assessments as interactive, shared, negotiated, flexible, intuitive and not always conscious;

I've read up a bit about the information background information about the person...So I have a feel for the person, who they are, where they are living ... I probably scan the home as soon as I go in...and try and find things that seem important to that person. Try and pick up clues in the home ...and then probably would make comments about the garden, or about the pictures on the wall, or photographs of family and try to really engage with them as to who they are what's important to them as a person (Sue)

I think my approach changes depending very much on the response I get from the person...and try and adapt that very quickly as to who I'm assessing (Sue)

I suppose much of my risk assessment is automated....(Karl)

Its me discussing with health professionals and social professionals how I perceived risks based on the evidence that I've gathered ...It's this relentless and at times frustrating but at other times enjoyable debate...between others...that helps me to evaluate risk (Karl)

In privileging subjective over objective, Karl was explicit in his reconstruction of the dominant hierarchical binary;

For me it's the subjective accounts ...I raise the point and then listen to the person's narrative really about how <u>they</u> reason ... And assess risk themselves ......Not only objective, but more importantly subjective evidence (Karl)

Daniel regularly used visual metaphors to account for his approach to assessments. He represented assessments as providing partial views, not objective 'truths'; a view that has the potential to change if we try different things, think about what we are doing and move to get different perspectives. Like Isobel, Daniel portrayed his assessments as going beyond a narrow referral focus;

So it's worth sometimes thinking of the big rather than the little when you're going into set-ups and having a look round ... again it's that experience ... is something not right here? ... Just looking wider than what you first went in for (Daniel)

Their physical problem's tucked underneath a mental health problem ......So to go straight for the physical isn't always the way. You've sometimes got to go around the houses ... and if you don't know where you're going you can loose sight ...or other people following can think 'what's he playing at?' (Daniel)

Such accounts reminded me of visual metaphors used in research literature to explore perspectives and the contested nature of realities, such as looking *'through the lens'* (Thomas, 2005). I examine accounts of contextual, complex risk assessments in more detail in chapters 6 and 7.

Having provided my analysis of practitioner accounts of risk and risk assessments, I will now offer some reflexive considerations and concluding comments.

Being reflexive

My reflexive notes contributed to my analysis and served as reminders of my thoughts and feelings. Maintaining total separation between my practice and interview roles was not always possible;

> *'...had brief chat about our overlapping roles. Again I wonder is this just your usual day-to-day friendly work colleague chat ... or should I also see it as me setting/underlining the scene for me as 'insider'? How do these things influence the interview?'* (from notes written immediately after interview with Daniel)

> *'I feel I 'enjoyed' this more than earlier interviews ... maybe because I was less anxious and more able to 'be there'? Also feeling that I could identify with many of the stories told by XXX. After the interview and during transcription I found myself reflecting more on my experiences and stories I would tell as 'interviewee'. Also something about the way she talks –words, phrases and accent – very familiar to me from childhood and family ... How did all this influence my performance in interview? How will all this influence my performance in analysis and presentation?* (from notes after transcribing XXX's interview)

Seeing the interview as a contextual construction, I am mindful of the performance aspect; myself and the practitioners constructed and presented our 'self' in the context of the interview. I question how much of what we said

in interview was a 'front stage' performance of how we want to be seen and what we feel we 'ought' to be saying (Goffman, 1956).

I was also mindful of the potential for participants to be influenced by their involvement once outside of the interview, and my associated ethical responsibilities (Watts, 2006). For example, in her reflexive account, Rachel implied that she was thinking about changing her practice;

> *It's just worth thinking about when I go back...When I read up what I've been writing ...* (Rachel)

Concluding comments

In this chapter I have provided my analysis of practitioners' accounts of the nature and assessment of risk in dementia care practice.

All practitioners' accounts included stories of realist, individualistic concepts of risks, and provided examples of particular risks as objective phenomena and possible hazards that need to be assessed and controlled. However, they also supported complex, subjective, negotiated, constructed and contextual concepts of risk. Practitioners' accounts of people living with risk and dementia included people being <u>at</u> risk of harm from potential hazards, from themselves, and from other people, and of being <u>a</u> risk/danger to others. Practitioners' accounts of risk assessments supported Manthorpe's (2004) description;

> *'Risk assessment is as much an art as a science in that it builds on shaky and incomplete evidence bases and incorporates values and images, emotions and contexts.'* p141.

They represented different perspectives on assessments, including rational, scientific, objective assessments and subjective, negotiated, contextual assessments. Some stories were about 'tools' helping practitioners to prepare for and structure complex risk assessments. Other stories portrayed 'tools' as restricting practitioners, in how they thought about and undertook assessments. In keeping with their multiple, complex concepts of risk, some stories portrayed assessments as contextual, flexible observations of people doing ordinary, practical, daily activities. Practitioners' accounts explored and challenged some dominant hierarchical binaries, such as standardised/observational, quantitative/qualitative, logical/intuitive and

objective/subjective. For example, some practitioners' accounts of assessments included stories of embrained, explicit knowledge ('knowing that') and tacit, experienced-based, subconscious, embodied knowledge ('knowing how') (Blackler, 1995, Harrison, 2002 and Lam, 2000). Such complex accounts of risk assessments are supported by recent practice guidance (Manthorpe and Moriarty, 2010).

Practitioners' accounts were full of stories of complex, contextual, negotiated risk assessments. All practitioners' accounts included stories of emotions, pre-conscious and non-rational decision-making, ethical dilemmas and psychological wellbeing. I examine such accounts within my analysis of practitioner accounts of risk management decision-making, in the next two chapters.

In chapters 6 and 7, I provide my analysis of practitioner accounts of contextual ethics in risk management decision-making. In chapter 6, I focus on accounts of *intrapersonal* and *interpersonal* contexts. In chapter 7, I analyse accounts of *environmental* and *societal* contexts.

Chapter 6 Contextual Ethics in Risk Management Decision-Making; Intrapersonal and interpersonal contexts

Introduction

This is the second of three chapters where I provide my analysis of practitioner accounts. In chapter 5, I analysed accounts of the nature and assessment of risk. In this chapter and chapter 7, I examine accounts of contextual ethics in risk management decision-making.

I begin this chapter with an account of creating theoretical representations of practitioners' accounts of risk management decision-making. I then provide my analysis of practitioner accounts of contextual ethics. I begin this with an exploration of accounts of *wellbeing, ethics* and *balance*. I continue with my analysis of practitioner accounts of *intrapersonal* contexts. Next, I provide my analysis of accounts of *interpersonal* contexts. In chapter 7, I provide my analysis of practitioner accounts of wider contextual ethics; *environmental* and *societal* contexts.

Towards the end of this chapter I provide some reflexive considerations and concluding comments.

Networks and models; conceptual framing of themes and connections

All practitioners' accounts of risk management included stories of ethical dilemmas and contextual complexities. Such accounts support Clark et al's (2007) assertion, that;

> '...the ethics of patient care does not exist in a vacuum, and it is influenced by interpersonal factors, professional obligations, organisational issue and legal constraints,' p592.

In an attempt to bring my analysis to some sort of ending, I developed reflexive, conceptual, thematic networks and models, as tools for organising, analysing and representing my research information. Influenced by the notion of researcher as *'Bricoleur'* (Denzin and Lincoln, 2000, p4) and by Deleuze and Guattari's (1994) critiques of modernist attempts to constrain knowledge and practice into false unity, I tried not to over-simplify or ignore contradictions and complexities within and across practitioners' accounts. I was also influenced by Boyes' (2004) argument that we should resist working

'*...towards closure and control*' p6. I did not attempt to present a single, unified view of knowledge and practice. Any representation of practitioners' accounts in discrete patterns would have been misleading. Like Watson (2005);

> "*I have resisted the temptation to reduce to distil the lives of individuals to a central motivation, but have instead lived with the complexity and ambiguity of their responses*" p12.

I was open to the possibility that difference within and between practitioners' stories may be a reflection of complex, contextual realties in everyday practice.

As outlined in chapter 4, I created 3 conceptual representations; a *Linear Representation* (Appendix I), a *Network Representation* (Appendix II) and a *Conceptual Kaleidoscope* (Appendix III). These representations were my attempts to portray practitioner accounts of risk management decision-making with people living with a dementia. Using my analysis guide (Appendix XI), I organised conceptual themes and represented them as a *Linear Representation*. I then developed this into a *Network Representation*, which I used to guide my analysis of conceptual relationships. I found visual metaphors useful when thinking about the relationships between these theoretical concepts of risk management decision-making (Arner and Falmange, 2007, Crowley, 2000, Heyman et al, 2010, Holstein and Gubrium, 2003, Janks, 2005, Koro-Ljungberg, 2004, Macleod, 2002, Richards, 2009, Samuels and Betts, 2007 and Thomas, 2005).

My imagination was triggered by accounts of realities as *kaleidoscope* (Jackson, 2007, Jackson et al 2007, Peters, 2009 and Weinblatt and Avrech-Bar, 2001);

> '*It is the lens of feminist enquiry that I bring to my work, or rather a kaleidoscope of feminist lenses, for feminism is a complex mix of political movements, theories, philosophies and ethics*' (Jackson 2007, p7).

With its multiple, moving lenses, *kaleidoscope* was helpful in thinking about shifting relationships between conceptual themes, elements and associations in the *Network Representation*. Like Jackson et al (2007), I was attempting to represent layers of context, thresholds, boundaries, movement and '*... ever*

changing alignments' (p6). Playing with the idea of how best to represent *kaleidoscope* as a fixed, 2-dimensional model in this report, I saw parallels with my earlier considerations of representing dynamic interview talk within static, written transcripts. My mind wondered from *kaleidoscope* to *mosaics*. I have therefore included a *mosaic* image in the models; a static picture consisting of small fragments with the potential of different patterns. Mosaics can be interpreted in different ways, depending on perspectives; technical and creative, science and art, and spiritual symbolism.

Influenced by feminist accounts of situated knowledge (Haraway, 1988 and Stanley and Wise, 1983), I was also attracted to the metaphor of *window*. I included a *window* image in the models (see Appendices II and III) to portray located understandings and partial perspectives, enabling views across thresholds, looking in and out, giving perspectives of where you are in the bigger picture (looking at self, walls, and through the window at trees, clouds, the world). In this way, I developed a dynamic model that acknowledges different perspectives and inter-relationships, within which I represent micro, meso and macro contextual ethics in risk management decision-making; a *Conceptual Kaleidoscope* (Appendix III). Within this model, I represent four concentric layers of contexts;

o **Intrapersonal** and **interpersonal contexts**, which I examine in this chapter

o **Environmental** and **societal contexts**, which I examine in the next chapter

However, I acknowledge these connections and patterns are like views through the *kaleidoscope*; tenuous, contested and forever changing.

Having provided my account of creating theoretical representations, I continue with an examination of accounts of wellbeing, ethical decision-making and balance. I follow this with my analysis of practitioner accounts of intrapersonal and interpersonal contexts.

Wellbeing, ethics and balance

Practitioners' stories of ethics, wellbeing and balance were so pervasive, that I focus on these concepts before exploring their use within practitioners' accounts of risk management decision-making.

Wellbeing; As noted in earlier chapters, several researchers have suggested a need for further research exploring wellbeing in risk management decision-making with people living with a dementia (Brooker, 2007, Clarke et al 2011a, Corner, 2003, DH, 2009b, Manthorpe and Moriarty, 2010 and Mitchell and Glendinning, 2007). Influenced by practice experiences and strengthened by related reading, one of my research objectives was; *'to consider this decision-making with a particular focus on psychological wellbeing and quality of life'*. I therefore created an 'a-priori' code; *'wellbeing and QoL'*. As stated in chapter 4, when analysing I noted that practitioners' accounts of wellbeing were within stories of contextual ethical dilemmas. I therefore amended this code to include ethical dilemmas.

Ethical dilemmas; As explored in my literature review, decision-making in practice can be complex and full of ethical dilemmas, and practice guidance can be ambiguous. For example, the *'Dementia Strategy'*, states;

> *'The right support, at the right time and in the right place, is especially important for people with dementia, to give them choice and control over the decisions that affect them'* (DH 2009a, p47).

Conversely, Alzheimer's Society (2009) argue;

> *'**No right answer:** a lot of the time, there will be no one correct answer or solution to a problem...'* p2 (original emphasis)

Hughes and Baldwin (2006) suggest;

> *'The moral field is decidedly messy and we must navigate our way through it carefully, whereas these theories and ethical principles can send us hither and thither'* p26.

Ethical dilemmas and balance; Thirty years ago, Norman (1980) challenged ageism and concepts of risk in health and social care. She resisted the focus on negative concepts of risk, and argued that we all take risks in life. From this perspective risks are ever-present, and decision-making can be dilemmatic when all outcomes are potentially hazardous. Norman (1988) asked;

> *'How does one balance the risks of institutionalisation (of the older person) against the risks of remaining independent?'* p13.

The metaphor of balance has since been consistently employed in accounts of risk management and ethical decision-making with older people (for

example, see Alaszewski and Manthorpe 2000, Alzheimer's Society, 2008a, Clarke et al 2009, DH,1997, Manthorpe and Moriarty, 2010, Robinson et al, 2007, Taylor, BJ, 2006 and Waugh, 2009).

With a focus on dementia care, Robinson et al (2007) used the metaphor of balancing rights and risks to examine perspectives on 'wandering'. Waugh (2009) suggested practitioners are;

> '...continually involved with dealing with competing tensions by balancing rights against potential harm,' p219.

Clarke et al (2009) argued;

> '...there is an obvious struggle to balance different elements within their duty of care, to ensure that the person is maintained in a safe environment, whilst at the same time preserving a good quality of life,' p94.

The balance metaphor has also been used in dementia practice guidance, such as;

> 'When considering the needs of someone with dementia, it is important to find the right balance between independence and the need for protection. There is no such thing as a completely risk-free environment for any of us...' (Alzheimer's Society 2008a, p1).

> '...this guidance...is based on identifying and balancing the positive benefits of taking risks against the risk of adverse events occurring,' (Manthorpe and Moriarty 2010, p6).

Practitioners' accounts of ethical decision-making included stories of practitioners' duty (deontology) and people's rights (justice);

> *I think we owe a duty of care to our patients to make sure they are well and they are in a safe environment... I owe that duty of care to my patient* (Teena)

> *These people ... have worked and they've had their homes and they've paid their mortgages and that sort of thing. Have they not got the right to ... to make some sort of choices however risky they may feel?* (Orla)

Practitioners' accounts of ethical dilemmas also included stories of balance. Within these accounts, practitioners explored how to choose and prioritise when duty and rights conflict, or when no 'side' weighs heaviest. These

included stories of trying to predict outcomes in conditions of complexity, uncertainty and pervasive risks;

> *The consequences may be that there is a risk that that person will come to some sort of harm ...That's the consequence of risk ...if you don't manage risk ... even if you do manage risk that person may still come to harm* (Orla)
>
> *A lot of the risk we can cover because everyone lives with risk. We live with risk. Everyone lives with risk* (Teena)
>
> *Risk management isn't negating risk...In some ways you can live with more risk. You know we all live with risk* (Neil)
>
> *Yes there may be risks but we all take risks in life* (Orla)

When analysing Hannah's account of pervasive risks, *'safety net'* and *'safeguards'* triggered images in my mind of balancing and being prepared for the possibility of falls;

> *You have to have the safeguards in place, don't you? ...I think people should be able to have risk ...But ...they need a safety net within that as well* (Hannah)

Daniels' story was of uncertainties and *weighing up* between two undesirable outcomes;

> *So almost everything that you're saying even the opposite of what you're saying has got its own associated risks ... You try and weigh up as best you can what the situation is, and what the risk is to not do something or to do it ... and what's the lesser of two evils* (Daniel)

Banks and Williams (2005) reported similar accounts in their earlier research with social care workers;

> *'...a story of a decision-making situation involving a difficult choice between two equally unwelcome alternatives and it is not clear which choice will be the right one,'* p1011.

Some practitioners' accounts of ethical decision-making and dilemmas were not of balance. Rather, they resembled Claxton's (1998) 'meandering' way of knowing (taking account of fringe details and making decisions with much wondering). Contrary to dominant discourse, *'wandering'* was not exclusively used to portray unsafe or disorientated walking. It was also used to represent a style of 'thinking about' and 'walking about' in assessment;

> *There were situations where I thought 'Oh I wonder if this, I wonder if that?'* (Daniel)
>
> *So it's actually practically getting them up out of the room and wandering round the house and looking at areas* (Sue)

I interpret their wondering <u>and</u> wandering as ways of thinking about contextual complexities and ethical dilemmas in risk management.

Within accounts of balance was the notion of a tipping point, where levels of risk were assessed as moving from acceptable to unacceptable. I examine practitioners' accounts of levels of acceptable and reasonable risk in more detail in chapter 7.

Having considered some accounts of ethics, wellbeing and balance, I will now provide my analysis of practitioners' accounts of intrapersonal contexts in risk management decision-making. I provide this analysis alongside related literature.

Intrapersonal contexts

Practitioners' accounts of risk management decision-making included <u>and</u> went beyond objective, rational applications of abstract rules. They also supported emotional, subconscious, subjective, contextual considerations of intrapersonal contexts and decision-making. These included stories of values, duty, fear, feelings, intuition, uncertainty, complexity and dilemmas.

Orla and Neil both portrayed practitioners as followers of ethical rules/codes <u>and</u> influenced by subjective values and attempts to control;

> *I think people say we're doing this under a duty of care when actually its people's fears about allowing folk to take risks.....or its people's own morals, standards* (Orla)
>
> *I do appreciate we have a duty of care however I think sometimes what we do ...is ... use the term duty of care when somebody doesn't comply with what <u>we</u> want them to do* (Orla)
>
> *Obviously there's a duty of care. You have to go down these routes but there are value judgments and I mean even by professionals - even objective professionals. We're not as objective as we like to think we are* (Neil)

> *Peoples safety and wellbeing is paramount...but there are different ways of looking at that...As to the values you give to certain things....dignity, independence, choice* (Neil)

Teena's account included her fears about '*wandering*';

> *The only one I really fear for is the wandering during the night ... you can't really do much about that if they are living on their own* (Teena)

Tariq tentatively portrayed practitioners' fears leading to risk-averse decision-making;

> *But then you're into that sort of* ((laughs)) *juggle because ... you don't really want to be at the situation at the coroners court ... I think it's in ...the back of everyone's mind ...You ...probably want to err on the side of caution than you do on the side of increased risk and it's a matter of how you try to get that* ((laughs)) *balance between the two* (Tariq)

Toward the end, Neil's account became a narrative of fear. I interpret his use of '*robot*' as portraying a desire to feel less fear in practice;

> *They're talking of developing robots for fighting because they won't feel fear* (Neil)

Orla represented practitioners as keeping within culturally expected boundaries, to protect <u>their</u> emotional vulnerabilities;

> *It's often much easier to go with the flow....And not step out of line or out of your comfort zone* (Orla)

Similarly, Neil reconstructed risk management <u>by</u> practitioners as anxiety management <u>of</u> practitioners. He also portrayed differences in practitioners' perceptions of their role on a continuum from total responsibilities to living with uncertainties;

> *Risk management is often anxiety management and it's anxiety management of the professionals as to how they see their responsibility...Now some professionals think that they have total responsibility for everyone for everything and ...I mean I have a legal responsibility ...which I fulfil, but beyond that...I think part of life is you live with a degree of uncertainty* (Neil)

As noted in earlier chapters, some research suggests that practitioners' fears are influenced by practice cultures. I explore practitioners' accounts of

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practice cultures within my analysis of practitioner accounts of environmental contexts, in chapter 7.

As explored in chapter 2, some literature explores concepts such as intuition, subjectivity, reflexivity and uncertainty in health and social care decision-making. Bourdieu (1990) suggested practitioners have an adaptive *practical logic* and *'get a feel'* for working in practice. Kitwood (1998b) argued;

> *'Moral judgements are, for the greater part, made subliminally and intuitively, and in the flux of everyday life,'* p409.

Likewise, practitioners' accounts included stories of *feeling like, getting a feel for*, intuition, subconscious, experienced based decision-making. Such accounts resisted the dominant discourse of logical, rational decision-making;

> *I suppose much of my risk assessment is automated.... It's only things out of the norm that then make me stop* (Karl)
>
> *I suppose it's a very complicated process and it's not always a conscious process and it's evolving and you can't open a book and learn it* (Daniel)
>
> *I normally initially just get a feel for about them...And get a feel for who they are and what they enjoy doing and how they spend their time in the house* (Isobel)
>
> *I would much rather get a feel for something and then put it to paper when you get back* (Hannah)
>
> *I felt like I couldn't leave her in that situation that day, the way she was...It felt wrong so I had to do something* (Hannah)

In addition to *'getting a feel for'*, Isobel also represented her decision-making as influenced by *'feeling like'*. She portrayed reflexive, contextual, emotional decision-making where there is no universal, 'right' thing to do;

> *Often when I'm there I kick myself a bit sometimes because I think I should know this off by heart and should know it straight away ... I beat myself up sometimes because I feel like I should know the answers instantly ... and then realise that time before I write the report is that vital reflection time, reflecting on whether I think I've done a good assessment* (Isobel)

She also portrayed her decision-making as influenced by previous experience;

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If you've known of a past experience where it's either gone wrong or you've took a risk and it's not worked out, I think that's definitely gonna influence what you think ...Definitely (Isobel)

In addition to stories of balance, some practitioners' accounts of ethical decision-making were also of imbalance. They told stories of difficult ethical dilemmas, with some residual feelings, ethical conflicts and dilemmas (Beauchamp and Childress, 2009). For example;

If I switch off when I go home, then I suppose I'm not overly concerned. If I go home thinking 'no, this isn't right and I'm not comfortable' and I'm thinking about it all evening, then I know that ... I need to do something...So I know that's one of my thresholds (Rachel)

When she went on the ward she started screaming and that broke my heart. That was one of the hardest things in this job that I've had to do, was taking someone out of their home where they love and putting them in hospital ... and even then I questioned whether I'd done the right thing ... All the way home. At night I couldn't sleep because I was thinking 'my gosh, was I over the top could the risks have been managed?' ... 'Have I brought someone into hospital when they didn't need to be there?' And it was horrible for the whole weekend. I just couldn't sleep on a night. I was thinking I don't know if I've done the right thing (Isobel)

In their stories of unresolved ethical dilemmas, Rachel and Isobel both represented crossing the threshold into unacceptable risk as when their professional practice and emotions continued into private/home self. These accounts portray some links with Banks and Williams' (2005) study, in which they argued that practitioners portray residual ethical dilemmas *'in the form of regret or guilt'* (p1015). Since completing these interviews, two further studies have also noted un-resolvable ethical dilemmas in dementia care (Clarke et al, 2009 and Waugh, 2009).

In analysing practitioners' accounts against literature, I also found interesting connections with a study of violence against women;

'The process of identifying risk can be biased...drawing conclusions about risk factors, and what are acceptable and unacceptable levels of risk, is not a neutral process. It involves someone else deciding

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> *what is "normal". These decisions cannot help but be influenced by individual values, ideologies and experience,'* (Kinnon and Hanvey 1996, p7).

Having provided my analysis of practitioners' accounts of *intrapersonal* contextual ethics, I now continue with practitioners' accounts of *interpersonal* contexts.

Interpersonal contexts

As explored in Chapter 3, Kitwood (1990 and 1997) introduced the concept *'malignant social psychology'* (MSP). He used this to represent how subconscious coping mechanisms enable practitioners to keep a psychological distance and manage their anxieties and ethical dilemmas when working with, *and caring about,* people with a dementia. This distancing ('us and them') can also be understood as a reflection of dominant cultural contexts and as a pragmatic mechanism enabling practitioners to do all necessary daily tasks. In challenging the damaging interactions of MSP, Kitwood (1998a) promoted *positive person work*. He maintained that this approach to dementia care practice could uphold personhood and wellbeing, arguing;

> *'...their wellbeing is crucially dependent on the interactions that are generated by others'* p30.

Many authors have since portrayed interpersonal contexts, such as communication and relationships, as important when making decisions with people living with a dementia (Allan and Killick, 2008, Barnes and Brannely, 2008, Bartlett and O'Connor, 2007, Boyle, 2010, Brannelly, 2006, Brooker, 2007, Clarke, 2006, Clarke et al, 2009 and 2010, Downs, 2000, Downs and Bowers, 2008, Ellis, 2007, Gilliard et al, 2005, Graham, 2004, Hoe et al, 2009, Hughes and Baldwin, 2006, Innes et al, 2004, O'Connor et al, 2007, Parker, 2001, Ryan et al, 2008 and Waugh 2009). Indeed Waugh (2009) argued that practitioners' portrayed their relationships with people living with a dementia as a central consideration in risk management.

Such perspectives overlap with ethics of care literature, which also asserts the importance of relationships and contexts in ethical decision-making;

> '...the ethic of care emphasizes the importance of context, interdependence, relationships and responsibilities...' (Koggel and Orme 2010, p109).

As noted in earlier chapters, some practice guidance and policies also promote relationship-focused approaches to risk management decision-making, for example;

> 'Positive risk-taking is about collaborative working, based on the establishment of trusting working relationships,' (Morgan 2000b, p17).

> 'It is not just an issue of being disrespectful when negative communications occur; it has a direct observable effect on people's well-being' (CSCI 2008, p20).

> 'We recommend that the Codes of Practice made under the Mental Capacity Act...should be amended to emphasise the importance of good communication and supportive relationships with families, so that joint decision making is encouraged...' (NCB 2009, pxxii).

Practitioners portrayed complex understandings of interpersonal contexts and decision-making. Some portrayed 'new culture' (Kitwood and Benson, 1997) and ethics of care perspectives. Such accounts were of negotiated, shared risk management, including stories of families, relationships, trust, moral sensitivity, acceptable levels of risk and reflexivity.

In his account, Neil questioned checklists and 'paper' assessments, and prioritised relatives and communication in decision-making;

> If you just ticked all the tick boxes ...People would go ... you couldn't do that ...He has to be in a home ...And so one of the lessons for me is to kind of gauge where we are with the relatives, what they want ...Because you can never be 100 per cent risk free (Neil)

> It's surprising what people tell you ... personally I think the best way ...of risk management is to have full rapport with the carers and context... otherwise ... there's a danger of just doing the checklist thing ... from a slightly detached point of view ... It looks good but it doesn't have any real connection ... it can just be a paper exercise (Neil)

Other stories portrayed family relationships as influential in making decisions about thresholds of acceptable risks;

If there's a husband or wife involved, it's very much they're the ones who make that decision...Because I think if they've been a carer they've got to a situation where there's something they cant cope with any longer (Sue)

I think carer support is vital really and when they've had enough and they draw the line they often feel guilty (Neil)

She was prepared to live with a lot of risk to maintain his independence and it was kind of against all medical advice (Neil)

His wife helped me understand how much ingenuity you can use to meet problems (Naomi)

There were also alternative accounts of being at risk from family, but these were less numerous. For example, Sue's story of a woman being cared for by her daughter;

...even basic care wasn't being given to her properly ... she wasn't being given adequate meals and drinks (Sue)

As with practitioners in Waugh's (2009) study, some practitioners represented communications and relationships with the person living with dementia, as a key consideration in risk-management decision-making;

A therapeutic meeting of minds ... that's the best way for me to describe it ...you build up that therapeutic rapport very quickly but there's respect and ...it's about a union ...of people with the same concerns (Karl)

People might personally make valued judgments about; 'well this is just not acceptable'. But if it's acceptable for them, and if it's the norm for them, and if it can be moved on by listening to them, perhaps meeting the same ends by different means, then I think that's actually more productive and more involving empowering...because it comes from them (Neil)

Rachel also represents such relationships as important in decision-making. However, I interpret her use of '*some form of a relationship*' as portraying an acknowledgement that, within practitioners' professionally demarcated contextual roles, there are limits to the nature and objectives of relationships practitioners have in practice;

When you're making a decision on somebody's capacity, especially if it's something as drastic as putting them into 24 hour care, you have

to have some form of a relationship with them, don't you?... If you don't know that person then you can't really make a decision on it, I don't think (Rachel)

Practitioners' accounts of relationships also included stories of power, honesty and trust;

Are they just saying that because of who I am, and I've got some form of authority because I wear a badge, and I'm a member of staff? ...So you need to kind of cut a few of those boundaries down I think before you make decisions for people (Rachel)

A colleague came with me and said to me 'you don't have to tell her that's where she's going. Just tell her that she's going for a ride' ... And I said 'How can I not tell her that's where we're going?' (Isobel)

I hope that somebody would begin to trust me enough to actually share their own concerns about where they're living and share their own emotions and feelings about the situation and just be more open with me ...It's the only way you can get a true picture of someone is to encourage them to actually share with you and feel comfortable enough to trust you (Sue)

They have to feel comfortable with the people they are talking to. They also have to feel comfortable with expressing their fears and their worries (Tariq)

Some practitioners' accounts were of trying to control situations, risks and decision-making. These included stories of *persuasion, cajoling* and *chivvying*;

I think this gentleman did eventually come round to the idea, but he was persuaded to (Sue)

Yes it's very task orientated really and it's very much cajoling and persuading, if I need to (Sue)

Trying to manage them to accept that ...they might need care in a 24 hour setting (Tariq)

There might be more chivvying people along in an enthusiastic sort of way...To build up that relationship to try to move people ...on to accepting services... (Tariq)

Teena portrayed falls as helping practitioners to gain control. In stark contrast to the balance and dilemma for the person who falls, Teena's

account can be interpreted as ethical balance becoming less precarious and so less dilemmatic for practitioners;

> *Sometimes you think it's a blessing. Although you don't want them to fall, but its one way of getting her out* (Teena)

Some practitioners' accounts were reflexive portrayals of empathy, validation and moral sensitivity;

> *I think well what ... if I went there? I would no longer be able to see my husband. I would no longer have my car. I would no longer have all the things that have meaning in my life and that's gonna affect my mental health. I'm going to feel depressed. I'm going to feel emotional. I'm gonna be angry at everybody* (Isobel)

In his account, Karl supported 'new culture' approaches to communication (valuing and validating subjective experiences of living with dementia). He also portrayed practice that supports 'old culture' approaches to communication, without the same level of narrative ownership;

> *It was ... wonderful really to engage with that lady and to step into her world* (Karl)

> *Health professional and social professionals are trying to pull them into our world* (Karl)

I examine practitioner accounts of practice cultures in the next chapter.

Having presented my analysis of accounts of intra and inter-personal context, I end this chapter with some reflexive considerations and concluding comments.

Being reflexive

Given my desire to proceed with my project, at times this analysis was an uncomfortable process. Resisting temptations to over-simplify complexities of accounts and practice, I wondered, wandered and meandered (Claxton, 1998). Although I had some ideas about where this may take my analysis, I was not certain. I tried to be open to ideas triggered. In the midst of undertaking this analysis, I found Bazeley's (2007) suggestions useful and reassuring;

> *'Let the ideas you are playing with permeate your whole being. Then, when you take time out to walk, soak under the shower, sit by the*

fire... that tranquil activity will allow your brain to process the information that you've been absorbing. If in these moments fresh insights do come (to your prepared mind), write them down (they can be perilously fragile)' p179.

Such strategies protected me from being overwhelmed by the amount of information and ideas I was trying to organise, connect, synthesise and represent.

Concluding comments

All practitioners' accounts included stories of ethical dilemmas and contextual complexities. This is the first of two chapters where I examine contextual ethics in risk management decision-making. I began this chapter with an account of creating theoretical representations of practitioners' accounts of risk management decision-making. Next, I considered three concepts that pervaded practitioners' stories of risk management; wellbeing, ethics and balance. I then continued with my analysis of practitioner accounts of intrapersonal and interpersonal contexts.

Practitioner accounts of intrapersonal contexts included and went beyond objective, rational applications of abstract rules. They also supported emotional, subconscious, subjective, contextual considerations of decision-making. These included stories of fear, intuition, uncertainty, and unresolved ethical dilemmas. Practitioners also portrayed complex understandings of interpersonal contexts in decision-making. These included stories of shared risks, relationships, negotiations, acceptable levels of risk and reflexivity.

Some practitioners' told stories of trying to reduce ethical dilemmas and control situations, risks and decision-making. These included stories of *persuasion, cajoling* and *chivvying*. As Moats and Doble (2006) suggest, such stories may imply that practitioners feel uncomfortable;

> *'When faced with the conflicting values of beneficence and autonomy, health care professionals may resort to persuasion as a way of resolving their ethical dilemma...This often occurs when they are not comfortable accepting what they perceive to be risk behaviour of a client, but want to feel they are upholding the principle of autonomy.'* p305.

In chapter 7, I provide my analysis of practitioner accounts of wider contextual ethics; *environmental* and *societal contexts.*

Chapter 7 Contextual Ethics in Risk Management Decision-Making; Environmental and societal contexts

Introduction

This is the third of three chapters where I provide my analysis of practitioner accounts of risk management decision-making. In chapter 5, I analysed accounts of the nature and assessment of risk. In chapter 6 and this chapter, I examine contextual ethics in risk management decision-making. In chapter 6, I provided an account of creating theoretical representations. My analysis focused on practitioner accounts of *intrapersonal* and *interpersonal* contexts. In this chapter, I provide my analysis of practitioner accounts of wider contextual ethics in risk management decision-making, in particular *environmental* and *societal* contexts. Towards the end of this chapter I provide some reflexive considerations and concluding comments.

Wider contextual considerations

Like many other researchers and practitioners in dementia care, I have been influenced by Kitwood. Some writers portray Kitwood as focusing on micro-social inter-personal contexts, at the expense of the wider political contexts of dementia care. For example Baldwin and Capstick (2007) suggest his later publications avoided;

> '...more contentious, political and socioeconomic critique of late capitalism and its disregard for the old and needy...' p107.

However, I see Kitwood as writing from personal <u>and</u> wider political perspectives, even in his later work. The year before he died, his rather prophetic conclusion is unambiguously political, and a passionate plea for transforming dementia care;

> 'It is becoming clear that the system of liberal democracy, whose organisation is allegedly rational, and whose economic life is grounded in the pursuit of profit, is fundamentally flawed ...The positive transformation of care practice...will challenge the stupidity and narrowness of the market mentality, and in particular that human services can be effectively delivered as if they were consumer durables' (Kitwood 1997, p144).

His reconstructed theories of dementia demand we pay careful attention to contextual factors. Yet, despite Kitwood's (1997 and 1998a) writings on the *'broader implications'* of ethics in dementia care, and Norman's (1980) earlier seminal writings on the rights of people with dementia, individualised and apolitical perspectives have dominated accounts of dementia care in healthcare literature and policy. However, since 2000 there appears to have been a growing interest in social, political and critical examinations of decision-making in dementia care, in particular around autonomy, rights, capacity and wellbeing. Although most of this discourse continues to be within social care literature, healthcare literature has recently contributed (Barnes and Brannely, 2008, Baldwin, 2008, Bartlett and O'Connor, 2007, Bolmsjo et al, 2006, Boyle, 2008a and b and 2010, Brannely, 2006, Brindle and Holmes, 2005, Clarke et al 2009, CSCI, 2007b, Darzins, 2010, Downs, 2000, Durocher and Gibson, 2010, Graham, 2004, Hughes and Baldwin 2006, Innes, 2002, Lloyd, 2006, McCormac, 2001, NCB, 2009, Parker, 2001 and Robinson et al, 2007).

I will now continue with an analysis of practitioners' accounts of wider contextual factors; environmental contexts followed by societal contexts.

Environmental contexts

My analysis of environmental contexts begins with practitioners' accounts of being at home. Next, I provide my analysis of practitioners' accounts of practice cultures, wellbeing and 'risky' services. As before, my analysis is undertaken alongside considerations of some related literature and policy

My practice and research is influenced by critical, sociological, feminist and postmodern explorations of complex relationships between the body, health, identity, culture, old age, power and context (Askham et al 2007, Butler, 1993, Cohen, 1998, Downs, 2000, Dyck et al 2005, Estes and Binney,1989, Gilmour et al 2003, Jamieson et al 1997, Katz, 1996, Kontos, 1998 Oppenheimer, 2006, Orulv, 2010, Reed-Danahay, 2001 and Twigg, 1999 and 2000). Their critiques of 'Western' individualised, biomedical, de-contextualised understandings of old age and the body are pertinent to my analysis, in particular contextual, spatial understandings of being at home. This literature examines the meaning and significance of home, and how

spatial understandings (such as public/private and safe/dangerous) are destabilised when people with dementia move to live 'in care';

> *'Meaning and experience of home also change over a life course, with the home becoming increasingly significant in the everyday life for many elderly and others whose social and geographical worlds 'shrink' through constrained mobility or chronic illness...'* (Dyck et al 2005, p175).

I would add that home is of particular significance for people living with a dementia, when other *'shrinkage'* (for example memory and cognition) may also occur.

Over 20 years ago, the *'Caring for People'* White Paper was enshrined into law with the NHS and Community Care Act, 1990. A key objective was;

> *'...to promote the development of domiciliary, day and respite services to enable people to live in their own homes wherever feasible and possible,'* (DH 1989, p5).

However, although such discourse represented the changes in care as supporting people to live at home, scarce resources led to gate-keeping tactics. Such tactics have since restricted access to community care services through the use of eligibility criteria (Rummery and Glendinning, 1999). Nevertheless, care at home continues to be promoted in dementia care policy discourse;

> *'Most people want to remain living in their own homes for as long as possible. This message is consistently given by the public, by older people generally and by people with dementia specifically...'* (DH 2009a, p50).

And Alzheimer's Society (2007b) estimate;

> *'...nearly two-thirds (63.5%) of people with dementia live in their own homes and just over one third (36.5%) live in a care home....'* p34.

Practitioners' accounts of home were passionate and reflexive. They included stories of complexity, ethical dilemmas, boundaries and acceptable levels of risk. They portrayed contextual understandings of risk;

> *...if her daughter's brought her in for an appointment with a psychiatrist straight away her risk assessment's not going to be what I see when I go and see her at home ...(Rachel)*

Go to her house and it's a completely different set of risks...and that's where she's gonna be, so that's the risk that matters in my opinion (Rachel)

With people with memory problems or dementia I want to do as much ... as many assessments in their own home (Naomi)

Initial assessment is always done in a person's home, and I think that's fantastic because then that means that person is in their own environment (Karl)

Like government policy discourse (DH, 1989, 2009a), practitioners' accounts were also about supporting people to live at home as long as possible;

We can try to support people and keep people at home if that seems to be the best for them, for their quality of life and their mental health (Karl)

To keep them at home just a bit longer, if that's what they want, just to enable them to live at home in a safe environment. That's what we aim (Teena)

Practitioners' accounts of home also drew on oppositional binaries such as inside/outside, public/private and family/stranger. Such accounts support practice and research discourses that people may be safer living at home because the familiarity of home can compensate for disabilities encountered when living with a dementia (Davenhill, 1998, Oppenheimer, 2006 and Orulv, 2010). However, practitioners' accounts provided multiple, contrasting representations of home. As with studies by Age Concern (2008), Clarke (2000) and de Whitt et al (2009), practitioners' stories portrayed living at home as being safe and protective (orientating, comforting, meaningful and belonging) _and_ being risky (vulnerability, isolation, loneliness and hazardous);

...people are able to function much better in an environment where they are very familiar. Where they know where the kettle is, where they know where the toilet is, where they know where the taps are ... and yes they might be at risk of forgetting to take medication or forgetting to eat, but if we can put plans in place to support those things that we know are going to be a problem, the very fact that somebody is remaining within their own environment for me it's

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worth exploring those risks and seeing if we can support that person to go home (Orla)

Naomi portrayed not recognising home as tipping the balance into unacceptable levels of risks;

We took her home she didn't recognise her home (Naomi)

Teena's story supported 'old culture' (Kitwood, 1997); portraying practitioners as experts who prioritise surveillance, safety and control;

We'd set up what we'd think would be best for this client. It could be moving from house to 24 hour care, or it could be moving into sheltered accommodation, where they could leave their flat but they're not actually getting out the building. So someone would be able to take them back and they'd still be safe. They'd be in a safe environment (Teena)

Isobel and Orla portrayed anonymous others as assuming that living at home was particularly hazardous, based on assumptions about living with dementia;

But I think it's very much ...If you've got dementia let's look at environmental risks (Isobel)

I've had experiences of discharging people who are living with dementia into their own home ... and that is seen as a very great risk (Orla)

When interviewing people who lived alone with a dementia, de Whitt et al (2009) developed the concept of *living on the threshold*. Reading this literature alongside my analysis of practitioner accounts of home, I saw some parallels with de Whitt et al's (2009) sub-themes of *being here, being there, being out* and *keeping out*. I was drawn to the notion of thresholds; present in practitioners' accounts as physical <u>and</u> psychological boundaries, in stories of home and in stories of acceptable levels of risks.

All practitioners' accounts included stories of living alone. Some portrayed the combination of living alone and 'wandering' out as a potential threshold; a 'tipping point' from acceptable into unacceptable risk;

My little alarm bells always are more attune to people who live alone (Neil)

I would be more concerned about somebody that lived alone, as opposed to somebody who lived with somebody (Isobel)

Teena's story triggered images of homecare trying to *'plug'* leaks into unacceptable risk;

> *Homecare could maybe go in four times during the day. They could go in during the night to make sure if they needed toileting and everything ... So you try and put as much services in as you can ...We will try and plug the risks* (Teena)

However, thresholds do leak. All practitioners told stories of risks and *'wandering'*; of physically crossing thresholds at home and metaphorically crossing thresholds into 'too risky'. Environmental contexts were portrayed as no longer contained, with transgressions represented as unmanageable and unacceptable;

> *I think if somebody's living on their own that's when the increased risk becomes apparent. Things like wandering is a real concern, because I don't think there's any amount of care we can put in to somebody's home to reduce that risk* (Sue)
>
> *You weren't gonna stop her ... from going out on a night. You couldn't lock her in and walking around the street with no clothes on, that wasn't gonna stop. So I just wanted to get her out of there as soon as possible* (Isobel)
>
> *If they're going out too much during the night, no homecare around ...sometimes we've got to move them into care homes* (Teena)

Likewise, Neil portrayed living alone and *'wandering'* as *'insecure'* risk. However, he resisted the dominance of risk discourse. He promoted a reconsideration of how we conceptualise our decision-making threshold, based on *benefits* or *needs*;

> *I think when they live alone perhaps and when they're wandering and they are vulnerable at home. I think they need a secure environment. So the risk is insecure and they need it secured. So again it's like benefit assessment or needs assessment. I probably work to needs assessment; what do people need? And if it's a secure environment then, whatever the needs are if it reaches a certain point then it does require 24 hour care* (Neil)

Sue's stories of home included persuasion, boundaries and hazards;

> *...there can be a sense that ...these people are coming into my home criticising me questioning me and I haven't got any problems at all...*

If I can persuade somebody then I'll take them into the kitchen and actually look at ...how they operate the cooker, any problems with the fire (Sue)

Practitioners' accounts of home were also about secured thresholds; keeping 'strangers' out;

I've managed to literally get me foot in and go and visit him a few times and I turn up he knocks me back. I can't even get in (Daniel)

As with stories of wandering, these stories included physical and metaphorical transgressions into vulnerability and uncontrollable risks;

When someone is so vulnerable that they're allowing access into their home by anyone, and they open the door and allow people strangers to come into the home, I think that's another area that we can't really reduce the risk (Sue)

As noted in chapter 5, such accounts imply a dichotomy of dangerous streets and strangers in opposition to being safer at home and protected by family. However such stories contrast with practitioners' accounts of home as a dangerous place, full of hazards. As noted in chapter 6, there was also an alternative marginal discourse of some family relationships as less protective.

Practitioners' accounts of environmental contexts and home were also of practice cultures and risk-taking. As explored in earlier chapters, some literature examines risk reduction/risk taking approaches in health and social care decision-making (see Kitwood and Benson, 1997 and Titterton, 2005). Practice guidance advocates 'safety first' practice (NPSA, 2007a) and risk enablement and positive risk-taking (Manthorpe and Moriarty, 2010 and Morgan, 2000a). Some literature attributes practitioners' risk-averse, controlling practice to being fearful and working within 'blame cultures';

'Such a defensive position is understandable in a litigious climate, where blame and scapegoating are feared,' (Manthorpe 2004, p146).

And;

'In the culture of blame, practice becomes cautious, conservative and controlling,' (Green 2007, p406).

Alaszewski and Coxon (2008) argued that practitioners perceive procedures, such as reporting *'adverse incidents'* (NPSA, 2008), as focusing on protecting organisations from risks to reputation and finance. Thus

practitioners are managing risks with and for others ('service users') <u>and</u> attempting to reduce harm to self and the institutions they work within (Clarke et al, 2011a, Cornish, 2005, Green, 2007, Heyman et al 2010, Rothstein et al, 2006 and Stamp 2000).

As noted in chapters 5 and 6, some practitioners' accounts of risk assessments were also stories of 'tools', blame and fear. Daniel was the only practitioner to explicitly talk about a *blame culture'*. He presented using the 'Sainsbury' as *'protection',* managing risks to practitioners;

> *The suing, the blame, the culture, and justifying things has got stronger and stronger. So therefore the risk assessment the record keeping and documentation is all proof that clinical people ... have done everything they can. So if there's something wrong, as does happen, they can show that they tried everything. So in a way it is your protection* (Daniel)

This point was also made in risk management guidance (DH, 2007b).

Hannah represented practice contexts as safety-first and practitioners being under surveillance (like Foucault's *'governmentality'*);

> *It is about keeping people safe and in some ways being seen to do that as well* (Hannah)

Their accounts can also be interpreted as portraying people living with dementia being *a risk to others*, in particular a risk to the wellbeing of the practitioner / organisation.

Orla's account of *'dramatic'* and irreconcilable practice differences portrayed a dichotomous world of risk-averse health staff that protect, as opposed to social care staff that support autonomy and risk-taking in context;

> *I think that what staff, social workers, are prepared to accept as an acceptable risk often differs really quite dramatically from what hospital care staff, nursing staff, medical staff are prepared to accept as risk...I think that's something...we'll never reconcile those two because again I guess as a caring profession as a health profession we are there to make people safe and better ... I'm not saying that social services aren't there to keep people safe and make them better but they see things very differently ...about supporting people to do what they want in an environment that's appropriate* (Orla)

Isobel and Sue also portrayed professional difference in risk-taking practice;

> *Therapist and social workers tend to take the positive risks more so than the nursing staff and they'll instantly think no they are at risk therefore they need to be out of the home* (Isobel)
>
> *I think ... some nurses may err on the side of caution because they do have a duty of care and ... there are certain procedures they need to follow to ensure somebody's ... completely safe* (Sue)
>
> *There was a difference in the way we looked at risk and I think possibly myself and the social worker were more active in positive risk-taking and possibly some of the nursing staff were very cautious ... I think we promoted more independence and would be willing to allow people to take risks, if that was their choice, rather than completely trying to protect somebody totally and not allow them to make choices* (Sue)

Naomi portrayed people living with a dementia as behaving differently in a ward context, implying that ward staff have different perceptions because they do not see people living with risks and dementia *'out there'*;

> *In the ward they're sitting 'Yes nurse, can I have a cup of tea?' and it's 'oh I can't move nurse' ...It's their perception, they've never had the chance to see people out there so...different setting different presentation* (Naomi)

Similarly, rather than differences between social/healthcare or between professions, Hannah's story was of differences in risk-taking between practice contexts and cultures;

> *I think particularly ward staff are much more protective, and are less willing to accept risk. And I can see why because they're on the ward where people are kept safe all the time. So they will often say oh that person couldn't possibly manage at home on their own ... partly because they don't see people managing at home on their own* (Hannah)

Neil and Daniel both represented differences in approaches to control and risk-taking as differences between <u>people</u> and life experiences, rather than professional of contextual differences;

> *With consultants, some are very risk averse and some are very happy to take risks because that's the nature of life* (Neil)

Daniel's story was of differences in continuums;

Well it's a very personal thing this and not everyone will agree ... the clinicians, regardless of what profession they are in, or what role they are in at the time, if they have got very different upbringings and different educations and backgrounds and different levels of ... 'I am this' 'I know everything' 'you will do what I say'... without regard to well 'it's up to you to choose' 'you're the patient you choose' 'I'll just do what you want', then ...you've got two extremes and you've got in-between. So different people approach the same problem or issue in extremely different ways ... (Daniel)

As explored in earlier chapters, there is an ongoing growing debate in literature and practice about QoL and psychological wellbeing for people living with a dementia. This has included questioning the dominance of 'safety-first' approaches to risk management in dementia care policy and practice cultures, in particular the prioritisation of physical over emotional wellbeing (Alaszewski and Manthorpe, 2000, Boyle, 2008a and 2010, Brooker, 2007, Clarke 2000 and 2006, Clarke et al, 2009 and 2011a, DH 2009a, Gilmour et al, 2003, Kitwood,1997, Manthorpe, 2004, Manthorpe and Moriarty, 2010, Moats and Doble, 2006, NCB, 2009 and Robinson et al, 2007). As one of my research objectives was; *To consider this decision-making with a particular focus on psychological wellbeing and quality of life,* I was particularly attentive to practitioners' accounts of QoL and wellbeing.

Practitioners' accounts of environmental contexts included stories of physical and psychological wellbeing. Hannah and Sue portrayed physical dangers and bodily functions as potential tipping points into unacceptable risks;

I did feel ... that things would escalate...That she might be in some physical danger ...If I didn't do something about it (Hannah)

In my experience it's been things like an increase in physical need really. It might be some kind of very challenging behaviour like faecal smearing ...And that's where a husband or wife say I just can't deal with this any longer (Sue)

However, unlike some dementia care research and policy, practitioner's accounts did not prioritise physical wellbeing over emotional wellbeing;

So even though they might be better fed, if they're gonna be miserable all the time that they're there its not necessarily a better thing is it? (Hannah)

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> *For that lady the quality of life and wellbeing would have been zilch in a safe environment* (Naomi)

Naomi represented some connections between personhood, wellbeing, QoL and risk-taking. I interpret *'just an existence'* as portraying the limits of safety-first approaches;

> *Wellbeing is ...trying to ... look at a person ... It's looking not only at their strengths but their quality of life and looking at who they are and what they are capable of and helping them achieve. ...It's looking at, respecting their wishes and giving them choices ...It's promoting who they are, and helping them hold on to who they are...and the skills they have, and maintaining that quality of life...So that it isn't just an existence even though they're safe. Its taking risks to maintain that quality and that sense of enjoyment* (Naomi)

Orla also portrayed risk-taking as promoting wellbeing;

> *I think its worth for the wellbeing really looking and exploring the positive risk taking* (Orla)

Some literature suggest practitioners' fears when working within a 'blame culture' can lead to increased use of prescriptive, standardised tools to justify decision-making (Kemshall, 2002). In her story of dilemma, power and negated autonomy, Rachel questioned standardised approaches;

> *What's a score?...It's just a number isn't it? And that lady ... she's going to have to have everybody sat down and everybody saying well 'what do we all think?' ... Unfortunately her opinion ... is only going to be as valid as we think it is... So even though her opinion is obviously quite a big issue...If we all sit there and say 'well no actually she's got no sense of what the risks are', then whatever she says that group of people sat in that meeting isn't gonna really respect what she's got to say, are they?...Because they've already decided for themselves... Our assessments show this so... she can't be right because that's what our assessments say...and it's difficult...Because you can't let her go home if she isn't safe* (Rachel)

Rachel's account supports MCA practice guidance (DCA, 2007) on *Best Interests* and literature on restricted rights (Boyle, 2010 and NCB, 2009). In addition, her questioning of standardised assessments has connections with

ongoing debates in literature which challenge the role and dominance of numbers in health and social care decision-making (Boyle, 2000, Brown et al 2008, Eva and Paley, 2004, Foord et al 2004, Hyde, 2004 and Jones-Devitt and Samiei, 2010).

Practitioners' accounts of environmental contexts were also of hazardous risk management. Some recent investigations have also highlighted some dangerous risk management practice in dementia care, for example Banerjee's (2009) account of the misuse of antipsychotic medication in care homes;

> '...around 180,000 people with dementia are treated with antipsychotic medication across the country per year. Of these, up to 36,000 may derive some benefit from the treatment. In terms of negative effects that are directly attributable to the use of antipsychotic medication, use at this level equates to an additional 1,800 deaths, and an additional 1,620 cerebrovascular adverse events, around half of which may be severe, per year,' p5-6.

However, practitioners said little about the dangers of medication. Their accounts of the dangers of living 'in care' included stories of disorientation, disconnection, loss, bereavement and contextual ethical dilemmas concerning physical and psychological wellbeing;

> *We underestimate the damage it can cause somebody psychologically going into a care home* (Orla)
>
> *I certainly think depression is a risk. That people with some insight into the fact that they're in care and they didn't want to be there* (Hannah)
>
> *I sat there and said I can not advocate that I think that's the right thing to do. I think yeah fair enough you are concerned about these things ...But I feel that she's got too many skills and her mental health may deteriorate further if she was going into care* (Isobel)
>
> *There was a lot of debate again around the risks of changing the environment because she wasn't physically well...But the thing was we had to balance that and say 'well look if we change her environment is that going to affect her mental health even further so therefore she just gives up and dies' ...Which would have been absolutely tragic* (Karl)

She isn't a lady that would be happy sat in a chair all day watching daytime TV. She likes to potter and look through windows and go and talk to people ... That's her at her best and her daughter knows that and has said we want to keep her walking as long as possible so ... and I agree with that... She's happy doing that even though there's a risk attached to it (Daniel)

Daniel also portrayed a need for practice cultures to be risk-taking, in order to enable rehabilitation;

You wouldn't be able to rehab somebody if you wouldn't take a risk (Daniel)

His argument has since been supported by policy;

'Lowering or eliminating the risks of activities or arrangements that are important to people may reduce some risk but at the potential expense of their happiness and fulfilment. They may also affect chances of re-enablement or rehabilitation, such as regaining abilities to walk or to go to the toilet independently,' (Manthorpe and Moriarty 2010, p47).

Continuing his story, Daniel represented complex dilemmatic decision-making, which considered relationships between autonomy, personhood, mood, cognition, sitting, falling and wellbeing. I interpret his *'lesser of three evils'* as risk-taking and choosing between risks, rather than reducing or removing risks;

I saw glimmers of her mood and depression and just apathy setting in and she's not then the lady she is for the rest of her life. She's very different very withdrawn, very quiet, doesn't want to eat much. Just sits all day ... And when she's on her feet she'll chat to people ...and it's a very different presentation. So I'm convinced that ... she would deteriorate emotionally, dementia-wise, maybe depression on the top. You know physically sitting there in one place isn't good for the body. So therefore the lesser of three evils is to keep her walking even though there's an associated risk of her falling (Daniel)

In her account of why people *'don't settle in'*, Rachel represented being 'in care' as disorientating, deskilling and frustrating;

It cuts off a lot of what you know. There's no end to it and it's a new environment. Simple things like if you've got a dementia and you

don't know where the toilet is and then you're put somewhere new. It's going to take you a bit of time and if in that time you can't find the toilet then yeah you probably are going to get quite frustrated and quite angry and that can come out as aggression. So I suppose everybody's circumstances are very different as to why they don't settle in, but are still revolving around that it's somewhere that isn't their home (Rachel)

She portrayed practitioners as attempting to support people with moving away from home, but implied there was a need for more;

We try to send people with like life history books and sheets of likes and dislikes ... but maybe that's just not enough (Rachel)

Norman (1980) asserted;

'...loss of one's home...can be experienced as a form of bereavement and can produce the same grief reaction as the loss of a close relative.' p14.

Thirty years later, practitioners told similar stories of bereavement and multiple losses, for example loss of home, independence and autonomy;

Just the loss of independence and the loss of their own home and being able to make the choices about their everyday life is taken away from them. They go in to basically institutionalised care and all the problems that come with that really, of adjustment ...and loss of freedom (Sue)

Loss of health and wellbeing, and de-personalisation;

The risk of chest infection, increased disorientation and distress because a new environment and communal living, risk of falling - they all go up if you move into 24 hour accommodation. There isn't the risk of wandering out the door ...and getting lost, but there are the other risks ...the effect on mood when they suddenly get bereaved of everything that makes them, them (Naomi)

Loss of self, meaningful occupation and control;

The bereavement of their whole lifestyle. Who they are and what they are, which is defined by place for a lot of people. It's a bereavement ... They can't potter and put the kettle on or make a cup of tea or even get themselves a glass of water when they want to...They sit there and be dusted ...(Naomi)

Rachel's passionate and reflexive account of ill-being portrayed multiple losses of home, possessions, and self;

> *It's their possession. It's their ownership. It defines who they are, their house ... and to move somebody out of that into what is going to be a small room that they don't own, that doesn't have their own things in ...To sit around with people at breakfast dinner and lunch that you don't know ... You don't always want to know...It's a huge decision. It must be horrendous, absolutely horrendous...You've got dementia and then you're there and you just never seem to leave. That must be very confusing ...and upsetting and if you can't express that as well ...It must be very traumatic* (Rachel)

Isobel's metaphorical account of loss and damaged wellbeing reminded me of the film *'Away from her'* (2006) (a story about changing relationships when a woman living with a dementia moves 'into care');

> *And to her to take that <u>away from her</u> was a big ... a big chunk out of her wellbeing* (Isobel) (my emphasis)

I was also persuaded by Teena's poignant story of loss of home;

> *If you put them in care they'll forget they're in care ...They might forget how long they're in care...I could go one day and they'll say 'did I come here yesterday?' and they've been there a week...But they'll never forget that's not their own home ......They'll never forget that* (Teena)

Such stories portrayed a similar image to Reed-Danahay's (2001) refugees;

> *'Alzheimer's patients in a nursing home are like refugees, fellow travellers placed together through circumstances rather than volition'* p50.

Some accounts of risky services were also of limited resources. I examine these accounts in the next section within *'societal contexts'*.

Having considered practitioners' accounts of environmental contexts, I will now examine accounts of societal contexts in risk management decision-making.

Societal contexts

In my experience, once people are labelled with 'dementia' assumptions are made about their lack of mental capacity, and decisions are made on their behalf, for 'their protection' and 'in their best interest' (Manthorpe, 2004). Practitioner accounts of societal contexts included stories of legislation, capacity, societal assumptions, policy and resources.

In her account, Hannah represented decision-making as not always including people who live with a dementia;

> *...if you've got someone with a dementia who lacks capacity and a family that want them to be in care and be looked after and they're not putting up a huge fight...I think they often go into care without much of a debate about it, because everybody agrees that it's the right thing to do and the person isn't arguing about it* (Hannah)

However, Tariq and Karl represented the MCA as leading to more open decision-making about capacity;

> *Whether they've got capacity to agree to this, or not to agree to that...It brings all their decisions very much into the forefront, which I don't think has always been the case* (Tariq)

> *We've both sat down and looked at the Mental Capacity Act and put how this lady's presenting and all the other risks that are involved; fire risk, hygiene, oh there's quite a number of different risks involved with this lady, and then put it against the key points of the Mental Capacity Act ...to help us understand whether we're making the right decision. Whether we're ensuring that this person's future is going to be supported in an appropriate way and the decision that we're basing that on is within legislative guidance. I said to a colleague 'look this is how she's presenting these are the points by the MCA' and even my colleague said 'oh well yes, yes I agree that this lady does not have capacity to be able to make informed decisions, and that there are significant risks'* (Karl)

Hannah also portrayed connections between ethical decision-making and MCA guidance;

> *So in terms of depriving people of their liberty or doing things that are in their best interests, if you're gonna put somebody in care where they potentially don't want to be...then you should always*

*have gone down that line of why are we doing it and is it the right
thing and is it in their best interest?* (Hannah)

Taylor, BJ (2006) argued that practitioners doing *'the right thing'* (p1423) are overly cautious in their decision-making, due to a litigious practice culture. However, Karl and Hannah's use of *'right'* can also be interpreted as portraying moral and ethical accountabilities <u>and</u> ensuring decision-making and thresholds are in accordance with MCA guidelines.

Rachel portrayed less certainty with MCA guidance. Unlike Karl and Hannah, she portrayed decision-making as confusing, uncertain and with no 'right' way;

> *I don't think it gives a definitive answer to anything, but maybe there
> isn't a definitive answer to give. So maybe its as good as it can be, but
> it is still woolly and I still think that people get confused at what level
> of responsibility they have to be prepared to say somebody hasn't got
> capacity to do something* (Rachel)

Some practitioners portrayed practice discourse as constructing, rather than merely representing contextual understandings of ethical decision-making. For example, Orla, Naomi and Isobel talked about assumptions based on diagnosis influencing risk management decision-making. The 'location' of risk is assumed to be with the person (Warner, 2008);

> *Quite often what happens clinically is that the term 'dementia' and
> the term 'discharge' don't sit very well together at all …And it tends to
> be discharge … equates 24 hour care* (Orla)

Although Naomi's use of *'we'* can be interpreted as referring to herself and colleagues, it can also be understood as reference to wider societal discourse and assumptions;

> *Risk is a daily thing isn't it? We all manage risk daily. Suddenly
> when people get a label … we take away that responsibility of risky
> living, or people will try to* (Naomi)

Isobel's repeated use of the phrase *'there seems to be'* could be interpreted as vague and distancing self from the narrative. Influenced by Foucault's (1980) *'governmentality'*, I see this as her reflexive consideration of *'really strange'* ways in which 'truths' are created and maintained in daily practices;

> *There seems to be this divide where, if you've got schizophrenia or
> bipolar, let's look at the risks to yourself or other people…If you've*

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got dementia, let's look at environmental risks ... There seems to be that clear distinction. It's really strange (Isobel)

She also portrayed some practitioners as making assumptions about the inevitability of residential care;

But they ... tend to label somebody and then think well the prognosis isn't very good therefore they're gonna end up in a home anyway...And you hear that even in the office ...Very much so (Isobel)

Her use of *'they'* and *'even in the office'* serves to emphasises her distance from colleagues' assumptions. I interpret such accounts as practitioners' reflexively monitoring their practice and the practice of others, placing decision-making in wider contexts.

Hannah portrayed assumptions about *age* also influencing decision-making. Again, I interpret her use of *'you'* as us/society/ dominant discourse;

You're more willing to accept that young people take risks, aren't you? ...Older people are meant to be good and meant to be looked after ...So you want them to be nice and cosy with their slippers on at the end of the day ... and not going out drinking and causing a problem (Hannah)

Maybe if you want to work with sweet little old ladies ... then maybe risk is harder to deal with (Hannah)

Teena's story portrayed minimal involvement in decision-making thresholds. Although presenting consultants as experts in control, she also implied that some behaviours (being *'settled'* or not) can lead to a re-examination of risk thresholds. I interpret her use of '*settled'* as supporting societal and practice discourses that represent submissive, quite older people as being no risk/no problem (Hannah's *'sweet'*), as opposed to assertive, noisy (*unsettled*) older people being risky/a problem/ deviant behaviour to be managed;

The consultants had to make that decision; 'I think it's time they go into care'. Usually we'd send them for a couple weeks sort of respite and if they're settled, that's fine, they will agree then to stay, but if they don't settle we've got to look at other plans (Teena)

Practitioners' accounts of societal contexts also included stories of policy and resources. Some research and policy suggests that limited resources influence practitioners' risk management decision-making, reinforcing risk-averse practice (Adams, 2001a, Atwal and Caldwell, 2003, Boyle, 2008b and

2010, Clarke et al, 2009 and 2011a, DH, 2009a, Mitchell and Glendinning, 2007, Moats and Doble, 2006, Morgan, 2000a and Parker, 2001). *'Sainsbury'* practice guidance states;

> *'Ultimately, risk management will be dependent on the availability of resources'* (Morgan 2000a, p26).

Practitioners' accounts of resources included stories of ethical dilemmas, eligibility, thresholds, limited opportunities and restricted autonomy.

Hannah questioned government discourse, in particular whether thresholds of eligibility in *'Fair Access to Care'* (DH, 2010a) are indeed 'fair';

> *About money, yeah... A lot of it is ... it's about a limited budget and ...fair access to care, isn't it? ...That's what it's supposed to be* (Hannah)

Adams (2001a) argued that in dementia services;

> *'Identifying situations as a risk warrants the allocation of scarce resources...'* p317.

However, Tariq's account challenged this notion. He portrayed some sorts of increased levels of risk acting as exclusion thresholds;

> *Someone will say we've done a risk assessment of so-and-so. We can't keep them anymore. They're too aggressive. They're too sexually inappropriate... and therefore we can't. Our criteria is that we don't have someone that is aggressive* (Tariq)

Some practitioners portrayed limited homecare resources and task-focussed approaches as deskilling and damaging to emotional wellbeing;

> *Sometimes it's time constraints... Sometimes it's easy to do for than with* (Naomi)

> *Putting their shoes on in a morning getting dressed might have a big impact on their wellbeing if somebody was going and doing it for them and let's be honest that's what homecare do...because they don't have the time to enable somebody to do it themselves* (Isobel)

> *We haven't got the back up support services that we need...There's a desperate need here I feel for a support team of possibly homecare staff but who are willing to actually encourage people to retain independence and have the time and skills to step back and let somebody continue to try a bit longer with the skills they have. We*

> *don't have that. If I refer for homecare to go in they've got a limited amount of time and they'll step in and provide a meal for someone ...and there's no real opportunity for that person to carry on with any skills they have and actually work alongside them ...In reality that's not happening* (Sue)

Some practitioners' portrayed scarce homecare resources as a tipping point into unacceptable risks;

> *Having a fall, ending up on the ward, not being able to go back home again because homecare can't give the input that's needed ...* (Teena)
>
> *Sometimes we can identify what's needed but the supporting package isn't available. So we then have to take a step back and say we'd like to take that risk but we don't feel its an acceptable risk* (Naomi)
>
> *We've had people sitting on the ward for 8, 10 weeks or more. Waiting for a four times a day package. By the time the four times a day package comes in they are so institutionalised to the ward that it fails* (Naomi)

Hannah portrayed strategic, organisational decision-making as utilitarian; cheapest/living in *'care'* as the default position, with services that attempt to enhance wellbeing being represented as 'other';

> *To keep somebody safe at home is more expensive than 24 hour care...and that doesn't always go down well* (Hannah)
>
> *If they don't want to agree a very big care package... you have to put together a really big argument as to why that's better than them being in 24 hour care* (Hannah)
>
> *These days they're quite prescriptive ...If someone needs a breakfast making they'll give you 10 minutes for breakfast. So if you want something slightly out the ordinary you've got to be able to demonstrate why that person needs something like more time* (Hannah)

She also represented 'them' as exerting power, through monitoring and controlling her daily practice (Foucault's *'governmentality'*);

> *'Please tell us why you haven't put this lady into 24 hour care because the risks are massive'. So they're kind of monitoring my decision-making as well* (Hannah)

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A decade ago, Parker (2001) warned of the dangers of utilitarian ethical decision-making in dementia services;

> '... exclusion and marginalisation of those with special needs and differences becomes possible and justifiable using a utilitarian argument... and services for people with dementia could be organized with the majority's concerns privileged over and above the needs of people with dementia...' p335.

Parker's point was well illustrated by NICE's recently rescinded policy of 'economic' decision-making (Alzheimer's Society, 2007a). Teena referred to this policy in her story of restricted access to 'anti-dementia' medication. Although acknowledging dilemmas between utilitarian policy and ethical principles, she represented this ethical decision as *'simple'*;

> *I know if you've got thousands of people on it £2.50 a day soon tallies up to a lot of money, but these people have worked hard all their lives ...they deserve something back ... And as I say you should do for others what you do for your own. So if you'd want that for your own parents so you want it for someone else's parents ... It's just a simple as that* (Teena)

Parker (2001) argued that people living with a dementia were excluded from 'mainstream' rehabilitative services. Similarly, Neil's story portrayed physiotherapy as *'luxury'*, constructed as too costly for people living with a dementia;

> *In the rehab teams the physios, they're very pressurised. They have to prioritise. They don't have the time and the luxury of spending a lot of input with people with dementia, because they can't remember the instructions* (Neil)

I found Neil's story of *'little lights going out'* a persuasive portrayal of people's fading wellbeing and gradual retreat into darkness, hastened by discriminatory practice. He was explicit in his portrayal of societal discrimination;

> *It's a subtle form of dementiaism and it's not a criticism, because I understand the pressures they're under, but you do feel the little losses the little lights go out just because people aren't getting that input* (Neil)

> *So I mean there's ageism and there is a dementiaism.... I think there is a taboo in the kind of intellectual age to lose your intellect is actually quite a fearful thing* (Neil)

I see clear connections between Neil's portrayal of societal *'dementiaism'* and Post's (2006) notion of societal *'hypercognitive'* perspectives;

> *'Many utilitarians make the error of combining the principle of greatest happiness of the greatest number ... with the narrow 'hypercognitive' definition of personhood'* p231.

Neil's passionate, metaphorical account also resisted dominant discourses underlying 'clustering' and decision 'tools' in utilitarian *'payment by results'* policy and practice (see chapter 3, CPPP, 2010 and DH, 2008);

> *You know on the normal evaluation of dementia which is a spectrum you go from a to z ... whereas I find it's more like a patchwork and there are little lights going on here there and everywhere ...You know when people talk about cluster this and cluster that and they're at this stage and that stage? Personally I don't see that at all. It's this wonderful little patchwork and all kinds of things evoke it and you know its very fascinating and full of surprises wonderful surprises* (Neil)

Tariq rejected the dominance of business models in policy and practice, portraying the government as tricksters;

> *So whether the business ethic really fits into people having their own decisions to making their own choices ...Because I don't think places like Tesco's ... their interest is people buying things isn't it? ... and competing with Sainsbury's ... It isn't making the experience better for the individual ......I can't really see how that business model really fits in with the health model because its all the wrong way round to me anyway* (Tariq)

> *I suppose it gives us a sort of illusion of choice as well doesn't it?* (Tariq)

Sue and Neil used the same images in their stories of restricted resources;

> *I work in a Cinderella service...Older people's services ...is not a priority service and I think the financial support is not given to them. That's just how it is, I'm afraid, and it makes me feel very angry* (Sue)

They have so little really. Mental health's a Cinderella service and dementia is a Cinderella of a Cinderella. And they are the bottom of the bottom of the pile really ...in terms of resources (Neil)

I think there's a lot of, a whole variety of different services fighting for the same pot of money, and we are right at the bottom (Sue)

A popular metaphor in healthcare discourse, *'Cinderella'* narratives portray themes of discrimination, neglect, abuse and lack of opportunity (Cameron, 2005). Practitioners' stories portrayed people living with a dementia as marginalised and excluded from resources based on judgements of worth. Unlike some fairy tales, practitioners' narratives did not include fairy godmothers or 'happy ever after' endings...

Having provided my analysis of practitioner accounts of environmental and societal contexts, I will now provide some reflexive considerations and concluding comments.

Being Reflexive

As described in chapter 4, my questions in interview were dependent on practitioners' stories. In contrast to most other stories, practitioners' stories of MCA were not triggered until I structured my questions around MCA, using closed and probing questions. In analysis, I experienced some dissonance regarding this 'steering'. Although I acknowledge I needed to ensure I worked toward my research objectives, I was also mindful of my performance of self in interview. I hoped that my 'steering' had not implied the possibility 'correct' answers.

In undertaking this analysis I was particularly persuaded by practitioners' reflexive, passionate and metaphorical accounts of loss, discrimination and damaged wellbeing. I am aware that my interests and critical, political perspectives of practice could have influenced my perceptions and analysis of these accounts.

Concluding comments

This is the second of two chapters where I have examined contextual ethics in risk management decision-making. In chapter 6 I analysed practitioner accounts of intrapersonal and interpersonal contexts. In this chapter, I

provided my analysis of practitioners' accounts of wider contextual ethics in risk management decision-making; environmental and societal contexts.

Practitioners' accounts of environmental contexts included passionate and reflexive stories of being at home, practice cultures and 'risky' services. Stories of home included ethical dilemmas, thresholds and acceptable levels of risk. These stories of home drew on oppositional binaries such as inside/outside, public/private and family/stranger. Practitioners portrayed living at home as being safe, protective <u>and</u> hazardous. All practitioners told stories about the risks of living alone and 'wandering'; of physically crossing thresholds at home and metaphorically crossing thresholds into 'too risky'.

Practitioners' accounts of practice cultures included stories of risk-taking in practice, and made connections between risk-taking and personhood, wellbeing, QoL. Unlike some literature and practice discourse, practitioner's accounts did not prioritise physical wellbeing over psychological wellbeing.

In stories of 'risky' services, practitioners presented some risk management strategies, in particular moving to live 'in care', as hazardous. These included stories of disorientation, disconnection, loss, bereavement and ethical dilemmas concerning physical and psychological wellbeing.

Practitioner accounts of societal contexts were of legislation, capacity, societal assumptions, policy and resources. These included stories of ethical dilemmas, eligibility, thresholds, limited opportunities and restricted autonomy. Practitioners told passionate stories of dilemmas between utilitarian policy and ethical principles, in particular regarding the allocation of resources. Some practitioners were explicit in their portrayals of societal discrimination, for example Neil's stories of *'dementiaism'*. A recent practice guide examines similar ethical dilemmas in dementia care;

> *'One likely consequence of believing that life with dementia must inevitably be negative is that it is not worthwhile for society to put much effort into improving the lives of people with dementia …Such a negative valuation is in danger of becoming a self-fulfilling prophecy'* (NCB 2009, p25-26).

In chapter 8, I provide an overview of my project conclusions. In the final chapter (chapter 9), I outline some opportunities for dissemination.

Chapter 8 Conclusions

Introduction

I begin this chapter with an overview of this report. Next, I provide some research conclusions alongside my research objectives. I follow this with a review of practitioners' concepts of thresholds and dilemmas in decision-making. I then consider ethics, quality and limitations in my research.

Report overview

I began this report with an introduction to my project. In chapters 2 and 3, I examined some key relevant literature. In chapter 2 my focus was on risk management and decision-making. In chapter 3, I focused on dementia care, dementia care policy and living with risk and dementia. In chapter 4, I provided an account of my theoretical orientations and methodology, and the methods I used to generate, organise and analyse the research information.

In chapters 5, 6 and 7, I provided my analysis of practitioner accounts. In chapter 5, I analysed accounts of the nature and assessment of risk. In chapter 6, I provided my account of developing theoretical representations of practitioners' accounts; contextual ethics in risk management decision-making (Appendices I, II and III). I then analysed practitioners' accounts of intrapersonal and interpersonal contexts. In chapter 7, I analysed practitioner accounts of wider contextual ethics; environmental and societal contexts.

In this chapter, I provide an overview of my project conclusions and in the next and final chapter I outline some plans for dissemination.

Project conclusions and research objectives

I will now provide some research conclusions alongside each of my research objectives. I consider each objective in turn, except for; *To contribute to future work in service development, professional development, and health and social care training,* which I examine within chapter 9.

My principal research objective was; ***To explore practitioner accounts of decision-making in risk management with people living with a dementia.***

Practitioners' accounts of risk management decision-making were complex and contextual, and there were differences within and between practitioner accounts.

Practitioners relied on, resisted and re-constructed dominant constructions of risk, risk assessment, risk management and decision-making. They supported, questioned and rejected dominant practice assumptions about the desirability of uniform, standardised risk management.

Practitioners' accounts of risk assessments included using standardised 'tools' to structure assessments and measure risk. Although some represented risk assessment tools as restricting practice, practitioners also represented some tools as being flexible enough to enable assessments to be structured <u>and</u> creative, art <u>and</u> science. Practitioners' accounts also supported arguments that considerations of risk assessments should go beyond the collection of information, to interpersonal communication and relationships. These included stories of negotiated, contextual, 'naturalistic' and shared approaches to assessments.

To describe and analyse assumptions and understandings influencing decisions made by health and social care practitioners

Practitioners assumed individual, realist <u>and</u> constructed concepts risk. All practitioners' accounts included complex, contextual stories of people living with a dementia becoming and being <u>at</u> risk of harm from hazards, from self and from other people and services. Practitioners' accounts of people living with dementia being <u>a</u> risk/danger <u>to</u> others were less common.

Practitioners represented risk management decision-making as logical, linear instrumental procedures <u>and</u> as complex, interactional, unpredictable, ethical, dilemmatic and contextual. Within these stories, practitioners made multiple connections at meso, miso and macro levels. They portrayed fragmented, fluid, understandings of decision-making located in changing, overlapping contexts. I used *kaleidoscope* as a metaphor to explore the multiple, shifting relationships between the conceptual themes and associations in practitioners' stories, and to represent practitioners' accounts of decision-making within four levels of contextual ethics; *intrapersonal, interpersonal, environmental and societal contexts* (Appendix III).

Practitioner accounts of decision-making included and went beyond objective, rational applications of abstract rules. Their accounts of intrapersonal contexts represented decision-making as logical, cognitive, experiential, emotional, subconscious, subjective and contextual. These included stories of fear, prediction, intuition, uncertainty and ethical dilemmas. Practitioners' accounts of interpersonal contexts in decision-making included passionate portrayals of acceptable levels of risk, sharing risks, trust, relationships, negotiation, power, control, validation, moral sensitivity and reflexivity.

Practitioner accounts of contextual decision-making included multiple, contrasting representations of living at home. They portrayed living at home as being safe and protective (orientating, comforting, meaningful and belonging) _and_ being risky (vulnerability, isolation, loneliness and hazardous). Some stories of home, living alone and 'wandering' portrayed a dichotomy of dangerous streets and strangers in opposition to being safer at home and protected by family. These contrasted with other stories of home as a dangerous place, full of hazards. Practitioners represented family relationships as protective, sharing risks and influencing decisions about thresholds of acceptable risks. Although in literature, there is an alternative discourse of people living with a dementia of being at risk from family, only one practitioner mentioned this perspective.

Practitioners portrayed complex understanding of practice cultures, risk taking and wellbeing, and questioned assumptions made about people living with risk, once they are labelled with 'dementia'.

Practitioner's accounts of the difficulties and risks encountered by people living with a dementia portray some connections with the work of Kitwood (1990 and1997). Their accounts of risk management decision-making went beyond biomedical-neurological constructions. They represented complex understandings of transactional relationships between contexts, risk management, wellbeing and living with risks and dementia.

To consider this decision-making with a particular focus on psychological wellbeing and quality of life

Some literature suggests a need for further research exploring wellbeing in risk management decision-making with people living with a dementia

(Brooker, 2007, Clarke et al 2011a, Manthorpe and Moriarty, 2010, Mitchell and Glendinning, 2007 and NCB, 2009). I hope my project can contribute to ongoing research that attempts to address this perceived gap.

> *'There are hidden dangers and risks that exist to emotional wellbeing in the form of boredom, helplessness, depression and giving up'* (Brooker 2007, p75).

All practitioners told stories about wellbeing. Although Brooker (2007) portrayed dangers to emotional wellbeing as *'hidden',* such dangers were not hidden in practitioners' accounts. Unlike some dementia care research and policy discourse, practitioners' stories did not prioritise physical wellbeing over psychological wellbeing. They portrayed understandings of decision-making that included complex, interwoven, emotional, contextual ethical dilemmas concerning physical <u>and</u> psychological wellbeing. Their accounts of risk management considered connections between wellbeing, autonomy, personhood, mood, cognition, engagement and QoL.

Practitioners' accounts incorporated contextual understandings of psychological wellbeing, such as the influence of communication, relationships, practice cultures and societal discrimination. Practitioners portrayed differences in risk-taking practice; these differences were represented as between social and healthcare, professions, people, practice cultures and contexts.

Practitioners portrayed risk-averse practice, task-focussed approaches and restricted access to resources, as deskilling and damaging to physical and psychological wellbeing. Like Boyle (2008b and 2010) and DH (2009a), practitioners represented a lack of homecare resources resulting in people living with dementia no longer having the choice to live at home.

Practitioners represented some risk management strategies, in particular moving to live 'in care', as hazardous. Within these accounts practitioners portrayed ethical dilemmas concerning physical and psychological wellbeing. These included stories of multiple losses; of independence, autonomy, health, home, possessions, meaningful occupation, engagement, relationships and skills. Practitioners' accounts of disorientation, disconnection, bereavement and loss were similar to Reed-Danahay's (2001) portrayal of moving to a nursing home as being *refugee.* These accounts

represented moving to live 'in care' as moving from the familiar to the unfamiliar. As not belonging, being displaced with no 'real' home. Perhaps this goes some way to account for being *'unsettled'*?

Daniel's metaphorical story portrayed a sense of alienation and loss of self;

> *I've seen people in nursing homes struggling desperately a bit like ... a ladybird on its back to try and right itself ... They're trying to get out of these chairs struggling, struggling, struggling. Staff walking past ... They either turn a blind eye or just don't see it* (Daniel)

His account reminded me of Elder's (1977) representation of being old in 1970's UK. Elder made parallels between alienation in old age and Kafka's story of *Metamorphosis* (Kafka and Pasley, 2000), where a man is transformed into a beetle. Like Kafka's (and Elder's) beetle, Daniel's *ladybird* story was about changing perceptions of need and worth, of de-personalisation and *'desperation'*. In her reflexive account, Isobel also portrayed a concern for personhood;

> *They've still got needs, they've still got a life, they've still got desires, they've still got dreams like everybody else. And if they aren't maintained, how are they gonna be the person that they are if nobody looks at those specific things about a persons life?* (Isobel)

Practitioners' stories of psychological wellbeing also included explorations of societal discrimination. Some of these resisted utilitarian decision-making and questioned dominant policy discourse on resource allocation. They portrayed strategic, organisational decision-makers as marginalising risk management decision-making that attempted to enhance wellbeing. Practitioners also told persuasive stories of people's fading wellbeing, hastened by discriminatory practice (Neil's *dementiaism*). These stories of loss, alienation and discrimination, have some similarities Post's (2006) *'hypercognitivism'* and with Bourdieu's (Calhoun et al 1993) concept of symbolic cultural *'capital'*; in particular that people living with a cognitive impairment are less valued in some cultural contexts. There are also connections with Age Concern's (2008) accounts of social exclusion, and Kronenberg and Pollard's (2005) accounts of *Occupational Apartheid*;

> *'...the segregation of groups of people through the restriction or denial of access to dignified and meaningful participation in occupations of daily life ....Occasioned by political forces, its systematic and*

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> *pervasive social, cultural, and economic consequences jeopardize health and wellbeing'* p67.

Practitioners' accounts of risk and wellbeing included stories of ethical decision-making and balance. In some stories practitioners represented ethical dilemmas where it may be difficult or not possible to feel a sense of balance or certainty;

> *It's getting that balance between wellbeing and safety ... and that for me can be really, really difficult* (Isobel)
>
> *In relation to looking at a person's quality of life and trying to find that balance there's no happy medium...We're just trying to find that balance* (Karl)

To consider this decision-making in the context of recent legislation, policy and practice guidelines and changes in the culture of dementia care (in particular the Mental Capacity Act, 2005)

Within this project I located practitioners' accounts of decision-making within wider practice discourses, in particular policy and guidelines. My analysis of practitioner accounts was undertaken and represented alongside this wider discourse. Practitioner accounts of policy and practice guidance included stories of MCA, *'Sainsbury'* and *'care clusters'*. They portrayed such policy and procedures as restrictive, prescriptive rules and as *'tools'* that guide decision-making. Practitioners also portrayed reflexive understandings of policies, which included stories of ethical dilemmas, eligibility, limited opportunities and restricted autonomy. All practitioners portrayed resistance to some government discourse and policy, for example some questioned NICE guidelines (such as NICE 2006a), thresholds of eligibility (DH, 2010a) and discourses underlying *'clustering'* (CPPP, 2010 and DH, 2008).

To consider ways in which discourse, narrative and reflexive analysis can contribute to understandings of practitioner decision-making in health and social care

I created and used a plan to guide my analysis (Appendix XI).These approaches to analysis contributed to understandings of practitioners risk management decision-making a variety of ways.

My narrative approach generated detailed, complex, contextual accounts of risk management decision-making. Some accounts were particularly persuasive, metaphorical and emotional.

A discourse analysis approach enabled some considerations of *'truth effects'*; how some practice discourses are understood and acted upon as though they are objective truths (Foucault, 1980, Stanford, 2007 and Warner, 2006). I explored dominant dichotomous, hierarchical and non-dichotomous constructions of risk management decision-making within practitioners' accounts. Practitioners' portrayals of risk management were along continuums; subjective <u>and</u> objective, structured <u>and</u> creative, risk <u>and</u> benefits, emotional <u>and</u> cognitive and psychological <u>and</u> physical. This contributes to understandings of how practitioners rely on, question, resist and reconstruct dominant discourses.

In addition, some practitioners portrayed Foucaultian understandings of discourse, for example how practice discourse signifies, constructs and maintains 'truths' about risk thresholds;

> *I put things like 'poor balance', which probably means they're at risk of falling, but I don't put that ... if I think the risk is huge, then you highlight it 'risk', but you only use the word risk when it's like flashing big...If you mention the word risk that means something drastic doesn't it? ... When we start saying 'risk', is when we start to have alarm bells ringing* (Rachel)

In undertaking reflexive analysis, I have tried to be open about my choices and assumptions, and considered how these may have influenced the content and quality of my research. As practitioner-researcher, I attempted to avoid uncritical reproduction of dominant ideologies and hierarchical binaries, such as research/practice.

When analysing, I reflexively explored and questioned my choice to focus on risks. In particular, I noted Rachel's reflexive rejection of risk as focus;

> *So the person isn't considering the risks, are they? ... I mean well I wouldn't if it was me* (Rachel)

and Neil's resistance to *'risk'* discourse;

> *There's risk and benefits...but we don't do benefit assessments and I think if we did ...we would have a different view of things ...If you are picking up a slight reservation, if not a criticism, of the overemphasis*

on that, it's that it can be a little bit too shrinking. But benefit assessment, what's the benefit of doing this and the benefit of doing that ... I know it's implied in risk management, but ...its often phrased in the negative...and therefore the emphasis is on the negative, slightly defensive, retreative...but benefit assessment ...I think that would be a better way ... the greater the benefit the better the more valuable the risk (Neil)

Within this story, Neil deconstructed and reconstructed risk management discourse and practice. He portrayed understandings of risk management that go beyond the *'shrinking'* practice of risk reduction. He proposed a reconsideration of how we conceptualise decision-making and a shift in practice towards considering and talking about the benefits and value of risk taking. A year after Neil's interview, NCB (2009) argued a similar point, proposing that *'risk assessment'* is a *'misguided term'* (p101) because it encourages practitioners to focus on minimising risks rather than considering the opportunities of risk-taking. NCB also recommend replacing *'risk assessment'* with *'risk benefit assessment'*. This proposal was also recently supported by Manthorpe and Moriarty (2010).

These approaches to analysis have enabled me to work with, and not over-simplify, the complex realities of research and decision-making in dementia care practice. Having provided some project conclusions against my research objectives, I will now focus my conclusion on practitioners' accounts of thresholds and dilemmas in risk management decision-making.

Thresholds and dilemmas in decision-making

Throughout my analysis chapters, I have included practitioners' accounts of thresholds and tipping points into unacceptable levels of risk.

Physical thresholds were particularly prominent within practitioners' stories of home, for example practitioners' stories of moving to live 'in care' and of 'wandering'. However, practitioners' accounts of acceptable levels of risk included stories of trying to control and secure physical <u>and</u> metaphorical thresholds. These included stories of environmental contexts that could not be controlled, with transgressions represented as unmanageable; metaphorically crossing thresholds into 'too risky'.

Practitioners portrayed decisions about tipping points as fraught with ethical dilemmas and complexities. Their stories represented tipping points as influenced by probability of risk, types of hazards (physical, psychological, financial) and feelings about risk-taking and possible consequences. They represented practice and discourse as constructing some *sorts of risks* being less acceptable, tipping the balance into 'too risky' (such as high probability of physical harm). Other *sorts of risk* (such as low mood, depersonalisation, and loss of home, occupation and engagement) were represented as less likely to cross the threshold into unacceptable risks. In some stories, practitioners' resisted daily practice and discourse that privileges threats to physical wellbeing and marginalised concerns for psychological wellbeing.

Practitioners' also portrayed different understandings of control and certainties in decision-making about acceptable levels of risks. Some practitioners represented risk management as attempting to control people and contexts. This included stories of using certain strategies (such as *persuasion,* relationship building, risk-avoidance and following procedures) to try to keep the risks within acceptable levels.

I see some connections between practitioner accounts of uncertainty in decision-making and the notion of *'false positives'* ('incorrectly' assessing a risk as high) (O'Sullivan, 1999). In practice, overestimations of risks as unacceptable trigger little if any responses. However, *'false negatives'* ('incorrectly' assessing a risk as low) are labelled as incidents to be investigated according to procedures (Macrae, 2008 and NPSA, 2007a and b). Practitioners portrayed their decision-making as under scrutiny, being accountable to anonymous others, especially if someone was physically injured. Their stories also represented some of the dangers of *'false positives'*, in particular dangers to psychological wellbeing.

'Tipping points' within practitioners' stories included when particular behaviours (such as those associated with bodily 'functions') pushed family 'carers' beyond their thresholds. Other examples of 'tipping points' were within stories of 'wandering', living alone and lack of resources to support people living with risks and dementia. However, practitioners' accounts of thresholds were often fuzzy and did not clearly demarcate levels of risk into 'high' or 'low'. Their complex, contextual accounts of assessing levels of risk

do not fit with O'Sullivan's (1999) neat realism of true/false demarcations. Their accounts of thresholds were often implicit; implied within the narrative detail of multiple concurrent factors, contexts and events within complex stories. Threshold were not clear, there were no certainties, no 'right' decision. For example;

> *I suppose I must have a threshold mustn't I?* (Hannah)

Some stories portrayed moving thresholds, where risks were not managed and practitioners were passive observers;

> *And then we're at the mercy of homecare support services; what we can do to help them out there* (Naomi)
>
> *Sometimes you don't like it but you're waiting for something to happen for the situation to change* (Teena)
>
> *They are just tossed around by events* (Neil)

Isobel initially indicated that her thresholds were '*obvious*';

> *I've often been part of making a decision because when it's obvious, when it's so clear that somebody can not be at home any more, because they are just so unsafe* (Isobel)

Seeking practice examples, I asked;

> *And you were saying that it's sometimes obvious that somebody can't stay there...What sorts of things do you think in your experience make it obvious?* (Me)

Although Isobel then included particular thresholds (such as vulnerability and falls), she also represented my question as '*difficult*';

> *...If the risks are too high...If they're constantly leaving the door open...If they're not locking the door, if they're falling...all the time ......It's a really difficult question.........I think when it's got to a point where... if all the resources have been exhausted...* (Isobel)

She also portrayed a desire for some certainty about thresholds through shared decision-making;

> *If I'm not a hundred per cent sure, I will get a colleague to come out with me. To just see what they think as well* (Isobel)

Karl's stories included physical and psychological thresholds;

> *I am stepping into their world as far as I'm concerned, because I'm stepping over their threshold. I'm going into their home* (Karl)

> *It was ... wonderful really to engage with that lady and to step into her world* (Karl)

Karl's representation of another world has connections with Ferguson's (2004) portrayal of social workers' *'liminal'* practice in 'safeguarding' children;

> *'Stepping into someone's home-effectively into another world-is a classic entry into a liminal state. This applies to all kinds of homes ... as all interventions are transitions: the crossing of the threshold, into the home, into the self and lived experience of the other(s),'* p188.

Other researchers have also reported ambiguity about acceptable levels of risk in dementia care (Clarke et al 2009, Robinson et al, 2007 and Waugh, 2009).

In considering practitioners' dilemmatic attempts to predict hazards and the need for timely decision-making in practice, I again see some parallels with practice in 'safeguarding' children;

> *'Everyday professional practice is often frenetic and busy. Practitioners are often under pressure to make decisions and process cases quickly. There is often an imperative to assess and categorise with undue haste. This can obscure domains of uncertainty'* (Hall and White 2005, p387).

As Hall and White (2005) suggest, in the complex, chaotic realities of daily practice, practitioners may seek certainties where there are none. However, practitioners did not *'obscure'* uncertainties. They consistently portrayed their experiences of decision-making as full of ethical dilemmas and uncertainty. Rather than attempting to demarcate risk management practice into discrete variables, and make predictions based on numerical calculations, practitioners acknowledged complexities and un-predictabilities in practice.

Practitioners' accounts of thresholds in decision-making also included stories ethics, emotions and practice cultures. These stories also represented government directives as increasingly pushing them into ethical dilemmas about rationing resources. Some stories of dilemma represented practitioners as emotionally vulnerable;

> *Risk management is often anxiety management and it's anxiety management of the professionals* (Neil)

When she got there and went on the ward she started screaming and that broke my heart (Isobel)

I think it is beginning to erode and destabilize things ...Xxx team are a very resourceful team. I'm sure we'll come through it ...but sometimes you think 'No, this is slightly unravelling a bit here'...and it's a bit like the dementia process itself. You can see things sort of drifting away then you can't hold on to them anymore (Neil)

As with some literature, practitioners' accounts of emotional vulnerability included stories of decision-making as unfinished and un-resolvable; as remaining, ongoing ethical dilemmas and uncertainties (Banks and Williams, 2005, Beauchamp and Childress, 2009, Clarke et al, 2009 and Taylor, BJ, 2006). If ethical dilemmas remain un-resolvable, an understandable reaction to such continual emotional anguish is that practitioner's *'unravel'*, 'burn-out' and /or leave (Atwal and Caldwell, 2003 and Wintrup, 2009).

Practitioners represented different ways of coping with un-resolvable ethical dilemmas and their emotional vulnerabilities. These included strategies such as emotional distancing, humility, questioning and eclectic, inclusive decision-making. For example, Neil's story can be interpreted as portraying decreasing moral sensitivity and emotional distancing;

I was very angry at the thought of ... to be stripped of everything that we value in our usual life... seemed very unfair. Whereas now, either I'm more accepting or I see it differently. I don't know. But I don't have that sort of rage about it (Neil)

As with Daniel's earlier story of alienation and *'walking past'*, such accounts can be interpreted as portraying the influence of contextual ethics of practice cultures and wider society. Like Daniel's ladybird, practitioners may feel vulnerable, struggling, ignored and unable to make a difference. As noted in chapter 6, I interpret Neil's use of *'robot'* as portraying a desire to feel less fear in practice;

If they could make robots to do all this it would be wonderful ... (Neil)
They're talking of developing robots for fighting because they won't feel fear (Neil)

Practitioners' accounts of coping mechanisms also included *'humility'* (Gergen in Cisneros-Puebla, 2008). These stories were of shared decision-

making, where practitioners' represented their understandings as partial, ambiguous perspectives;

> *My perspective is just my perspective so for me to make a decision to ... you know that would change somebody's life quite drastically I wouldn't feel comfortable doing that on my own because my perspective is only my perspective ...To get an all round picture, I think you have to have everybody involved* (Rachel)

However, in some practice cultures, practitioners may be wary about being seen as experiencing dilemmas and uncertainties. They may feel they need to perform as 'expert'.

Practitioners' stories of ongoing ethical dilemmas also portrayed questioning as a strategy. Asking questions, rather than providing answers;

> *What happens if she doesn't get a bath every week? Where are we with the duty of care?* (Naomi)
>
> *Are they just saying that because of who I am, and I've got some form of authority because I wear a badge, and I'm a member of staff?* (Rachel)
>
> *Why should she get used to it? Because that meant so much to her...The meaning of her life. She'd always been a walker* (Isobel)
>
> *What's a score?... It's just a number isn't it?* (Rachel)

Rather than limiting decision-making to instrumental and procedural logic, practitioners represented reflexive, flexible, contextually adaptable, *'in-between'* strategies to decision-making (Zinn 2008, p277).Their accounts of complex ethical dilemmas were of 'both-and' continuums (Arner and Falmange, 2007), for example stories of cognitive <u>and</u> embodied, creative <u>and</u> procedural, rational <u>and</u> non-rational approaches.

Having provided some project conclusions, I will now consider ethics and quality.

Considerations of ethics and quality

My judgements about research quality have been guided by ethical and epistemological considerations. I have considered ethics and quality throughout this project. In chapter 4, I provided a summary of my approaches

to research ethics and quality, including the concepts of validity, reflexivity and usefulness. I will now re-consider my research against these concepts. Considering interview ethics, before starting each interview, I reminded each practitioner they could end their involvement at any stage. In an attempt to ensure practitioners were not left feeling 'troubled' by the interview, I paid attention to and responded to cues of discomfort/distress. Following interviews, I was attentive to the possibility that a practitioner may wish to discuss some feelings triggered with myself, their supervisor, or others. I also took copies of appropriate employee support services leaflets to each interview. Other ethical consideration included the anonymity of practitioners who took part in the interviews, and the confidentiality of interview recordings and transcriptions (see chapter 4).

In considering the validity of my project, I have tried to ensure that my arguments are plausible and credible enough to others. Within this report I have justified my decision-making, in particular that my methodology was appropriate for my research objectives, and given the complexities of decision-making in practice. I have provided sufficient detail of my methods (see chapter 4) to enable readers to judge some of my research practice. In justifying my choices, I have also referred to relevant literature throughout this report. I have tried to be transparent enough to enable readers to make judgements about the credibility of my analysis and conclusions (Cho and Trent, 2006).

My claims for validity also include the concept of reflexivity as process. I have been explicit about my 'insider' status as practitioner-researcher. I am not neutral, and have been open about my choices and how these may have influenced my research. I have examined power dynamics and tried to enable practitioners to have some voice throughout my project. I hope I have provided enough detail of practitioners' voices in transcripts to enable readers to make their own interpretations.

Another measure of worth is usefulness and transferability to similar situations. I have tried to work towards worthwhile and achievable objectives. I hope I have provided enough detail in my report to enable comparison with similar practice situations. I agree with Lather (1986) that claims of absolute knowledge can be arrogant. The 'truths' of my research are emergent, partial

and context specific. As noted in chapter 4, the 11 practitioners who took part in the interviews were limited to a small subgroup of practitioners who are involved in risk management decision-making with people living with a dementia. They worked within a particular NHS trust, in a particular geographical locality, at a particular time. However, despite the limitations of 'situated' knowledge claims, they are still of some use in practice (Fook and Gardner, 2007, Hammersley, 2002, Wetherell et al 2001 and White, 1997). Rather than trying to get at 'objective truths' in practitioners' accounts, my focus has been on *'fractured objectivity'* (Crowley, 2000) and *effects* of 'truths'.

Within my research and dissemination, I hoped to examine restrictive discourse and open up possibilities for exploring difference and change in practice. In the next chapter, I explore how this provides a basis for some opportunities for practice disseminations.

I also claim some generalisability as my considerations went beyond local to take account of wider discourse and contexts. From this perspective, my project can also be judged against whether it has any relevance for dementia care practice outside of these interviews. I explore this further in the next chapter.

Having considered ethics and quality in my research, I will now provide my account of some of the limitations of my project.

Project limitations and reflexive considerations

I begin by considering methodological limitations and continue by exploring some practical limitations. I also include some reflective considerations of my impact on the project quality.

My methodological choices involved some compromise. I explored, but did not use grounded theory, participative action or observational approaches. As practitioner, I was interested in how grounded theory attempts to address separations between theory and research. However, I felt this would not be a credible choice, as I was interested in complexities and not assuming a convergence of experiences. From critical practice perspectives, participative action was of interest, and I feel my project has much in common with this approach. However, I was mindful of the practical limitations of undertaking

this project with busy practitioners, whose level of involvement was restricted. Practitioners would not usually have the privileges of time and access that enabled me to undertake this project. Although I tried to involve practitioners, I acknowledge this was not a participatory endeavour. Like Tanggaard (2007), I feel it was not possible for my relationship with practitioner interviewees to be '*symmetrical*'. I am mindful of the partiality of informed consent and participation in my research project. I made most of the decisions. I chose what stories to tell and how to tell them. I interpreted and selected the information before including it in this report. As ethno-methodology is an approach to studying daily life in complex social environments, I also considered this approach. However, I agree with Horlick-Jones (2005) that direct observation of '*risk work*' may not be desirable or possible. The sensitive, private and unpredictable nature of risk management with people living with a dementia does not lend itself to this approach. For practical and ethical reasons, I made alternative methodological choices (Mason, 2006, Watson, 2006, Watts, 2006 and Wetherell et al 2001).

Other practical limitations included my choices about the sources and amounts of research information that I planned to access and generate, and the depth of analysis I planned to undertake. I intended to generate/ access research information from practitioner interviews, reflexive notes, case records, key government policies, practice guidelines and related media portrayals. I had planned to analyse all these resources/texts at the same level of analysis. However, when transcribing interview recordings I realised my plans were not realistic for a research project of this nature and scope. After consultations with my supervisory team, I amended my plans for analysis, and limited my primary analysis to practitioner interviews. Reflexive notes, policies and practice guidelines were included at a secondary level. Although I did not include some information for analysis, I agree with academic supervisors that I could 'revisit' this at some point, as the foundation of a different but related research project.

As stated at the beginning of this report, it was never my intention to privilege practitioner perspectives in dementia care. Rather, I hoped to contribute to the work of others who explore perceptions of risk with people living with

dementia and their carers. In the early stages of my project, I consulted some key contacts in the trust, including the service user and carer research group. We agreed to meet again after my report was written, to explore ways in which useful information from this project could be disseminated. However, I am aware of the limited nature of this involvement, mostly due to the realities and priorities of my work as practitioner.

When transcribing, I was aware that practitioners told stories that presented self in different roles, such as 'fighter', 'helpless' and 'hero'. Again, although of interest, any plans to explore this further were unrealistic for this project.

Based on my practice experiences, it came as no surprise that all practitioners' accounts included stories of walking, 'wandering' and falling. I had intended to examine these in an additional chapter, but this was not possible within the limitations of this report. I therefore integrated some of these stories within my report. I also plan to use this material to inform my practice disseminations.

In considering myself as interviewer, I am aware that I sometimes took a lead in shaping stories, as active listener and co-constructor. By including my research objectives in the *'Participant Information Sheet'* (Appendix V) practitioners were primed that they 'ought' to be talking about risks and policy. One of my research objectives was *'To consider this decision-making in the context of recent legislation, policy and practice guidelines and changes in the culture of dementia care (in particular the Mental Capacity Act, 2005)'.* In analysing practitioner accounts, I therefore created *'policy'* as an 'a priori' code. Unlike Alaszewski and Alaszewski's (2000) study, policy was not *'conspicuously absent'* (p123) from practitioner's accounts. However, some of these stories were initiated by a focused question from me.

From 'Gestalt' perspectives, I was also mindful that stories of interest for me may stand out, whilst other concepts/stories could have merged into the background. For example, stories of *capacity, policy, risky services* and *resources* stood out for me because of their passionate, reflexive narratives <u>and</u> my research objectives <u>and</u> because these stories stirred my emotions located in my similar practice experiences (Hill, 2009, Randall et al 2006, Vincent et al, 2007 and Watts, 2006).

Having explored my project conclusions and considered ethics, quality and limitations, I will now conclude this chapter.

Concluding comments

I began this chapter with an overview of this report. Next, I provided some research conclusions alongside my research objectives. I followed this with a review of practitioners' accounts of thresholds and dilemmas in decision-making. Towards the end of this chapter, I considered the ethics, quality and limitations of my research.

Practitioners' accounts of risk management decision-making were complex and messy, and I have not reduced them to a singular, uniform narrative.

Practitioners relied on and resisted dominant discourses. They supported, questioned and rejected dominant practice assumptions about the desirability of uniform, standardised risk management. All practitioners' accounts of risk assessments included contextual stories of people living with a dementia being at risk of harm from hazards, self, other people and services. Accounts of people living with dementia being a risk/danger to others were less common.

Practitioners portrayed understandings of decision-making that included complex, interwoven, emotional, contextual ethical dilemmas concerning physical and psychological wellbeing. They represented risk management decision-making as logical, linear instrumental procedures and as emotional, complex, interactional, subconscious, unpredictable, ethical, dilemmatic and contextual. All practitioners' accounts included stories of unfinished and un-resolvable ethical dilemmas.

Within these stories, practitioners made multiple connections at meso, miso and macro levels. They portrayed fragmented, fluid, understandings of decision-making located in changing, overlapping contexts; intrapersonal, interpersonal, environmental and societal.

Practitioners' accounts of intrapersonal contexts included stories of fear, prediction, intuition, uncertainty and residual ethical dilemmas. Practitioners' accounts of interpersonal contexts in decision-making included passionate portrayals of sharing risks, trust, relationships, negotiation, power, control, validation, moral sensitivity and reflexivity.

Their accounts of contextual decision-making included multiple representations of living at home. Living at home was portrayed as being safe, protective <u>and</u> dangerous. For example some accounts represented a dichotomy of dangerous streets and strangers, in opposition to safer protective homes. These contrasted with other stories of home as a dangerous place, full of hazards.

Practitioners represented some risk management strategies, in particular moving to live 'in care', as hazardous. These included stories of multiple losses and ethical dilemmas concerning physical and psychological wellbeing.

Practitioners' stories of psychological wellbeing also included explorations of societal discrimination. They resisted utilitarian decision-making and questioned dominant policy discourse on resource allocation.

Practitioners' portrayed thresholds of acceptable risk as complex, multi-faceted, contextual, ethical, dilemmatic, constructed, subjective, fluid, vague, negotiated, disputed, movable, flexible, precarious, liminal and sub-conscious.

In my literature review, I only identified 5 researchers who have focused on *practitioner perspectives* of risk management in UK dementia care (Clarke et al, 2009, 2010, 2011a, Corner, 2003, Gilmour et al, 2003, Robinson et al, 2007 and Stamp 2000). I hope my study has contributed to their work.

In the next and final chapter, I consider my plans for dissemination alongside my final research objective; *To contribute to future work in service development, professional development, and health and social care training*

Chapter 9 Disseminations and practice

Introduction

This is the final chapter of my report. In chapter 8, I provided some research conclusions alongside most of my research objectives. In this chapter, I consider dissemination opportunities alongside my final research objective;

To contribute to future work in service development, professional development, and health and social care training.

I begin this chapter with an account of my approaches to dissemination. Next, I consider some opportunities for dissemination in practice. I then explore opportunities for dissemination alongside some contemporary policy and practice guidelines. I continue by providing an example of one previous dissemination performance. Finally, I offer some reflexive considerations and concluding comments.

On dissemination

My approach to dissemination is as process rather than end product. My choices, priorities and plans for dissemination reflect my approaches to research and practice, and are shaped by the realities of my work, in particular the limitations, opportunities and flexibilities granted by management and organisational priorities.

As practitioner-researcher, I resist research/practice dissemination binaries, in the hope of developing helpful alternatives in practice. I see a need for more reflexive versions of dissemination that acknowledge contextual complexities and uncertainties in practice (Barnes et al, 2003, Brannigan and Moores 2009, Boyes, 2006, Edwards 2002, Hugman, 2005, Pollard et al, 2009 and White et al, 2006). I am influenced by critical, narrative theories of stories as tactics within the politics of everyday practice. As 'insider' researcher, I have capitalised on prior practice experiences, knowledge and networks and am aware of some potential barriers and enhancers of dissemination. By positioning some disseminations within narrative discourses of everyday practice, I hope to enable explorations of some dominant practice concepts of taking risk with dementia (de Certeau, 2002 and Tangherlini, 2000).

Opportunities for dissemination

As practitioner, I am OT and 'team leader' within older people's services, within an NHS trust. I work in different contexts with people living with a dementia, and /or their families and carers. I am part of a multi-disciplinary team, and 'manage' a team of therapists, providing supervision and support. I am involved in service and professional developments, including policy implementation projects and 'in-service' training. I am also involved in facilitating practice placements and training with local universities.

I hope that understandings developed through my research will contribute to several aspects of dementia care practice.

I will now explore opportunities for disseminations in practice, within the overlapping areas of; *publication and academic networks, thresholds of acceptable risk, falls, case discussion, supervision and training, service user involvement, service developments, professional networks* and *creative media.*

Publication and academic networks; I hope to maintain some links and share some work with researchers with shared interests, such as with Charlotte Clarke, Chris Boyes, Stella Jones-Devitt, Hazel May, Jonathan Parker and Nick Pollard.

Although I have published in the past, my future plans to disseminate this study though publication need to be realistic within my other workplace priorities. Previous decisions to publish have been based on my judgments and the advice of trusted others on the practical relevance and usefulness of this work (for example Bower, 2006). I am particularly interested in publications that offer opportunities for disseminations in practice, for example in contributions to practice focussed publications (such as *Signpost* and *Journal of Dementia Care*). I can also see some merit in writing for publications that enable opportunities for sharing my research with other researchers and writers with overlapping interests. Possible areas of focus for such publications could be based on my literature review or risk management in dementia care, and on practitioners' accounts of psychological wellbeing in risk management decision-making.

I have recently been asked about my interest in dissemination through contributing to practice focused a book. Although I am unable to commit to

this opportunity at present, I plan to negotiate and prioritise such dissemination opportunities with workplace managers.

However, I also support arguments made by Cash (2009), Richardson (1994) and Sandelowski et al (2006), that in order to have some impact in practice it is useful for researchers to consider flexible, creative, disseminations that include, but go beyond publication;

> *'It seems foolish at best and narcissistic and wholly self-absorbed at worst, to spend months or years doing research that ends up not being read and not making a difference to anything but the author's career,'* (Richardson 1994, p517).

When considering approaches to dissemination, I am influenced by a belief that, as practitioners we do not simply apply decontexualised objective evidence (Gordon, 1998 and Schon, 1987).

Thresholds of acceptable risk; Heyman et al (2010) recently suggested that risk thresholds are often implicit, full of uncertainties, and leave many questions about how and why *'dividing lines'* are constructed. Whilst undertaking my research, some publications have examined risk threshold in dementia care. Robinson et al (2007) concluded;

> *'Future research around wandering in dementia should explore what constitutes an acceptable risk to individual stakeholders...'* p402.

Waugh (2009) argued;

> *'...the acceptable level of risk was debatable, creating tension between different players.'* p219.

This perceived lack of research continues to be of interest, and I see a need for further research in this area. Within my research, I examined practitioner accounts of acceptable levels of risk and attempts to manage physical and metaphorical thresholds. These were stories of complex, contextual, subjective, negotiated, disputed, vague, flexible, precarious uncertainties and ethical dilemmas. I hope my project can make small contributions to understandings of how practitioners account for thresholds of acceptable levels in risk management decision-making in dementia care.

Knowledge I gained from practitioner accounts of acceptable risks will influence my dissemination and practice. One example is my plan to incorporate this within some training and development work with therapy

colleagues in general medical practice. This includes exploring thresholds of acceptable risks and risk-taking, for example when working with people who are living with a dementia and recovering from a fractured neck of femur. Such projects are particularly welcomed and practitioners who feel this is not their area of 'expertise' and by managers seeking improved performance statistics through *'timely discharges.'*

Falls; Stories of walking and falling pervaded practitioner accounts of risks. In practice, I am involved in local falls prevention projects and developing falls assessment screening tools. Knowledge gained from practitioner accounts has already disseminated through my work in this area. Again, such projects are welcomed by managers seeking improved performance statistics on *reducing falls,* and 'compliance' with NICE guidelines and NPSA directives.

Case discussions, supervision and training; Practitioners' portrayed some coping strategies for working with complex and 'residual' ethical dilemmas. Within these accounts, practitioners represented inclusive concepts of decision-making as cognitive, emotional, partial, contextual, shared and ambiguous practice. My plans for dissemination include supporting practitioners to develop such strategies and skills in managing complexities and ethical dilemmas. I see some merit in Wintrup's (2009) suggestion that we use 'real' case discussions to enable explorations of ethical dilemmas and emotions triggered. I propose to develop existing 'in-service' training and 'complex case discussion' supervisions in line with these concepts. I hope we will be able to reflexively explore feelings about risk management decision-making, including use of thresholds. I plan to promote the use of reflexive, negotiation and critical questioning skills to examine everyday 'common-sense', dominant discourses and political contexts in practice (such as *risk, being safe, wellbeing* and *assessment*). In this way, there are opportunities to examine assumptions and question 'truths' in decision-making. In doing so, I hope that feelings and uncertainties can be acknowledged and explored, and that strategic questioning can be reconstructed as a strength, rather than a weakness. Recent policy guidance on risk management in dementia care is supportive;

'Listening and negotiation skills are important to risk enablement,' (Manthorpe and Moriarty 2010, p20).

'Some people find it helpful to think about their own fears in relation to the activity and therefore their own perceptions of risk...It may take time and skill but the outcome will be that risk empowerment is less dominated by fear and overestimates of danger,' (Manthorpe and Moriarty 2010, p46).

In addition, Adams (2008) and Brown et al (2008) support questioning as a strategy in complex, ethical decision-making in practice;

'... if people strive to ask critical questions, they will ultimately produce more knowledge than if they seek the single 'right' answer' (Brown et al 2008, p3).

Informed by this project, I also propose to develop dissemination opportunities regarding knowledge of risk assessments, through my existing practice roles in professional supervision, 'in-service' developments, practice placements and university workshops. This includes supporting students and newly qualified professionals to explore assumptions, justifications and interpretations when using assessment tools. I hope my research can contribute to understandings of how practitioners rely on, question, resist and reconstruct dominant discourses (Banks and Williams, 2005, Clarke et al 2011a and b, Crowley, 2000, Fook and Gardner, 2007, Manthorpe, 2004 Stanley, 2005 and White at al 2006). SCIE have recently developed their best practice guide for practitioners involved in assessing the mental health needs of older people. This includes comprehensive training resources on risk management and dementia care, available though their website. I feel these will be valuable resources and tools for dissemination within practice placements and 'in-service training'. I have already placed their web-link on the student placements information website. My future use of these materials will be informed by knowledge gained undertaking this research.

Service user and carer Involvement; In planning my research I undertook some consultations, which included sharing my plans with a local user and carer research group. I also read literature on dissemination written by service users and 'carers' (such as Samele et al, 2007).These consultations

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influenced my plans for dissemination. I plan to share my work and explore ideas for disseminations with the group later this year.

Service 'developments'; I have recently begun to contribute to current local 'work-streams' to 'shape' future dementia services. My contribution to this work is informed by knowledge I have gained undertaking this research.

OT professional networks; Discrimination and loss were key concepts within practitioners' accounts. These concepts were included within stories of assumptions, rights, loss of home, lack of engagement, depersonalisation and damaged emotional wellbeing (for example Naomi's story of *'being dusted')*. Such accounts have connections with my role as OT and there are parallels with some recent research in OT and dementia care literature. Pollard et al (2009) examined the political and systematic marginalisation and segregation of some people from meaningful occupation. Boyle's (2010) current research examines human rights and living with a dementia. Clarke et al's (2010 and 2011b) ongoing research includes an examination of risk management and meaningful occupations with people living with a dementia. As an OT influenced by critical theories and postmodernisms, I am encouraged by the increasing interest in political, critical and postmodernist perspectives of OT portrayed in literature (Brown et al 2008, Creek 1997, Finlay, 2002, Hammell, 2009, Kinsella and Whiteford, 2009, Mackey, 2007, Pollard et al 2009 and Weinblatt and Avrech-Bar, 2001). As I am already involved in OT professional networks and training, I am considering disseminations relating to OT, risk, assessments, engagement and wellbeing. For example, within an OT special interest group, I am exploring possibilities for research disseminations that link into and move beyond existing journal clubs, to include reflexive examinations of OT roles in risk assessments, occupation, engagement and inclusion. I hope that timely support from government policy will help to ensure this is a realistic plan;

> *'A good starting point for considering risk can be thinking about how much a particular activity is likely to contribute to – or take away from – the quality of life for the person with dementia,'* (Manthorpe and Moriarty 2010, p47).

Creative media performance; I have made some enquiries amongst existing networks regarding the potential of IT and creative media. This

includes exploring the use of animation, drama and 'virtual' learning resources. When developing and facilitating mental health training with social work students, I came across *Animated Minds*; a series of animated documentaries exploring mental health issues, produced by Mosaic Films and Channel 4 since 2003. I was interested in the potential of such web-based materials to engage people in active learning. I was also interested to read Sandelowski et al's (2006) research on stigma and HIV-positive women, and Cash's (2009) research on experiences of living with a dementia. Both provide accounts of disseminating their research through use of 'real' scripts, performance and DVD. I am in the process of exploring ways I can use animation to support learning around accounts of risk management in dementia care. I have made contact with *'Animation in Therapy'* (a project developed by OT's and animators, to support people interested in using animation in mental health practice). However, this has been limited by practice priorities. It may be an idea that someone else may wish to pursue...

Having provided some examples of opportunities for disseminations in practice, I will now explore my dissemination alongside some policy opportunities.

<u>Policy opportunities</u>

From a policy perspective, my dissertation is timely. Since the Mental Capacity Act (2005) introduced legal rights, numerous government directives and practice guidelines have included discourse on risk 'enablement' and psychological wellbeing. Several include or focus on risk management with people living with a dementia (Alzheimer's Society, 2008b, DCA, 2007, DH, 2007b, 2007c, 2009a, 2009b, 2010c, Manthorpe and Moriarty, 2010, NICE/SCIE, 2006a and NCB, 2009). I will now consider some of this guidance alongside opportunities for dissemination.

The pervasiveness of risks and the benefits of risk-taking were key concepts within practitioners' accounts. Practitioners portrayed some risk management attempts to control risk as potentially hazardous (for example leading to a loss of living skills and psychological ill-being). Practitioners' stories of the potential benefits of risk-taking included persuasive arguments for a

reconsideration of how we conceptualise risk management decision-making and a shift towards talking about and valuing the benefits of risk-taking. As indicated earlier in this report, some recent practice guidance documents also support moves toward positive risk-taking and the promotion of psychological wellbeing in dementia care. Both NCB (2009) and Manthorpe and Moriarty (2010) resist the dominant safety-first discourse of dementia care, and consider the dangers of avoiding risks;

> *'The term 'risk assessment' should be replaced by 'risk-benefits assessment', in order to highlight the importance of benefits which may be lost in the attempt to reduce risk,'* (NCB 2009, p102).

> *'Risk enablement is based on the idea that the process of measuring risk involves balancing the positive benefits from taking risks against the negative effects of attempting to avoid risks all together,'* (Manthorpe and Moriarty 2010, p8).

Although portraying risks as measurable, objective realities, Manthorpe and Moriarty (2010) later argue that social and societal contexts are more likely to influence decision-making than statistical calculations. Manthorpe and Moriarty (2010) and NCB (2009) both incorporate practice guidance frameworks with a clear focus on ethics and psychological wellbeing in dementia care risk management. As with practitioners' accounts, risk enablement and wellbeing are associated with activities of daily living;

> *'Risk enablement goes beyond the physical components of risk, such as the risk of falling over or getting lost, to consider the psychosocial aspects of risk, such as effects on wellbeing or self-identity if a person is unable to do something that is important to them, for example, making a cup of tea,'* (Manthorpe and Moriarty 2010, p9).

Likewise, NCB (2009) argue;

> *'A risk-benefits assessment ...encourages the person carrying it out to consider the risks of not providing or permitting the activity in question: for example the risks of walking outside or alone should be weighed against the risks of prolonged boredom and frustration.'* p102.

In analysing practitioners' accounts or risk management, loss and wellbeing alongside these policy developments and related literature, I saw potential for Brooker (2007) and Clarke et al's (2011a) suggestions for auditing risk-

management documentation, and examining content regarding emotional wellbeing ;

> ' In auditing risk assessment documentation and care plans, it is useful to see whether decisions have been made purely on the basis of physical safety, or whether attempts have been made to look at various options and activities from the point of view of the service user and their emotional wellbeing' (Brooker 2007, p75).
>
> 'Professional teams should review the comprehensiveness of their assessment, the extent to which physical risk is privileged (to the detriment sometimes of psychological and emotional well-being)...' (Clarke et al 2011a, p3).

I plan to undertake a small pilot project that acts on these suggestions, using the 'risk enablement framework' (Manthorpe and Moriarty, 2010) and 'ethical framework' (NCB, 2009) as guidance for good practice. I am consulting with my managers to negotiate whether this can be incorporated within my current practice responsibilities, in particular planned developments in therapy or dementia services. If supported by managers, I would consult the governance department, Clarke, Brooker, DH and NCB. My contribution would be influenced by knowledge I have gained undertaking this project.

In addition, NCB recently published a teaching resource based on its 2009 report, which includes an adapted version of their ethical framework (NCB, 2011). I intend to use this resource to explore ethical dilemmas through dissemination in complex case discussions, supervision and training.

However, I am mindful that government discourse in risk management guidance is inconsistent (for example, see Manthorpe and Moriarty, 2010 against CPPP, 2010 and NPSA, 2011). When analysing practitioners' accounts of ethical dilemmas and resources against government attempts to 'liberate' the NHS, I feel that some current political contexts are more obstacle than an opportunity. DH recently stated;

> 'Dementia is a priority for the Coalition Government and the National Dementia Strategy sets out an ambitious, but achievable, agenda for improving the quality of life for people with dementia and their carers' (DH 2010c, p2).

However, the governments' 'efficiency' measures are presenting ethical dilemmas in practice. NIHCE (2010) *Quality standards* for dementia care may enable possibilities for practice dissemination through training, but after exploring their use of numerical performance measures of quantity as quality, my faint enthusiasm for their policies on quality was tempered.

Having considered my dissemination alongside some policy opportunities, I will now provide an account of one previous dissemination performance.

Previous performance

Whilst undertaking my research analysis, I facilitated a seminar at COT's annual conference. From a critical perspective, I viewed this dissemination as an opportunity for resistance, for questioning dominant ideologies in OT practice and research. Gate-keeping was through peer review and I did enough to be allowed in, whilst trying not to suppress or distance myself (West, 2001). In performance, I wanted to be practitioner and facilitator, not expert or academic. In keeping with my epistemological and methodological choices, I used story telling, reflexivity and passion to guide my writing and seminar performance, challenging notions that researchers and writers should be dispassionate and detached. I can see this was also rooted in my attempts to provide strong, persuasive and engaging arguments (Du Bois, 1983, Finlay and Steward, 2006 and Mason, 2002). I tried to be as accessible as possible, and hoped the seminar could be a trigger for thinking, for sharing and for questions. In my judgments of the quality of my performance, I asked myself questions based on criteria outlined in chapter 8, for example;

- Did I explore and question some assumptions about OT, research and risk management in dementia care?
- Did my dissemination have any practical relevance for others?
- Did I ensure my choices and assumptions were transparent?

I have since been contacted by people who were present at my performance (including students, newly qualified practitioners, managers, lecturers and researchers). They provided feedback, requested more information and wanted to continue discussions (see Appendix XIII). In this way they are now part of the 'production of knowledge' from my research.

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As with other aspects of this doctoral programme, a written version of this performance was assessed by academics against university criteria. Their judgements was; *'strong, safe, level 8'.*

Having considered dissemination, practice and policy, I now provide some reflexive considerations and concluding comments.

<u>Being reflexive</u>

In ending this report, I am mindful of the compromises and emotions involved in undertaking this project. I have managed this research around my daily practice. I have worked at the interface of the complex and ambiguous worlds of practice and research. I have tried, and failed to work within realistic time-lines. My writing, rewritings, and integrated 'new' knowledge have been delayed by the lived realities of the rest of my life.

In practice, I continue to be influenced by the political contexts of dementia care. Now the government is 'Liberating' the NHS (DH, 2010b), I am submerged in a practice culture dominated by controlling 'pathways' and measuring financial outcomes. As explored by Hugman (2005) and Jones-Devitt and Samiei (2010), I am regularly confronted by colleagues who feel we should measure financially focused outcomes in order to prove our worth. As stated in chapter 2, it is easy to see the appeal of approaches that, rather than focus on 'activity' or 'input', try to make efficient use of scarce resources by choosing support/services that have 'best results' (for example in enhancing wellbeing and QoL). However, there are ethical dilemmas about how to judge what is 'best' and prioritise outcomes. Based on my practice experience, I was not surprised to hear practitioners' stories of alienation, discrimination and exclusion from services. In keeping with Post's (2006) *'hypercognitivism',* Bourdieu's (Calhoun et al 1993) *'symbolic cultural capital'* and Kronenberg and Pollard's (2005) *Occupational Apartheid,* people living with a dementia can be judged as not worth the expense of some health and social care. In practice and research, I try to resist a market-based ideology that I find increasingly alienating (Carey, 2008).

Concluding comments

I began this chapter with an account of my approaches to dissemination. Next, I considered opportunities dissemination in practice, and considered some of these alongside some contemporary policy and practice guidelines. I continued by providing one example my previous dissemination.

Like practitioners' decision-making, my disseminations are contextual and will be shaped by the priorities of my work as practitioner. The contextual realities of my daily practice offer opportunities and impose limitations. In common with my suggestions at beginning of this report, Manthorpe and Moriarty (2010) also suggest a timeliness for changes in dementia care;

> *'There is wide support for changing the emphases of dementia care to risk enablement.... It is clear that there is much goodwill to make it a reality and to leave a legacy of commitment to risk enablement ...There is a groundswell of support for seizing opportunities to considering quality of life gains as well as potential harm...'* p56-57.

In my practice disseminations, I hope to seize some *opportunities* to work with a *groundswell of support.* I hope my research can make some small contributions to existing understandings of practitioners' decision-making and dilemmas in risk management with people living with a dementia.

However, I am mindful that my plans for dissemination have to be realised in a managerial and political context where emphasis is on economic measures of performance. Given that scarce resources are a particular point of concern, I feel it is a reasonable expectation that risk management decision-making in dementia care will be increasingly fraught with ethical dilemmas. Like Hughes and Baldwin (2006), I am mindful there may be *'no political will'* (p104) to improve service provisions in dementia care. Like Jones-Devitt and Samiei (2010) I am sceptical of models for improving health and social care that rest on dichotomous assumptions of public bad/private good. As I write, the government is lifting their 'pause' on *liberating* the NHS and Southern Cross's financial risk management leaves their services in crisis. As Kitwood and Tariq suggest, politics is part of our daily practice;

> *'...the stupidity and narrowness of the market mentality, and in particular the idea that human services can be effectively delivered as if they were consumer durables'* (Kitwood 1997, p144).

I can't really see how that business model really fits in with the health model because it's all the wrong way round to me anyway (Tariq)

From a practical perspective, this report must have an end. I must submit it *as though it were* a finished product. It must be static, fixed for a particular audience, at a particular time, for particular reasons. However, as I write this report the kaleidoscope turns. The NHS is going through what is widely reported to be the biggest changes ever envisaged since its creation. In practice I am regularly informed of the latest shifts in the complex contexts of dementia care, and am expected to change my practice in response. The story continues. This is not an ending.

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APPENDICES

Taking risks with dementia; Exploring practitioner accounts of risks and decision making

Appendix I: Thematic List

Taking risks with dementia; framing risk, boundaries and balance
A *linear representation* of key themes of practitioners' accounts
[Core Themes, organising themes and basic elements]

Becoming and Being at Risk; Practitioner accounts of the nature and assessment of risk
- **Risk**
- people living with a dementia becoming and being AT risk from potential hazards and from self
- people living with a dementia becoming and being at risk from others
- people living with a dementia becoming and being a risk to others

- **Risk assessment**
- what is being assessed
- how risk assessments were done; forms and tools
- how risk assessments were done; contextual

Contextual Ethics in Risk Management Decision-Making; Intrapersonal and interpersonal contexts
- **Wellbeing, ethics and balance**

- **Intrapersonal context**; emotions and subjectivity
- 'duty'
- fear
- 'gut' feelings
- uncertainty, complexity and residual dilemmas

- **Interpersonal context**;
- relationships
- communication
- control and power

Contextual Ethics in Risk Management Decision-Making; Environmental and societal contexts
- **Environmental context**
- home
- practice cultures
- risky services

- **Societal context**
- legislation and policy
- assumptions and dementiaism
- resources

Thresholds
- reasonable and acceptable risk
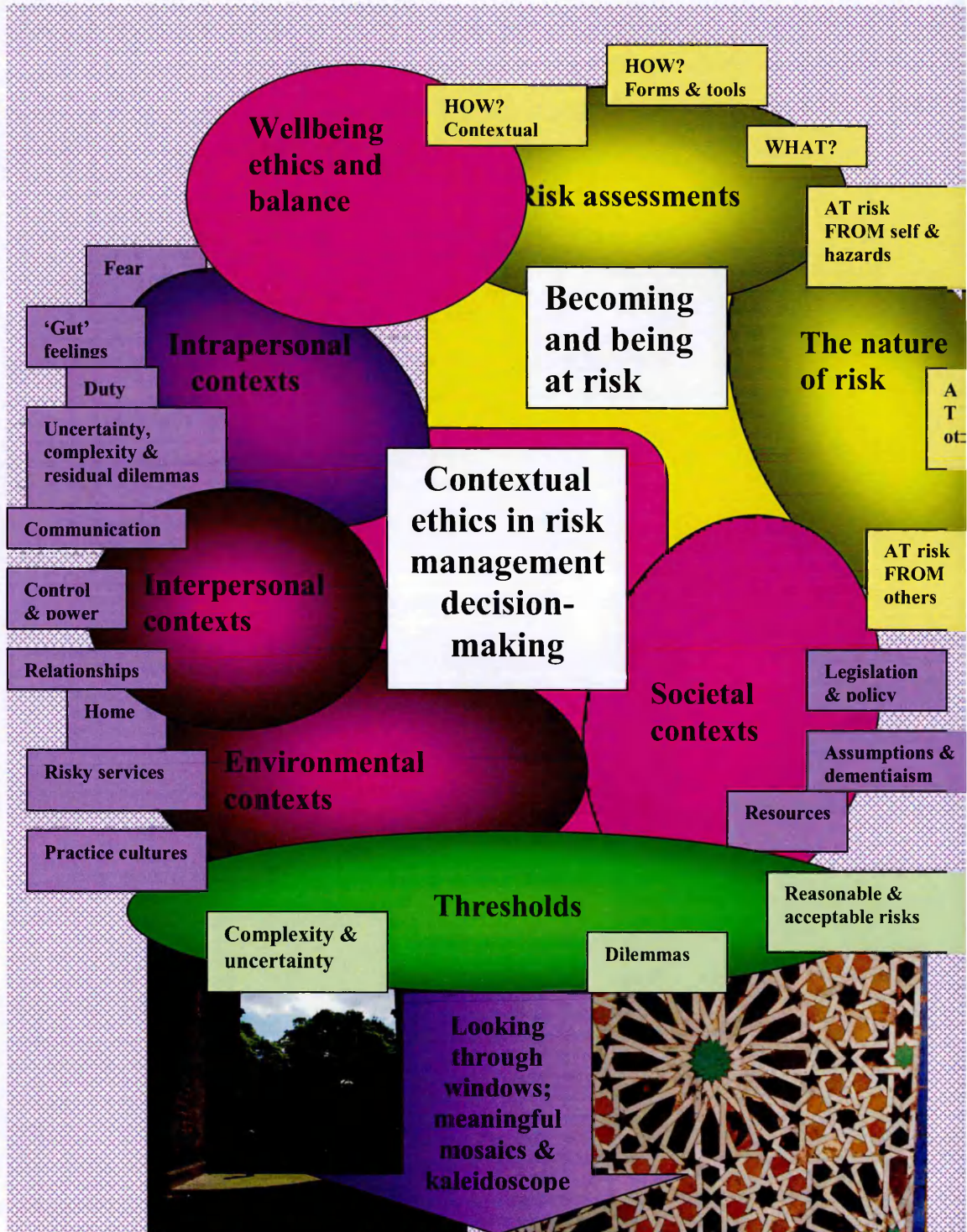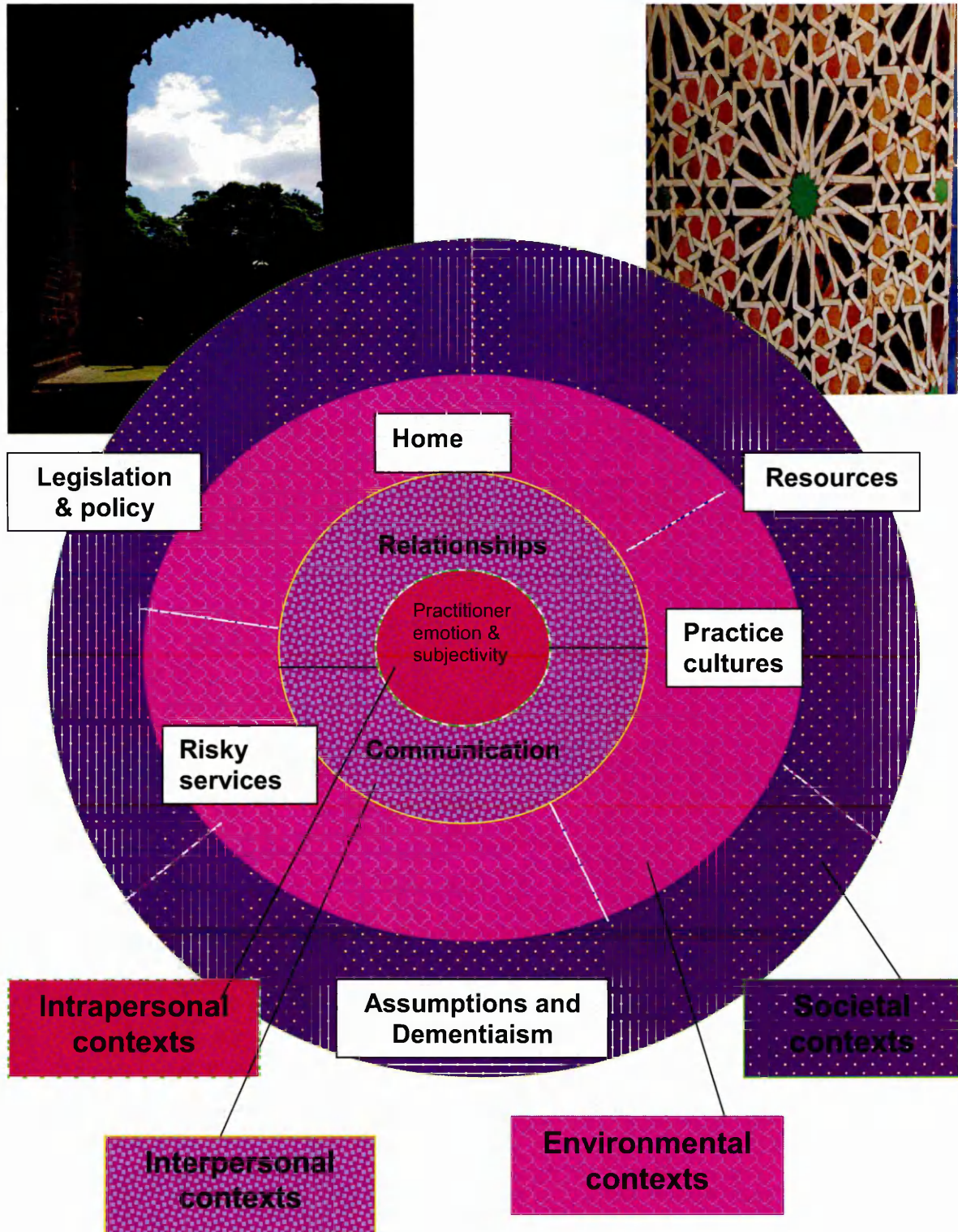- complexity and uncertainty
- dilemmas

Appendix III: A Conceptual Kaleidoscope

Windows and mosaics; looking through contextual ethics in risk management decision making

(Influenced by Ajjawi, 2006 and Jackson et al, 2007)

Appendix IV: Some Terms

- CHI; Commission for Health Improvement
- COT; College of Occupational Therapy
- CPPP; Care Pathways and Packages Project
- CSCI; Commission for Social Care Inspection
- DCA; Department of Constitutional Affairs
- DH; Department of Health
- Discourse/discourse; Boyes (2006) and Taylor and White (2000) differentiate between *discourse* to indicate everyday use of language and *Discourse* to indicate a body of knowledge, or dominant 'truths'. I did not see a need to differentiate in that way.
- EBP; Evidence based practice
- LREC; local research ethics committee
- MDT; multi-disciplinary team
- MCA; Mental Capacity Act (2005)
- MHF; *Mental Health Foundation*
- MSP; *'malignant social psychology'* (see Kitwood, 2007)
- MHNE; *Mental Health North East*
- NICE; *National Institute for Clinical Excellence* (now NIHCE)
- NIHCE; *National Institute for Health and Clinical Excellence*
- NPSA; National Patient Safety Agency
- NCB; Nuffield Council on Bioethics
- *NVIVO;* software programme created by *QSR International Limited*
- OT; Occupational Therapy
- QoL; Quality of Life
- SCIE; *Social Care Institute for Excellence*
- 'Western'; is not meant to deny diversity, or imply that 'Western' or 'non-Western' beliefs or people are homogeneous. This term is an over-generalisation and is used as a pragmatic device; a sign to depict traditional assumptions underlying dominant philosophical beliefs of Europe, N. America and Australia e.g to contrast 'Western' Greek/Roman understandings of science based on Newtonian

physics, with 'non-Western' understandings of science in countries including India & China, based on traditions of Hinduism, Taoism, Buddhism, and Islam.

- XX trust; local NHS foundation trust, indicated as XX for reasons of confidentiality

Appendix V: Participant Information Document

Sheffield Hallam University

Research Participant Information Document
(Ref:RPI408)

Taking risks with dementia; Exploring practitioner accounts of risks and decision making

Dear

I am inviting you to take part in a research project. Before you decide whether to take part, it is important that you understand why I plan to undertake this project, and what it will involve. Please take time to read the following information and discuss with others as you wish. If anything is unclear, or you would like more information, you are welcome to contact me.

Sue Bower (Researcher)

The Purpose and Background of the Research Project

My project sets out to examine ways in which practitioners talk about their decision making in risk management when working with people living with a dementia.

In contemporary mental health services, concerns for risk pervade much of what is talked about and written about. Older people living with a dementia are seen as being particularly vulnerable due to the possibility of diminishing mental capacity to make decisions on their own behalf (see Kitwood, 1997, and Adams and Manthorpe, 2003). The Mental Capacity Act (2005) and the subsequent Code of Practice (DCA, 2007), attempt to guide people who are working with or caring for people who lack capacity to make certain decisions. Practitioners and carers are presented with dilemmas about enabling people in their choices and attempting to control the predicted risks. Previous research indicates that

practitioners prioritise concerns about physical harm, whereas people living with a dementia and family carers are more concerned about risks to emotional wellbeing, such as isolation.

I plan to undertake interviews with approximately 10 health and social care practitioners, and to examine key related documents (such as risk management notes and government policy). My approach is influenced by studies of decision making (such as Benner, 1984 and Greenhalgh and Collard, 2003, Holloway and Freshwater, 2007 and Mattingly & Fleming, 1994), which argue that we develop stories to make sense of our work with people and to explain ourselves to others.

I hope my findings will contribute to discussions that can inform dilemmas and negotiations about choice and risk taking for people living with a dementia and their families and carers.

I am undertaking this research as part of my studies for a Doctorate in Professional Studies with Sheffield Hallam University (SHU).

Why have I been invited to take part in this study?

You have been identified by your manager as a practitioner who has experience of working with people who are living with a dementia.

Do I have to take part in this study?

No. You decide whether or not you wish to take part in this study. If you decide to take part, you are still free to withdraw at any time, without giving a reason. If you choose to withdraw, the information you provide will be removed from the study and destroyed.

What will happen to me if I agree to take part in this study?

If you decide to take part, please complete the *Research Participant Consent Form* (see attached, Ref: RPC408). As the interviews will be undertaken in work time, please inform your line manager that you are planning to participate. Once you provide me with the written consent, I will contact you to arrange the interview. We will plan one initial interview, plus a follow up by

negotiation, if appropriate. Each interview should last approximately 1 hour. I plan to undertake the interviews between June and October 2008. The interviews will take place within the trust, but exact place and time are negotiable. The interviews will be audio-recorded, and I will keep brief written notes. I will begin each first interview with an open question, for example; *'Can you tell me about your experiences of working with people who are living with a dementia?'*

Each interview recording will be anonymised and transcribed into a written format. We can arrange follow up contact if you wish to check the content of written transcriptions. All information collected (interview transcripts and written documents) will be analysed. My analysis will be made available to participants.

Possible risks of taking part

If you choose to take part in these interviews, this will involve you reflecting on your experiences of risk management with people who are living with a dementia. It is possible that this may 'stir up' feelings that cause some distress and/or may cause you to question your self, your actions and the actions of others. It is important to remember that you can end your involvement at any stage of the interview. Following the interview, you may wish to discuss some of the issues raised with your supervisor, or with other confidential support services (such as the staff consultancy and counselling service).

What happens if something goes wrong?

If you have any concerns about this project, please contact Cathy Hill (see contact details below).This project is covered by indemnity insurance, through the NHS and the university.

The nature and limits of confidentiality

This research project will *NOT* involve direct access to people living with a dementia or their carers. I have taken guidance and have been given permission to access <u>anonymised</u> examples of case records, in particular completed risk assessment and risk management documents, and reports of review meetings.

Throughout the project, all information about service users, carers, service provision, service providers and individual practitioners will be anonymised and written in a manner that respects confidentiality. Each interview recording and brief interview notes will be made available only to the individual participant, my academic supervisor and myself. The recordings, electronic and written paper information will be anonymised and locked in a secure NHS area for 5 years. You will not be identified in any report or publication. Pseudonyms will be used in transcripts. All interview recordings will be stored electronically, protected by NHS security and 'firewall'.

Limits of confidentiality It is important to note there is a limit to confidentiality and anonymity. As a health professional, I have a professional duty that overrides the principle of confidentiality. I will remind you of this duty at the beginning of the interview. Whatever you talk about in the interview will be in confidence, UNLESS;

- *you disclose that a person is in danger of serious harm*
- *you disclose unsafe/ dangerous/abusive practice*
- *there is a legal justification (such as a court order)*

If you begin to disclose in the interview, I will again remind you of the limits of confidentiality. If a decision is made to disclose some confidential information from the interview, I will first discuss this with you. My response will proportionate, and *will NOT involve any disclosures of information that could identify you.* My actions will be undertaken in accordance with trust policy and procedures (see *Safeguarding Adults)* and with guidance from my manager, work-based supporter, chair of local research ethics committee or the director of my academic studies.

What happens after the research project has been completed?

In addition to being written up in my thesis [Doctorate in Professional Studies (Health and Social Care)], I plan to share project findings with 'service user' and carer organisations, such as the Alzheimer's Society, and with practitioners. In practice, I am

involved in facilitating service development and professional development training programmes. I hope that understandings developed with this project can contribute to this work. I am also exploring the possibility of using community networks, IT and creative media to share information in an accessible way, for example use of web space, newsletters and animation. I may also publish an article in a practice journal.

Ethical and scientific approval

My proposal for this research project has gone through the following quality and independent research ethics procedures;

- XX Mental Health Research and Development Consortium
- XX Service user & carer research group (XXXX Trust)
- Alzheimer's Society (XXXX)
- Academic supervisory team (Faculty of Health & Wellbeing, Sheffield Hallam University)
- SHU Independent Scientific Review & Research degree sub-committee
- NHS Ethics Approval (National Research Ethics Service [NRES])

Thank you for taking time to consider your invitation to take part in this research project.

Sue Bower (Researcher)

If you decide to take part please send a completed Consent Form (see attached, Ref:RPC408) **before _date_/to:**

Sue Bower, address; xxxxxxxx

Email; xxxxxxxxx

If you have any queries or concerns about any aspect of this project, please contact: XX (Academic Supervisor) Sheffield Hallam University, Collegiate Campus, Sheffield S10 2BP Telephone: XXXXXXXX Email: XXX

The content of this information sheet was guided by:

- College of Occupational Therapy Research Ethics Guidance
- NHS National Patient Safety Agency National Research Ethics Service
- XXXX Research & Development Consortium

References

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Appendix VI: Interview Guide

Interview Guide (IG108)(adapted from Kvale, 1996 and Seidman, 1998)

Research questions	Interview guide & questions
Research Question relating to AIM; How do practitioners account for decision making in risk management with people living with a dementia? **Research Question relating to OBJECTIVES;** ■ How do assumptions and understanding influence decisions made by health and social care practitioners? ■ How do such decisions impact on the lives of people living with a dementia (with a particular focus on wellbeing and quality of life) ■ In what ways is this decision making influenced by recent legislation, policy & practice guidelines and changes in the culture of dementia care (in particular relating to the Mental Capacity Act, 2005)?	Begin with **BRIEFING:** ■ Introductions & context setting ■ Clarification of issues relating to confidentiality & risks **INTERVIEW QUESTIONS:** ■ <u>Opening question;</u> *Can you tell me about your experiences of working with people who are living with a dementia?* Taking cues from opening story: ■ **Follow ups may include:** *What got you interested in...?* ■ **Probing may include:** *Can you tell me more about...?* ■ *Can you tell me about situations when you worked with a person with a dementia who you felt was living in a risky situation?* ■ **Probing may include:** *Can you tell me more about what you thought was risky and why...? and How did you feel about /at that moment....?* ■ *Can you tell me about situations when you have been involved in risk management when working with people living with a dementia?* ■ **Probing may include:** *Can you tell me more about how you decided what to do ...? Can you tell me what happened next?* ■ *Can you tell me about something that you have been told or read that influences your work with people who are living with a dementia?* ■ **STRUCTURING statements/questions may include:** *I would now like to ask you about..A moment ago you were telling me about...* ■ **REFLECTING statements may include:** *It sounds like you have lots of experience of../..have thought alot about... how do you feel about...do you have any ideas about...?* End with **DEBRIEFING** time for : • review of key points • reflection & consideration of feelings • information for support as appropriate • confirming next steps in research process & checking informed consent

Appendix VII: Participant Consent Form

Sheffield Hallam University

Faculty of Health & Wellbeing Doctorate in Professional Studies (Health and Social Care)

Research Participant Consent Form (Ref:RPC408)

Please return completed form BY DATE to;
Sue Bower (Researcher) Older People's Services,
Address; xxxxxxxxxxxxxxx Email;xxxxxxxxxxxxxxx

Taking risks with dementia; Exploring practitioner accounts of risks and decision making

1. I confirm that I have read and understood the *Research Participation Information Document* (RPI408)	
2. I confirm that I have had an opportunity to discuss this project with others and find out additional information	
3. I understand that my participation is voluntary, that I am free to withdraw at any time without giving a reason and that if I do so information provided by me in interview will be removed and destroyed.	
4. I understand that my participation will involve taking part in 1 or 2 interviews (each approx. 60mins) which will take place within the trust, with exact place and time being negotiable.	
5.I agree that my interview(s) can be audio-recorded and transcribed, and the interviewer can take brief notes	
6. I understand that I will have an opportunity to check the content of these transcriptions before the dissertation is written up.	
7. I understand that some parts of the transcription from my interviews may be used as anonymised direct quotes in the dissertation document	
8. I understand the limits of confidentiality, as outlined in the *Research Participation Information Document* (RPI408)	
9. I agree to take part in the Research Project named above, as outlined in the *Research Participation Information Document* (RPI408)	
10. I agree to inform my manager that I plan to take part in this project	
11. I agree for you to contact me at the following work address/phone number/email:	

If you choose to consent, please sign to confirm in the 11 boxes above, AND sign below;
Name of Participant (Capitals)   Signature of Participant   Date

Name of Researcher (Capitals)   Signature of Researcher   Date
PLEASE RETURN COMPLETED FORM TO SUE BOWER AT ABOVE ADDRESS

Admin; When complete: 3 Copies: participant, researcher & academic supervisory team. Ident. no; PC

INTERVIEW TRANSCRIPTION 6 120908 ISOBEL

Occupational Therapist

Comm

Female

Ok so if we start you tell me about your experiences of working with people with dementia

Mmm ... I'll talk first about when because initially when I worked with people with a dementia it was mainly on the wards

Yeah

Based here ... and I did sort of half the wards and half community and also in memory monitoring and that was my first sort of experiences with working with older people with predominantly a dementia ...

Was that once you had qualified as on OT or ...

It was no it was when it was about my third rotation ... but the times before then I had worked in nursing homes but I didn't know the knowledge that I had

Right

1.00

...so it was my first sort of real as a therapist experience ... I remember thinking when I first went on to the ward ... I remember thinking ... my gosh because I could hear people shouting and you know crying and I thought my gosh I cant believe this is what goes on because it was like my first ... but I quickly quickly got into it and realised just how much I enjoy I'd always enjoyed working with older people anyway but particularly dementia because I felt it was very much particularly from an OT point of view when I got on rotation and the senior OTs it was all very a bit ambiguous and nobody seemed to really know exactly what was going on there's so much change going on so I basically didn't have much support there so I did a lot of reading about it and did a lot sort of a lot of research particularly around reminiscence and things like that and then that initial fear what I had when I first went on the wards ... I then had to support if students every came on and things like that

Right yeah

2.00

So it was good for me then to be able to say you know what its... I cant even describe what it was I don't think it was fear it was more the unknown more [than anything else]

[you mean like when you were] saying earlier oh gosh like when you heard the people shouting and that

Mmm yeah [because that was the]

[Yeah you talking about that] experience

Yeah

Yeah

For that … the main thing what I noticed being on the ward was … although it just seemed so institutionalised and the activities that went on didn't seem that therapeutic that were going on and the ward staff just didn't really understand why what was being done … why OTs were even on the ward so it's a real real battle when you're a basic grade to be thinking you know this is just not what I trained to do ((laughs)) I was very I think I was very naive when I did my training ((laughs)) but … I quickly sort of established a bit of a … a therapeutic programme that we did on the ward with specific clients and made sure that there was the availability to do one to one work as well as group work 3.00

Mmm

… so once I'd once I established that on the ward I also did home visits for the memory monitoring service and that was the first time I had come in contact with memory services as well … so I did … a lot … they would send referrals to do assessments … basically majority of them were home safety assessments

Mmm

And that really coming out of the ward was a real good opportunity to see actually people with a dementia in their own home

Yeah

And it really that was my first hand experience you could see that the difference how you could see someone in their own environment

Mmm

4.00

Which made a big difference … and that itself was… doing the risk assessments I did a lot a lot of reading about the safety of people at home because it seems as though those early experiences really meant that I had to ensure that someone's well being and safety were both met

Mmm

As much as I could when I did those assessments and I remember the first few that I did I remember thinking … what risks are there but the more I've heard and the more I went with other OTs it became a lot more apparent about the need to make sure people were safe … and the more I worked with people with dementia the more I wanted to sort of be more involved in it and … just to have more experience really … so that and then once once I'd finished that rotation I then got the senior position over at ***place name *** … and worked with adults

Mmm

5.00

And then when I'd done that and I'd had enough I really was waiting for a position to come up back over hear now I'd heard a lot about community mental health teams and the generic working

Mmm

231

And stuff like that but I thought there was something in that … I could contribute to as opposed to be quite defensive about it and when I got here a lot of my caseload now is working with people with a dementia predominantly with the ones that don't go through the memory monitoring because of vascular origin or whatever and I find … when I speak to other people in the team who aren't OTs the first thing they say is when they get people well what are we going to do and that's the first thing that's said and I don't think they realise that just because someone's got a dementia related illness they've not got skills and that tends the ethos that happens … oh what we gonna do

Mmm

6.00

I'll make sure the carers are ok and make sure … you know their environment's alright but in terms of the person and their skills not

Mmm

Not a lot seems to be done

Did you say earlier you think there's an you assumption that they haven't got any

Yes

Is that what you're [saying]

[very] much so …

Right

Very much so … so … a big part of my role here is when a referral does come is I try my best to go out with them with the nurses or whatever and look at that person's skills or what they can do

Mmm

And I did a presentation not that long ago on a piece of work I've been doing about reminiscence with somebody because a lot of what the ethos is as well they think oh reminiscence is literally just talking about the past but they don't see the skills or the benefits of that with confidence and self esteem [or whatever]

[Mmm mmm]

So those pieces of work I really really enjoy doing with people … so that's where I'm at now really

7.00

Mmm mmm … and if we just talk a bit more about risk assessment and risk management in particular … when you were starting to describe your role you talked about being asked to look at home safety

Mmm

Is that … would you say that's quite a big proportion of what you're asked to do still in your [workload]

232

[In the] role I'm in now yeah a lot of referrals that come to me are for home safety assessments and risk assessments to do with kitchen … whether someone's safe to still make their own meals

Yeah

Because a lot of the assumption as well is oh they've got a dementia they need home care

Right

And the reason I got involved with one particular lady is because one of the nurses came to me and said she wants to be able to make a meal but I don't know if she's safe enough to do it

Mmm

So when I went and I did quite a few sessions with her because I find often just doing one session with somebody's not you cant really get a good indication so I did quite a lot of sessions with her and we postponed for about 7 months having to have home care which really really worked
8.00

Mmm

Although everybody else was really not happy with it but the risks involved with her was not necessarily it was more worried I think that the family were that she couldn't do it and worried that because she's not gonna remember she's gonna forget to she's gonna leave the gas on or whatever

Mmm

But that worked really well

Mmm

But a lot of the referrals I do get are for home safety assessments

Mmm mmm … so what other things apart from is somebody safe to cook what other things [might]
In terms of risk

Yeah might you be looking at or would be asked to look at
I get a lot of referrals for bathing assessments

Yeah

To see whether they're safe to bathe … but I would say that a big chunk of them is for just a general home safety assessment

Mmm

Or a kitchen assessment that's about it
9.00

Mmm … and when you're doing the assessment do you see risk as separate to what you're doing or…
No

Do you see yourself as doing a risk assessment and then doing an OT assessment

No

So can you describe to me when you go to somebody's house how you go about doing the assessment

<u>How</u> I do it

Yeah

Erm ... ((laughs)) well prior to going I would make sure I know as much information as I could about the person before I went ... initially when I go and see somebody I explain why I am there

Yeah

What my role is ... what I will ask them to do and I normally initially just get a feel for about them

Yeah

And get a feel for who they are and what they enjoy doing and how they spend their time in the house

Yeah

And then they have the opportunity to ask me anything about and they tend to why am I here and whatever

Yeah

I would spend quite a bit of time I try and make sure that I leave at least 2 hours to go see someone to do a full assessment

Yeah

10.00

Some people might say that's a bit too much but I always try and just sit and speak to somebody first and that can take quite a while get a feel for what they do what they're good at what they have difficulty with ... what is it about they feel they're struggling with more than anything I will then ask them to give me a little tour of the house

Mmm

To be a bit nosy and ((laughs)) they're quite open to do that majority of service users ... I would then sort of look at each room individually I would do the general transfers

Yeah

To see if they're ok with that [I would]

[With their] mobility

Yeah while we go into each room ask them about are ok getting on and off the bed

Mmm

234

I would depending on what I felt was necessary assess that to see whether they are able to do it ... I would then if the referral was saying the more specific difficulties with cooking

Mmm

11.00

I would then ask them to make maybe a drink just initially just to see how they get on and assess that I would not probably do like a massive whole meal thing

Mmm

On the first assessment ... I would probably then arrange to go see them again

Mmm

To do more a more fuller kitchen assessment or ... and then through that probably things are identified where they may not be able to use the switch on the gas cooker

Mmm

Or they may not be able to turn the heating on in the living room

Mmm

Or ... they're having difficulty with locking the door or they tend to leave the door some things tend to be identified then and I would come back and do more of a fuller fuller risk assessment stroke home assessment

Mmm ... you mean come back ... what do you mean by come back and do that then

Just do another visit

Arrange to go [again]

[yeah]

Yeah and you [said that sorry]

12.00

[If there's] if there's any bits that ... because sometimes it can take a long time to A discuss everything at the beginning and then do a tour of the house by that time maybe they're tired and I would more than likely tend to do another visit because ... I may not have picked everything up

Yes

I may need to see them at a different time of the day to depend whether the risks are more or less so more than likely I always go and see someone again

Yeah yeah but you said that some people think even that is a long time that 2 hours

Yeah [yeah]

[and yet] you're saying it might not even be enough [time so]

[yeah]

Why do you think its justified that time where some body else might be surprised that you're spending that time on an assessment

235

Why do I think its justified

Yeah

… because I'm trying to do the assessment to the best that I can as a therapist

Mmm

I'm not just gonna rush in there and rush out because I have I'm not saying I haven't done that

Mmm

There's been times when I've gone to assess people and I've literally been there maybe half an hour and only done what its asked for on the on the assessment <mark>13.00</mark>

You mean you don't usually do what just what's asked for [on the]
[no]

Yeah

Never ((laughs))

((laughs)) so what else goes on then you were saying you try and be nosy

I try if say for example the referral says oh can you do a bathing assessment

Mmm

I tend not to do that because I still ask them to give me a tour of the house

Mmm

So I can go through what actually you know are they orientated are they good at problem solving you know all that

Mmm

… Just looking at that one thing I can always there's always other things that I pick up

Yeah

And I and it might be that although I've left those 2 hours

Yes

It might just take me half an hour they might want me out

Yeah

And that's fair enough

Yeah

But I do try and leave that time because I do not want because a lot of my job is recommending whether I think someone's safe to be at home or not

Mmm

And that is a big responsibility

Mmm

And I do not want to make that decision in an hour
<mark>14.00</mark>

Mmm

Or 10 minutes

Mmm … you said sometimes you have done that so what circumstances would lead to you doing it

When I know when I've had a phone call from … you mean when its been short

Yeah

When I've had a phone call about another patient that's in crisis

Yeah

Or something like that and I've had to leave

So for other pressures on you to get off and

Yeah

Do other things

Yeah its not been out of choice

Yeah

No not at all and I do always make sure that when I've done the assessment I come back and I try I always leave like a day before I write it up because I always feel I can never think properly once I've done something straight away

Mmm

So I write it up the day afterwards and there will always be a report

Mmm

And I've also I've often looked at other OTs and they do not necessarily do a report based on what they've found it literally just goes in the notes but I feel then that's really important to be sent to the GP to everybody that's involved

Mmm
<mark>15.00</mark>
So they know they've had an OT assessment

Mmm … and … what goes on in that time when you're thinking then

… a lot of reasoning really if there's … I often come across little just an example I went to see this lady and she had these really steep steps up into her into her kitchen of all places

Mmm

From the living room … and I was thinking well how … what's the best way to enable her to do that more easily so she isn't gonna fall down these steps

Mmm

Because she wanted she had the ability to go up and down them

Mmm

But it was more so the risk involved of her falling down them

Mmm

And I can remember thinking you know so a lot of that time is really problem solving and looking at I tend to as soon as I come away from somewhere I look on the internet and look for maybe ways to solve that problem or ring other I often ring maybe other OTs and say I've got this issue [and can]

[mmm]

16.00

What would you do about it another lady I went to see last week I'm going today to see her again actually she has real difficulty … she had a stroke and although she's not got complete full … functioning she also has a dementia as well that she finds getting into bed very difficult because of the position of the bed and they can't move them … she's already got a grab rail on the bed I came away and I thought and I tend to say to people I'll come away and I'll ring you or I'll think about it … and I came up with a bit of a plan about a slide sheet which would enable her get up the bed a bit easier

Mmm

And I often when I'm there I kick myself a bit sometimes because I think I should know this I should know this off by heart and should know it straight away … and I beat myself up sometimes because I feel like I should know the answers instantly

Mmm

And then realise that time before I write the report is that vital reflection time

Mmm

17.00

And reflecting on whether I think I've done a good assessment

Mmm

Do I need to go back again

Mmm

Am I not 100 per cent sure about it

Mmm

And if I'm not I will go back again

Mmm and you say some of that is with yourself reflecting on yourself
Yeah

But sometimes it might include talking to other people [about things]
[Yeah] very much so and I always try as well if there's family involved

Yeah
To get them there at the assessment

Yeah

Because they really you know you get a lot of rich information [from them]

[yeah]

Particularly at times where they say they're leaving the door open on a night

Yeah

They're opening the door to strangers

Yeah

I wouldn't know that if they weren't there

Yeah … so… in some instances might you get a different story from people's family than you may get from the person themselves or is it [the same]

[Normally] always

Always

Yeah

Not just sometimes

No its normally always

So how do you manage that then getting conflicting information from people

… manage that in terms of explaining it to the service user or
18.00

Or how you make sense of the risk assessment if you're getting different sorts of information from people

Mainly I try and get the information A from what the service user thinks

Yeah

And also if there's any other professionals involved that they may have … come in contact with

Yeah

I do then try and go at a different time as well to see if they're any more confused at a certain time or if they're having difficulty or is there a time when they're better … to see to see what the differences might be … and often you tend to find that families because we do do a hell of a lot of work with carers and families

Mmm

In this service more so that I've ever worked really … I think really its weighing everything up

Mmm

And looking at in certain circumstances what are their skills like the patient

Mmm

... and would they ... what is what they're saying the family necessarily relating to their skills in a certain area
<mark>19.00</mark>

Mmm

Its really I find that bit very difficult because like when I'm doing the report I can only say family have noted that or that family have stated that

Yeah

I don't know that 100 per cent I can only go on what they are saying

Yeah ... yeah ....

And that I do find that bit quite difficult

Yeah ... and in terms of things that you think may be a bit riskier and need managing in some way

Mmm

Is there ever any difference between how you see that and a family carer may see that

Yeah ... a lot ... we ... just one prime example was a lady that I went to see and her family wanted her to go into care

Yeah

... and I sat there and said I can not advocate that I think that's the right thing to do I think yeah fair enough you are concerned about these things

Mmm

But I feel that she's got too many skills and her mental health may deteriorate further if she was going into care

Mmm
<mark>20.00</mark>
There are strategies that we can put in place

Mmm

And its very hard to try and get some family members to see that taking those positive risks

Mmm

Can be really beneficial in the long term

Mmm

But they tend to ... tend to label somebody and then think well the prognosis isn't very good therefore they're gonna end up in a home anyway

Mmm

And you hear that even in the office

Mmm

Very much so

So you're saying some colleagues feel that way as well

Mmm very much yeah … and it … the positive … I think as a therapist and social workers tend to take the positive risks more so than the nursing staff and they'll instantly think no there are at risk therefore they need to be out of the home … and we often get I don't do them but the nurses often get asked to do a mental health report for … to determine whether someone's gonna needs EMI care or respite care

Mmm

Sorry residential care

Mmm

21.00
And that's a massive decision to make

Yeah yeah … if we just go back to carers…

Mmm

Why do you think…there may be that difference in how they feel about positive risk taking you were saying that it tends to be quite often difficult for carers

Mmm

To feel the same way that you may feel about positive risk taking

I think because they see that person a hell of a lot more than I would

Mmm

… and I think it comes because they're family because they're more they don't want something bad to happen to their relative

Yeah

They don't want … and I … I've often when I've done an assessment and I've gone home and I've thought you know if that was my mum I wonder how would I would feel

Mmm… mmm

And that I'm really really big on reflection and I often try and write everything down that I've reflected on and I often I'll ring my mum and I'll say you know I went to see so and so a lady today and you know if it was you I think I would feel exactly the same
22.00

Mmm

And that for me is sometimes very difficult

Mmm

Because I have to empathise and say I understand how you feel but as a from a professional point of view I feel this would be beneficial to you mum or dad

Mmm

Whatever … so I think its having that understanding that they are going to have those feelings and those … worries

Mmm

And … often if you acknowledge that for people and acknowledge that they're concerned about certain risks

Mmm

… 9 times … well half and half sometimes they do come round to what your opinion
Mmm … but you said it may be because they don't want anything … bad or hurtful [to happen]
[mmm]

To their family

Mmm [mmm]

[So how] do you manage you were saying that you might talk to your mum or somebody and say well if it was you I might be like that but if you're … after you're assessment you're talking about positive risk taking
23.00
Mmm

What do … what do you do about thinking about the fact that some harm could come to somebody … how do you manage that

…… that's something I … I find really really difficult

Mmm

And I would be more concerned about somebody that lived alone

Mmm

As opposed to somebody who lived with somebody … but … harm can really come to … to anybody really

Mmm

If they're living at home … I go see people who have schizophrenia and bipolar and they can be more at risk than even people who have a dementia related illness

Mmm

… so for me its really weighing up everything and looking at their life as a whole to determine whether that that the thing that I'm saying that … they're they could live with or they could live using the cooker
24.00

Yeah

Because that seems to be a key thing … and putting strategies in place that might that might help or may help the carer to sort of relieve the stress in a way

Mmm

But for that … I often use colleagues and I often use supervision and reflection

Mmm

And speaking to people have I made the right decision

Mmm

Because I often question the decisions I've made

Mmm

Often particularly when it comes to risk because I do not want to be the one that in the back of my mind I think … well I've done that but are they gonna be safe

Mmm

And I do question it a lot …

But you go to colleagues and use it in supervision
Yeah yeah … [and I will]

[but also]
Also get if I'm not 100 per cent sure will get a colleague to come out with me

Yeah …yeah
To just see what they think as well
Yeah … but earlier you said that your colleagues might see things quite differently to you so is that why its useful to have colleagues <mark>25.00</mark>
Yeah both really if I would ask one of the other OTs from the other the other team

Right yeah
To maybe come with me or its sometimes useful to have their perspective as well

Mmm
Because they do risk assessments

Mmm
And they look at it … maybe slightly different

Mmm
To me but its useful to have their take on it [as well]

[Mmm mmm]… you just said that cookers are key sometimes
Mmm

They figure a lot in risk assessments
Mmm

What is it about cookers you think that they figure so much [in what you have to do]

[The main] yeah it seems to be that nearly every person I go to that has a dementia and their carers are saying oh she cant use the cooker she cant use the cooker and when you've assessed they can use the cooker perfectly fine but it's the fact that they leave the gas on and that's the that's the main issue

You mean

For people

The idea that there might be an explosion

Yeah

Yeah

==26.00==

Yeah and the worry that they leave the gas on and there's a fire and they can end up dead because the gas has been left on

Yeah

And that's people's main concerns but again with that straight away often people just want to isolate the gas straight away

Yeah

And not look at possible alternatives to manage that risk

Yeah

So they could the person themselves can you can give them some empowerment to be able to help manage that risk for themself as well

Mmm

But no a lot of particularly other people in the team want to isolate the gas straight away

Why … why do you think they … assess the situation differently then the level of risk differently… or the way that it should be managed

Yeah

They think its different to you

… I think a lot of its to do with the profession and the training that they've gone through

Mmm

… and they tend I think other professionals may not look at the skills somebody has

Mmm

They look at what's … how do I say it … they look at what risks there are but not the skills what they may have to manage that risk
==27.00==

Mmm

Do you know what I mean

Mmm

244

... they tend not to look ... I've been sat in many many meetings and its never about what the persons skills are and what they tend to be good at

Mmm

I think that's the main the main difference

And you think that comes out of their training

...... I think so because a lot of I think nurses training is about <u>managing</u> and not ... and managing the deficits or managing the not ... the other week I said to one of my one of my friend who's a psychiatric nurse and I said to her what is your role what do you do ... and she couldn't answer me and the first thing she said was monitor ......

Mmm ......

<mark>28.00</mark>

... Monitor what monitor medication monitor mental health and ... it wasn't it just wasn't specific but I think that's the main one of the main differences is ...

So if she had asked you ...did she ask you

No she didn't

What would you say

I don't know I would have probably said same thing ((laughs)) I don't know

((laughs))

Yeah ...,

Can we go right back there's something I'm interested in that you said really on was about wellbeing and safety

Mmm

Cos you started off talking about home safety and being asked to do all these things

Mmm

But then you started to talk about wellbeing and safety and you've not really said much about wellbeing since then can you say a bit more about

Mmm

What that's how that fits in to risk assessment and risk management

... for me ... I feel as though wellbeing is like ... I wouldn't say its above risk I wouldn't say its above safety but I think its very very parallel because if you've got a pa ... you see everybody uses different terms patient

<mark>29.00</mark>

Mmm

Service user but I'll say patient ... that you know really wants to stay at home or really want to be able to go in the garden

Mmm

But they cant go in the garden because their family think that they shouldn't be going out because they're gonna wander off

Mmm

To take to lock that door and to take that away from that person because yeah that might be risky that they're gonna wander off

Mmm

... I'll give you a specific example ... one of my one of the ladies I went to see often walked around the neighbourhood

Mmm

And came back ... she'd leave the door open

Mmm

But she'd always know to come back

Mmm

She knew exactly the route she'd taken so I said to her once let's go and I went with her and she took me the route she knew exactly where she was going she come back the thing that she wasn't that she was forgetting was to lock the door so the family said no she can't go out because she's just gonna leave the door open and she did actually get burgled one day ... but the fact is what my point was ... this lady she gets a lot of ... you know satisfaction from going for this little walk and it meant a lot to her and she every time I went she'd often speak about I've been for me walk this morning she'd do it every single day <mark>30.00</mark>

Mmm

And to her to take that away from her was a big ... a big chunk out of her wellbeing you know a big impact on her wellbeing and my ... it got quite heated between me and the family because that's what I was saying to her there were ways that we would be able to try and look at her maybe shutting the door or but lets not rule those out

Mmm

For now ... and for me that cross over between risk and wellbeing was really really significant that

Mmm

So I did a bit of a reflection about it and ...... but it was again family saying but she's not but she'll get used to it she'll get used to it but why should she get used to it because that meant so much to her life <mark>31.00</mark>

Mmm

And so much to her the meaning of her life

Mmm

She'd always been a walker

Mmm

Yeah she doesn't go up to the ***local countryside area*** like she used to but that meant so much to her

Mmm

And if she wasn't doing that … its gonna have a big impact on her anyway it turns out that they had enough money to go private into a home and I said well if that's what you're gonna do make sure she still has that opportunity to go and have that walk

Mmm

Because that meant a lot her

Mmm

So for me … its getting that balance between wellbeing and safety

Mmm

… And that for me can be really really difficult

Mmm

Because you know we often go see people to determine you know do they need homecare

Mmm

To help them get washed and dressed

Mmm

Do they need homecare to and for that person … putting their shoes on in a morning getting dressed might have a big impact on their wellbeing if somebody was going and doing it for them and lets be honest that's what homecare do

Mmm

<mark>32.00</mark>
Because they don't have the time to enable somebody to do it themselves and you get … I did homecare for 3 years so I know the time factor is you just cant do it so you're going in and you're doing taking that independence from someone

Mmm

And when I was at university I was completely going against what I was training to do

Mmm

I was taking someone's independence

Mmm

So that … those first hand experiences of doing homecare I know how it was

Mmm

To take someone's wellbeing away from them …

Mmm ... do you see a direct relationship between taking somebody's independence away and taking ...wellbeing away

I think so yeah I do

Yeah

Yes because I think particularly if the clients that I've got if they were taken away from one of those tasks that they do on a daily basis that has meaning if that's taken away their wellbeing is ... has been effected in someway

Mmm

33.00

But for everybody you know the definition of wellbeing or what wellbeing means is different to everybody

Mmm

And ... but I do think that the safety the risk and managing and maintaining someone's wellbeing is a fine line

Mmm

And sometimes I ... I struggle with that

Mmm ...mmm...

I really do and I think many people do

Mmm ......how do you know that people do ... other people

Because when staff are saying you know she should go into a home or he should have homecare but then he's not gonna let them because he wants to do it himself

Mmm

And ... I don't know if it's the right thing to do

Mmm yeah

So its really just hearing other people say it

Mmm

And ... my ... my mum's a social worker so I often have conversations with my mum and she ... she'll say that she has the same sort of feelings

Mmm

About ... she works with people with a dementia as well
34.00

Mmm

And having to make that decision that someone's going into care is very very difficult for her

Just talking about decisions and care ... are you asked to be involved in those sorts of decisions as well

Yeah

Directly

Yeah … I have often gone out with … with the nurses as an OT to determine whether somebody needs should go into care or … whether its got to a point where someone can not be managed safely at home any more and then … we are thinking about that I have not gone out directly gone out and … the nurses will go out and recommend which home they should go in to

Mmm

Either EMI or residential or nursing home or whatever

Mmm

I've been there but I've only been to determine whether what's someone's skill level is

Mmm

And to determine the behaviour or whatever and see how that might … their needs might be met in a certain home
<mark>35.00</mark>

Mmm

But I do not enjoy doing that at all … at all

What is it

I'll be honest and hold my hands up I hate it and if one if a referral comes through for that … I've even spoke to my manager and I've said … I'm only going to do a certain bit of it …

Yeah

… I do not feel that I … I don't feel comfortable with saying someone should have EMI nursing care someone should have residential care so that decision I'll speak to the nurse about it and we'll have a discussion about it and yeah I think that's alright I think that's just a massive decision to go and make in one… one hour ……I think its outrageous to be honest … and that's what happens …

Is it the actual decision or the time or what is it … because you said you hated it … and you feel uncomfortable about it

I really feel uncomfortable about it because I think you know to… all you doing is going and speaking to somebody because when … when they do when they go … when a nurse and I remember when I first came and I went out on one with a nurse all they did was speak to them and the family they never saw them functionally … they never saw them doing a doing an activity
<mark>36.00</mark>

Mmm

It was literally hello … how do you get on … it was mainly the family speaking to family and then oh ok I think I think you need EMI nursing

Mmm

Or you're alright in residential … and its probably got a to a point where yeah family think ok they … all social services have been exhausted and we've had home acre we've had day care and its not working

249

Mmm

That's fair enough

Mmm

But I do think they need to be researched a bit more

Mmm

Before making a decision

So the nature of the assessment is that you are saying is one of the things that makes you feel uncomfortable

Yes [it is]

[That] its about talk [rather than]

Yeah and it no its about having to make that decision whether someone goes in to care …
`37.00`

So[who should be making]

[Not whether] should they go into care but which type of care they should go into

And who do you feel should be making that decision

I think that decision should be made collaboratively as possible with the with whoever the key worker is the family or whatever but I think what happens is as a mental health service we go in and say oh yeah because of this this and this they deserve they should go into EMI

Mmm

Without discussing that with the service user or family

Mmm

Do you know what I mean

Mmm

And its very much well because we are professional we know best … well I don't think we do

Is that explicitly said or is that the feeling that you get that [professionals]

[I get the] feeling I get the feeling

Yeah
`38.00`

……and you know particularly for carers they are the ones that live with somebody who's got a dementia day in day out and they're the ones that … that know what their wishes are

Mmm

How they work what makes them tick what they enjoy in life but … when you look when you look at one of these … I'll have to email you them actually ((laughs))

Yeah ((laughs))

When you look at one of these … they're called nursing reports that's why I don't actually fill them out but I have been out to go out and do one

Yeah

And I said no because I am not a nurse … there's you know mobility … mental health … communication blah blah blah there's nothing anywhere about what they enjoy doing what makes … what hobbies they have what fills their day routine nothing like that

Mmm

It's a case of what they <u>cant</u> do

Mmm

Which means they want a certain type of care

So they're looking that's the focus of it you're saying is what cant be done

Yeah

What that person's not able [to do]

[yeah] … do they have any problems with behaviour … do they have any problems with communication do they have any problems with mobility <mark>39.00</mark>

Yeah … yeah

……and ……I've been on them because I was interested to know what they how they make the decision that they make … and I've often been part of making a decision because when its obvious when its so clear that somebody can not be at home any more because they are just so unsafe

Mmm

Or … then I've even put a part in that report although its done by the nurse I've said can you please ensure that in this report you say which ever home is chosen that they make sure she can go out for a walk that they can make sure that she's got this activity to do on a daily basis

Mmm

… but that's not included if an OTs not involved in that

… why do you want to make sure that it is included what is it that's important about it for you

For someone's personhood for someone's wellbeing for them … because that is such a life changing event to go into a home <mark>40.00</mark>

Yeah

And I don't think people realise … they just … I hear so many … she's got dementia therefore it doesn't matter anyway … and it … and it … sometimes I go home and I when I've been to do assessments and I feel really upset because oh my gosh they're going to go into this home and that's it feels very much like that's it for them

Mmm

And I think the consensus is if they got it well that's it then … you know … so I felt well I've only done like a few but I've put this little bit in because I feel they need to take some of that dignity with them they need to take some of that person what makes them them

Mmm

With them so they can carry on being that [person]

[Mmm]… and what do you think happens if they don't do that if they cant do that
<mark>41.00</mark>
……Well they … that question is a good question because I think well what would it what for me if I went there

Mmm

I would no longer be able to see my husband I would no longer have my car I would no longer have all the things that have meaning in my life

Mmm

And that's gonna effect my mental health I'm going to feel depressed I'm going to feel emotional I'm gonna be angry at everybody

Mmm

And that's another thing when people with a dementia are verbally aggressive … aggressive medication give them medication and that'll help it but no one ever looks at what it is about that they're angry because there not just angry for no reason

Mmm

But ……oh …

So when you think about yourself do you think that's what may happen to these people when you imagine it for yourself is that what you imagine for people who are going in where these things aren't looked at in terms of their [personhood]

[I feel] so because regardless of whether they have they have a dementia they're not they've not turned into a vegetable
<mark>42.00</mark>

Mmm

They've still got needs they've still got a life they've still got desires they've still got dreams like everybody else

Mmm

And if they aren't maintained how are they gonna be the person that they are if nobody looks at those specific things about a persons life

And have you seen examples with people where those things aren't looked at

… In … in this report we … there's … there's nothing about what their selves are what they are able to do what you know please make sure they've got a TV in their room or please make sure they've got their books ready or please make sure that she has she has opportunity to go for a walk at 11 o'clock everyday because she's done that for years

Mmm

There's none of that in the report it's a case of because of her behaviour she's not she's verbally aggressive she can lash out at people therefore she need EMI nursing care

Mmm

…… and that's what its about

Mmm

<mark>43.00</mark>
So I said to my manager the other week I am not ……I'm not happy about the way these report are done

Mmm

… and I feel I have a good contribution although I don't like it I feel I have a good contribution to make in terms of … as though I'm an advocate for that person as though that's not even been looked at

So are you saying even though its something that you hate doing
Mmm

You're going to be doing
No I don't have to do it

Mmm

But shall I say I feel I … I don't know its something I hate but then on the other hand I feel I have a good contribution to make as a therapist to be involved in

Mmm

Does that make sense

Mmm … yeah yeah ……
But I hate doing it ……

Yeah
((laughs))

You know if people are in that situation and you were saying that there's its sometimes obvious that somebody cant stay there
Mmm
<mark>44.00</mark>

253

So you're looking at that transition really

Mmm

From home

Mmm

What sorts of things do you think in your experience make it obvious … what sorts of things happen to make it obvious

That they cant no longer stay [at home]

[yeah] yeah

… if they … its really hard to give typical examples of people … in terms if the risks are too high

Mmm

If they're constantly leaving the door open if they're if they're not locking the door if they're falling

Mmm

All the time … if they're …… it's a really difficult question …

It was just that you were saying that sometimes it just seems obvious when its got to [that point]

[yeah]
45.00

I just wondered what the [in your experience]

[its really]

Makes it more obvious

Yeah

When in some cases its not as clear

No I think when its got to a point where … if all the if all the resources have been exhausted

Yeah

Like day care

Yeah

Maybe respite

Yeah

Home care befrienders where they aren't working any more … and that person may ……there was one lady … I'll have to do an example because I cant think off top of my head
((end of tape and turning tape over)) …

Can I just stop you there while you doing … ok so you were going to give me an example
46.00

254

There was one lady that I went to see … and home care rung me extremely concerned about her … she was … she was going out of the house on a night with no clothes on walking round the streets with no clothes on … she didn't have any family she didn't have any neighbours that sort of looked out for her … she had homecare but they only came on a morning and on a night she would have cigarettes and throw them straight on to the floor … the carpet was completely burnt she was extremely extremely incontinent … and she'd had I don't know how many continence assessments but that wasn't working … she was eating cat foot she was opening tins with forks … really … there was just a lot going on … my first … impression really was to try and get her to somewhere safe so she eventually was brought the next day she was brought to brought into hospital … and that was the first time I have ever brought anybody into hospital

<mark>47.00</mark>

Mmm

… because of the risk … at home

Mmm

She was falling all the time as well …

Mmm

And it was about ok she does have homecare she has all these services coming in but at that point nothing seemed to be you know you weren't gonna stop her from trying to … you know from going out on a night

Mmm

You couldn't lock her in and walking around the street with no clothes on that wasn't gonna stop

Mmm

So I just wanted to get her out of there as soon as possible and eventually she did from hospital go into a home

Mmm

The hardest thing for me I will be honest at that time was trying to convince her to come to hospital …… and a colleague came with me and a colleague said to me you don't have to tell her that's where she's going just tell her that she's going for a ride …

<mark>48.00</mark>

Right

…… And I said how can I not tell her that's where we're going … so initially she was oh no I'm not going I'm not going I don't need to go I don't need to go … but I told her that she'll be safe you know we'll look after because she had a cat and the most thing she was bothered about was the cat

Right

… and I said the cat's going to be fine lets … and she had some photos of it lets take the photos of the cat we'll look after the cat and that was the main thing that she bothered about

Yeah

So as soon as I said to her that the cat's gonna be ok she was fine she got her shoes on and she came but for me when we got there ……although I you know I'd said to her we're going to the hospital I want you to see one of the doctors she was ok but when she got there and went on the ward she started screaming and that broke my heart that was one of the hardest things in this job that I've had to do … was taking someone out of their home where they love
49.00

Mmm

And putting them in hospital

Mmm

But it was … and even then I questioned whether I'd done the right thing … all the way home at night I couldn't sleep I couldn't sleep because I was thinking my gosh was I over the top could the risks have been managed … have I brought someone into hospital when they didn't need to be there

Mmm

And it was horrible for the whole weekend I just couldn't sleep on a night I was thinking I don't know if I've done the right thing … and that's why when I went to her initially I got the GP out to determine whether she'd got an infection whether there was something medical causing her to be so poorly and so confused … it wasn't she was <u>so </u>incontinent to a point that the sofa had to be removed because it was just saturated

Yeah

And I said to the GP please can you just get her into hospital but he wouldn't take her because she was refusing to go

Mmm

50.00
So the only thing that we could get to this to sort out was getting her out of there and getting her into hospital so test could be done

Mmm

……I debated and debated so when I went to go get her and hopefully convince her to come to hospital I took a colleague with me

Mmm

For her to see how she was for her to see how she was doing in the home

Mmm

I mean she wasn't feeding the cat she wasn't and there was no family available or anything … so for me when I thought that afterwards I thought no you wouldn't have made that decision if you didn't think it was the right thing to do

Mmm

For this woman to be safe

Mmm

But … it were … for weeks afterwards I thought oh I don't know if I've done the right thing but I've rung when she'd eventually gone into the home she was really really settled

256

Right

Really happy … not distressed whatsoever so that put my mind at rest

Yeah yeah

So that was the only time that I've ever had to bring anybody out of their home and know that they're probably not going back
<mark>51.00</mark>

Yeah …. have you been in situations… where people have refused but still had to go into a home or hospital against their wishes … because you said she was this lady you were talking about she was ok once she felt ok about her cat

Mmm

She would go with you

Mmm

Have there ever been examples of people who [wouldn't go]

[yes] I haven't I haven't myself been involved

Mmm

But I know that …… I know of cases

Yeah

Within the team where that's happened

Yeah … what about services have you recommended services or changes to people's home environment that they've not wanted to happen

… yeah like the lady … particularly the lady who who eventually went into care but that was down to her family who privately organised for it … we you know I came up with lots of solutions of how she could still go for the walk we could try and get some equipment for the door to make sure she locks the door
<mark>52.00</mark>

Mmm

And things like that they weren't having any of it

Mmm

They'd already made the decision that she was better in care

Mmm

So all those things that I'd spoke to them about

Mmm

And even gave them catalogues about and leaflets and … you know even … saying to the Alzheimer's society and get some support from them

Mmm

They ... no and the end of the day they had power of attorney and they had decision ... they had to make the decision what they felt was best for their family member

Did that occur because she was seen not to be able to make those decisions because of capacity

...power of attorney

Mmm

Yeah ...

So ...

And we often do ... we often have to make ... we often make ... do mental capacity act assessments as well

Right right

<mark>53.00</mark>

...But again what is difficult for people to get their head round with capacity is they think if you can not make a decision about your finances that means you cant make a decision about anything

Yeah

And ... what's difficult to get across to people particularly who aren't in mental health services is that that's not ... that's not what its about its about whether they can understand that information about that particular decision

Yeah

Not about everything

Yeah

And its normally to do with finances

Yeah ...... just in relation to the capacity and the guidance and other guidelines that are around is there any particular guidance from anywhere that you think influences your practice or colleagues practice in risk assessments and in risk management

<mark>54.00</mark>

...... that's a really difficult question ... when we initially go out and see somebody we'd always do the sainsbury's risk assessment that <u>has</u> to be done

When you initially go out [you mean you're doing it when you're round] there or you actually do it when your with somebody or ... [before] or

[initial assessing] [I tend to do it] no when I when we initially go out ... I would and maybe depending on the time or whatever I try to do it when I'm there ... and look at and that's mainly about do they have past suicide risk

Mmm

Are they at risk themselves ...

How does that happen then ... you take some paper with you that has the assessment on [or is]

[yeah]

Yeah

Yeah

Yeah so you write in that as you speak to somebody or ...

I would ... normally when I go to see somebody ... and they may ... there is a possible diagnosis of a dementia

Mmm

I will ask any family member to be there if they could

Mmm

I will discuss it sort of all of us

Mmm

And see do they have any history of this do they if there's bits that they don't know of I'll just come away fill the bits in that I can and then try and look at the rest
55.00

Mmm

But we have to do that

Mmm

It's a standard within the service

Mmm

And then HONAS as well

Mmm ... so you're doing HONAS and sainsbury's

Mmm

And is that in addition to what you're saying is...getting a tour of the house

Yeah [yeah]

[And] observing people doing [things]

[we] don't have any as far as I'm aware a standard risk assessment for home assessments as an OT

Mmm

That's what we would do as a mental health practitioner anyway

Mmm

But no not that I'm aware not that we use here ...

Mmm ...

There's nothing standardised

Ok

As far as I'm aware

So what you described earlier is what happens next after the HONAS and the [sainsbury's]

[yeah] yeah I would do that because obviously I … I with it being a community mental health team I do see people … as a mental health practitioner
<mark>56.00</mark>

[Yeah]

[Initially] … and would do that … but 9 times out of 10 there's always an OT bit of a need somewhere

Yeah

So if … if that's the case I would just visit them next time

Yeah

And maybe do a … a more home assessment

Yeah yeah

With the more practical risks because that's not really that assessment is not really about the practicalities or the functional risks that somebody can have on there there's nowhere about can they make a drink

Mmm

Or can they turn off there's none of that that is really about their mental health

Mmm mmm …

And I think what happens is … if there is if a nurse goes out and does that they would not automatically do the other assessment that I would

Yeah

…… so that's where the difference is
<mark>57.00</mark>

So that could change how somebody's risk assessment's done then is that what you're [saying]

[Very] much so very much so

Yeah … depending on who goes

Yeah … yeah but I think that's the same even with home … home assessments or risk assessments I do really believe that it differs whoever's the assessor if I went out and maybe you went out we might agree on some things

Mmm

But for …… she didn't understand how she used the … microwave or she didn't know how to use the vacuum cleaner properly

Mmm

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And kept you know its we may see that slightly different

Mmm

And the level I think the level of risk as well … to what degree and what severity the risk is I think whoever's doing it it differs as well

Why do think it differs

… people … I think it comes back to the positive risk taking because if somebody if I went with somebody and they felt that wasn't that risky but I felt it was … just thinking of whatever to give you an example of it like dosette boxes

Mmm

… not everybody has them

Mmm

And some people manage them quite well but then some people will think well she is remembering to take them but she's taken 2 tablets or you know it depends what someone's interpretation of how risky that behaviour is

Yeah

And I <u>do</u> think that differs between people I don't know why that is but it does maybe that's from past experience maybe its from the profession that they've come from maybe its their desire to do the job

Yeah

You know but I do think it differs

But you because earlier you said some of the differences might be from profession
Yeah
But now you've … but you are also saying that there might be just the difference between <u>people</u>
Yeah

I terms of how they understand a level of [risk]
[yeah]

And then what should happen [next]

[yeah] I don't think … in terms of … home risk assessments …other disciplines are as clued up … <u>whenever</u> a referral comes in and says are they at risk at home they refer it straight to me

Mmm

They don't think that that's their department they don't think that they can look at someone's risk in the home now I know fair enough I am more equipped to do that

Mmm

... But I still think there's a big chunk missing where other people other disciplines don't do it

Mmm earlier you mentioned social workers

Mmm

That they might be ... more similar

Social workers tend to do a lot ... in the 2 professions I think in team that I'm in because we have nurses social workers and myself ... we think a lot more on the same wavelength

Mmm

A lot more they will want to keep somebody at home as long as possible as I would whereas predominantly nurses would say no there's not safe
<mark>1.00.00</mark>

Mmm ... do you think there's difference within the profession as well or do you think it is mostly about the difference between professions ... individually because you thing some of it might be about [people's experiences]

[I do]think ... yeah I do think individually as well because if you've known of a past experience where its either gone wrong or you've took a risk and its not worked out

Mmm

I think that's definitely gonna influence what you think

Mmm

Definitely

No matter what profession you are

Yeah yeah definitely ... and I do and I think it also may differ if you've worked in adult services

Mmm

Well I know it does

Yeah

Because when I came over here

Mmm

Seeing a pen on the table I nearly had a fit I were like there's a pair of scissors out because that just wouldn't over there never in a million years would you have a pair of scissors out it just wouldn't happen unless you were in a structured group with 2 members of staff and only 3 patients

Mmm
<mark>1.01.00</mark>
And when I'd go out and do assessments with people coming from over there

Mmm

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Well they've said they're aggressive shouldn't we go together

Mmm

You know so it shaped my thinking about and I was really when I first came a bit over top with risk to be honest in terms of … you shouldn't go alone because they've been abusive towards you or you know don't if that's a male and he's being sexually inappropriate then you should go … do you know what I mean

The idea of people themselves being risky [you mean]

[Yeah] yeah

And are you saying that's changed then … for you

Yes it has it has changed because I'm now in a service where the risks are different its not necessarily about whether they you know they've got a past history of … using a knife

Mmm

Or past history of sexually inappropriate behaviour

Mmm

Or … that tends to be very much as though … oh well no they don't really need … if they have its oh well they're over 65 therefore they're not gonna be risky 1.02.00

Right

… you know and to me I was I couldn't believe it when I was once it was when I first started back here and we were sat in an … in a CTM meeting and this woman was being really really manipulative and really telling one person one thing and telling one person one thing

Mmm

So it was concluded that you should really go in twos because she was accusing people of

Mmm

Now if that had have happened in ***name of previous place of work*** there is no way you would have ever been in a situation where you were on your own with that client

Mmm

But over here …

Mmm

And I said but there needs to be consistency one person cant be going in and then two going in at another time because that's not that's giving conflicting views to the service user

Mmm

But no nobody agreed with me at all

Are you saying that's about somebody's age you think that's about assumptions that are made about [people's age]

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[I think] so it was it felt as though oh because she cant well what's she gonna do she's not gonna hit you or she's not gonna get up and get her stick and hit you <mark>1.03.00</mark>

Mmm

And to me that's not the point

Mmm

You know these are risks you know this lady is accusing people of stealing or accusing people of saying something to the doctor then you need to go in twos

Mmm

Because you've got nothing you know nobody everybody just thought I was being really OTT

Mmm

And I don't and I think that was because I've come from somewhere where risk assessment was before anything

Mmm

Anything you did you had to have risk assessed it you know when I first went in took a patient into the kitchen there would never be any knives out there would never be pans out it was literally just … maybe we'd do some baking or something that involved just the hands

Mmm

You know so for that and then to come here and you know … I don't I'm not saying its not taken as seriously but I do think its … I feel its because oh well they're old they're not going to do anything anyway <mark>1.04.00</mark>

Mmm … because most of the risks you've talked about in the last hour has been about people being … at risk
Mmm

People with dementia being at risk
Mmm

Not so much about them being risky [to other people]
[Presenting risks] yeah yeah

But this [we're talking about in terms of]
[I just realised that] yeah

Adult services
Yeah

What you [were bringing]
[Its] yeah that's true

Yeah

I've just realised that

And that's what people are not looking as much at you're [saying]
[yeah]

In older people's services
Yeah

Them being risky to other people
Yeah I think so

Yes

I think so and its more that if they are aggressive or disruptive or whatever its quickly medication given

Yeah

And then [it'll sort it out]

[yeah which is what you said] earlier yeah
<mark>1.05.00</mark>
Yeah but I yeah I was really it took me a long time to get used to it and even just going out to see somebody you know … that had presented as … I remember when I came for the interview and one of the questions was if you got a referral on duty where somebody was presenting as aggressive violent … what would you do I said I'd get all the information I said I would go out with somebody else

Mmm

And they asked well why would you go out with somebody … because they presenting as violent if your client is six foot odd

Mmm

Man who's got full mobility and they try and crack you its gonna hurt

Mmm

But they and they asked me why would you go out with someone else

Yeah yeah

Because in my mind I had … the risks to yourself and other people in my mind all the time

Yeah

All the time

Yeah

But I think its very much … there seems to be this divide where if you've got schizophrenia or bipolar lets look at the risks to yourself or other people

Mmm

If you've got dementia lets look at environmental risks

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Mmm

And that there seems to be that clear distinction its really strange
<mark>1.06.00</mark>

Mmm … about the focus of risk [and what]

[yeah]

What the risk assessments [about]

[yeah]

And how you manage risk

Yeah

And you think you're … you focus on those things more than anything else

No it's the feeling that I get

Mmm

That it tends to be more about ok well are they gonna fall

Mmm

Or are they gonna you know not so much that they …they have a dementia therefore they may … … have some depression with it

Mmm

And may want to harm themselves

Mmm

It doesn't tend to be like that

Mmm

It tends to be more are they gonna leave the gas on are they gonna do you know what I mean

Mmm

Does that make sense

Mmm mmm yeah … I'm aware of time

I've totally babbled

No you haven't at all

What time is it

We've just done over an hour and 5 minutes

Right I'm gonna shush now

No I don't want you to shush … I'm just aware of your tome really

Yeah

And I don't want you to be running late but I did want to say …
because you've said a lot but is there anything else you want to say
No [I don't think so]

[about risk and risk management and decision making]
No ((laughs)) I've talked enough

Ok thank you

Appendix IX: Transcription Notations

- WHAT is said
- HOW is it said
- This is not linguistic research
- Not NEUTRAL; my transformation to text
- Acknowledging the COMPROMISE
- Accessibility to readers; READABLE
- Analytical interest; USEABLE
- Listening again
- 'Jefferson Lite'

What I am 'marking'	How / symbols used
Person speaking	*Iinterviewer; Heading 5 + Pink Times New Roman 13 Bold & Italics* **Participant; Heading 6 Times New Roman 11 Bold**
Anonymised info for purpose of confidentiality	***names***
Emphases	underline
Louder	CAPITALS
Overlaps	[ ]
Hesitations	… (short) ……(long)
Not understood /not clear/ confidential	xxxxx
NVC, interruptions & anything else that may help reader	((information provided here))
Title of transcription with number and date and pseudonym	**'INTERVIEW TRANSCRIPTION 1010808 Neil' Heading 1 Arial 16 Bold**
Profession	***'Nurse' Heading 2 Arial 14 Bold Italics***
Base (hospital/unit community /day)	**'comm' Heading 3 Arial 13 Bold**
Gender	**'Male' Times New Roman 14 bold**

Elliot, 2005, Gee, 1986, Kvale, 1996, Parker,l 2005, Poland, 2003 and Riessman, 2001.

Appendix X: Reflexive Memo

ISOBEL 6I120908

NOTES & REFECTIONS BEFORE INTERVIEW;
It doesn't feel like only yesterday I did the interview with Tariq. Feel motivated and feel good to be doing and planning the interviews. Maybe there has always been the fear and doubt in me that I would not be able to do the 10 interviews I planned – people would not be interested, or feel too busy, or not want to spare me the time... other more important or more appealing priorities.

This is also a person I have met before a few times –in meetings and training sessions. I also I know where the place of work is. On travelling there I know my way and feel prepared. So that could account for why I feel less anxious than any of the earlier interviews.

When I arrive Isobel informs me that the room we were to use has been double-booked. Strange feeling this does not bother me in the slightest, maybe because it provides me with an opportunity to demonstrate/ perform as flexible, grateful, kind...? I agree with Isobel that a space in the library with be fine with me, as long as it is ok with her and the librarian, which it is. This is quite different to previous space which has been closed offices with more privacy and less chance of interruptions.

NOTES & REFECTIONS DURING INTERVIEW;
As soon as we begin I feel the least anxious and most relaxed of all interview to date. Could be something to do with Isobel, the venue, my previous experiences....not sure ... but I am sure this influenced the stories told. So much to talk about, but being aware of her time and being a busy practitioner we did finish – 8 minutes over the planned hour and could have carried on.

NOTES & REFECTIONS AFTER INTERVIEW a (within next few days);
I feel I 'enjoyed' this more than earlier interviews ...again maybe because I was less anxious and more able to be there? Also feeling that I could identify with many of the stories told by Isobel. After the interview and during transcription I found myself reflecting more on my experiences and stories I would tell as 'interviewee'. Also something about the way Isobel talks –words, phrases and accent – very familiar to me from childhood and family ... How did all this influence my performance in interview? How will all this influence my performance in analysis and presentation? As transcribing becomes more practiced, more routine, I find I am thinking and making more notes as I transcribe. In the middle of transcribing Isobel's stories (page 14), I am struck by her use of the phrase '*away from her*' ... just there ... standing out from her story... its the name of a film just released that tells the story of a woman living with dementia ... a film I am planning to see very soon.

NOTES & REFECTIONS AFTER INTERVIEW b (August 2009 –January 2010);
- OBSERVATIONAL NOTES; see above
- THEORETICAL NOTES; hunches, connections, categories. Not being fixed in my realities
  - o Policy and procedures assume certain perspectives on risk
  - o Risk assessment and decision making though stories [CONNECTIONS?]
  - o Risk assessment as going beyond [CONNECTIONS?] doing not just talking, being nosy
  - o Risk assessments as 'getting a feel for' [CONNECTIONS?]
  - o *Lets be honest* ...Home care as risk. Risk management as postponing home care.
  - o Benefits of positive risk taking [CONNECTIONS?]
  - o Well being, choice, self, desires, dreams, personhood, independence and risk
  - o Risk management as difficult, a big responsibility and worrying [CONNECTION?]
  - o Decision making; [CONNECTIONS?]
    - Who knows best? *I don't think we do*
    - Problem solving, solutions and being reflective
    - Report writing as reflection time
    - *Struggling;* Balancing wellbeing and safety; *parallels*, fine line
    - Weighing everything up. Wanting 100% certainty. Questioning self.

- Being shaped and knowing through experience
- *Doing the best that I can* and *trying to do the right thing* x4
- Thresholds; Going home, feeling upset, can't sleep. *Have I <u>done the right thing</u>?*

o Moving to residential care PASSION; [CONNECTIONS?]
- *Massive* decisions to make. *The hardest thing.* Life changing events.
- *I don't think people realise*
- Need to *take their dignity …take some of what makes them them*
- *Feels very much like that's it for them*
- Loss of partner and meaning, anger, depression

o Passion, loss, anger,<u> **outrage**</u>, rights, *broke my heart. Why should she get used to it? <u>(Parallels re settling in?)</u>....**Away from her....**

o Private/practitioner self; If I went there…If that was my 'mum' [CONNECTION?]

o *Babbling;* is that when more stories are pressing? [CONNECTION?]

• PERSONAL NOTES; feelings about self and others

o So many stories to tell; poetic, rhythmic use of 3 to emphasise... [CONNECTION?]

o Steeped in reflection and reflexive moments for both

o Lots of ownership; use of *'I', 'I' said……to be honest...* [CONNECTION?]

o About being different, wavelengths and valuing honesty [CONNECTION?]

o Me as definite insider 'you know all that'… 'difficult' and 'good' question were ok?

• METHODOLOGICAL NOTES; See 2 reflexive essays

PLAN for ANALYSIS of PRIMARY DATA *(not linear or separate)*

PRIMARY DATA (11 interview transcriptions)

1. **CREATE TEXTS**

2. **COLLATE, READ & RE-READ TEXTS**

3. **6 further READINGS & LISTENINGS (R&L) of each transcription, MAKING NOTES:**

• **R&L 1 (paper) 'naïve' LISTEN to each story ; familiarise & get sense of WHOLE;**

• **WHAT DID WE DISCUSS? MAKE BRIEF NOTES**

• **R&L 2 (paper); FOCUS on RESEARCH OBJECTIVES (NVIVO; 5 a priori codes (C)) ;**

• *explore practitioner accounts of decision making (C1) in risk management (C2) with people living with a dementia (C3)*

• *describe & analyse assumptions and understandings influencing decisions made by health & social care practitioners*

• *consider this decision making with a particular focus on psychological wellbeing & QOL (C4)*

• *consider this decision making in the context of recent legislation, policy & practice guidelines and changes in the culture of dementia care (in particular M Capacity Act, 2005)(C5)*

• **DEVELOP inclusive, simple, broad, open CODES /'MEANING UNITS'**

• **R&L 3 (paper); return to RE-LISTEN TO EACH STORY as a WHOLE NARRATIVE, MAKING BRIEF NOTES on CODES**

Preparation for and use of 'NVIVO' SOFTWARE, ready for stages 4-9.

• **R&L 4 (NVIVO); Step 4 analysis plan LOCATE INDIVIDUAL NARRATIVE**

• **R&L 5 (NVIVO); Step 5 analysis plan DISCOURSE ANALYSIS**

• **R&L 6 (NVIVO & throughout) ; Step 6 analysis plan REFLEXIVE ANALYSIS**

• **NEXT R&L 7-9: (NVIVO)(p13-16); Move away from readings; Step 7 analysis plan; COLLATE OPEN CODES into CATEGORIES & networks ACROSS ALL 11 TRANSCRIPTS. Step 8; EDA. Step 9; Analytical notes throughout**

R&L 3 (paper); GENERAL NOTES ON GATHERING INFO. & CONSTRUCTING KNOWLEDGE;

- Coding: making the discourse *'manageable'*. It collects & prepares the way; code then analyse. Pragmatic, not analytic. May be straightforward (eg clear link to research objectives) but may not be apparent until later in analysis, therefore;
- Interpretations; preliminary is explicit & produces the narrative. 'secondary' level necessitates editing to manage & take a closer look.
- **Iterative, cyclical** process; move between coding & analysis
- Begin by coding as **inclusively** as possible: **broad & overlapping,** including borderline & vague connections, to help identify patterns & *in preparation for analysis*
- *'interrogate the text'*. Consider; what, why, how & me (what do I do & what do I think)?

Note CONTENT (NB: *WHAT* but not *HOW* or *WHY*) & prepare for use of software

- Kvale p3, participant as 'informant'/mining
- Silverman, 2001, *'the status we accord'*;
o not focussing true/ false, but on **functions** of accounts
o **form/content**: depend on each other; 'misleading polarities'
- **how, what & why (form and content)**
- **context & content over linguistic structure** (Foucault, 1980 & Bourdieu, 1990) **linking individual & institutional**

Preparation for and use of 'NVIVO' SOFTWARE, ready for stages 4-9.
ORGANISE CONTENT
Prepare & structure notes **ongoing REFLEXIVE NOTES** for NVIVO memo
- OBSERVATIONAL NOTES; content; what I see, hear, ...
- THEORETICAL NOTES; hunches, connections, categories. Not being fixed in my realities...
- PERSONAL NOTES; feelings about self and others...
- METHODOLOGICAL NOTES; notes to self about research choices

R&L 4; Locate INDIVIDUAL NARRATIVE (includes WHAT, HOW &WHY?)

DEVELOPING SIMPLE CODES into GENERAL THEMES & CONCEPTS

'Narrative research does not discover what the truth is, but rather how someone makes sense of an event ...' p82 Parker, 2005.

CONTENT, FORM/STRUCTURE & PERFORMANCE;

- Note use of words focusing on **research objectives**
  o How was this story organised, selected & constructed?
  o What is the **sequence** (order, selection & connection)?
  o How are events ordered?
  o Time & place?
  o Core plot & complicating actions?
  o What is genre, themes & episodes?
  o Dominant & marginal plots & themes?
  o Signals for beginning & end?
  o Valued end point?
  o Turning points'?
  o Unexpected features?
  o Use of alliteration & repetition?
  o Are symbols & metaphors used? How?
  o Visual images triggered by accounts?
  o What 'kinds of people' eg experts, passive?
  o What are presented as important ideas/ 'foreground'?
  o What is missing?
  o Rhetorical strategies & re-structuring; are some events marginalised if they don't fit with plot?
  o Why are events ordered like this (**consequence**)?
  o To remember, justify, persuade, engage, mislead?
  o Words used to construct the world & make things happen. Interest in constructive & functional dimensions;
  o Search for **patterns** (in the language associated with research area) of variation & consistency;
  - Are there differences in content or form?
  - Are there similarities in content or form?
  - For example turn taking, recurring elements
  o What are the **functions** of this account?
  - To persuade, justify, blame, present self in a certain way…?
  - Are values implicated?

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- What are the **consequences** of this account?
  - What about links with wider patterns /wider contexts?
    - Parker, I (2005) p27 what is the narrative about?
    - What is the <u>function</u> of this account?
    - What is interesting?
    - What is the 'rhetorical purpose'? Does this construction send a message?
    - Does the narrator evaluate events? Does narrative imply approval/disapproval?
    - Who was this story constructed for?
    - What is at stake; in whose interest is this narrative?
    - Is there a moral to this story? Is there a narrative ethic?
    - What cultural resources does this narrative take for granted?
    - What is out of context?
    - What is complex?
    - Are there competing or contradictory themes?
    - Are there consistencies & inconsistencies in the story?
    - are there ideological dilemmas?
    - What's missing? Do gaps suggest alternative narratives?

PRESENTATIONS OF SELF & TECHNIQUES OF '*PERSUASION*' (Riessman) WAYS OF INTERACTING, REPRESENTING, IDENTITY SCRIPTS & PERFORMANCE OF SELF;

  - How are socially situated identities <u>co-constructed</u> in the interview?
  - Does practitioner speak in a global/ abstract way that distances 'self'?
  - Does practitioner speak in a personal way situated in local experiences?
  - Does practitioner refer to self, using '*i-statements*' eg;
    - Cognitive; I think, I know…?
    - Affective; I feel, I want…?
    - Action/state; I am…,I went to the house…?
    - Constraint; I can't…, I have to …?
  - Use of para-linguistics, such as laughing, pauses, interruptions?
  - Is narrative detailed & emotional?
  - Is narrative vague & 'disconnected'?
  - Particular events that stirred emotions?
  - Particularly descriptive, elegant parts?
  - Interplay of what & how ('manner') spoken?
  - Are some words & phrases intensified?
  - Use of detail?

- o Use of direct speech of others?
- o Appeals to me as interviewer/practitioner?
- o What is role in genre eg circular, crusader, battles, being detective?
- o How does practitioner present self as particular 'type'. Through dominant discourses, eg person centred, compliant?
- o Does this story maintain intrinsic worth of/ legitimise practitioner as 'being' professional?
- o In what ways does this story maintain professional boundaries?
- o What stories are told of 'other' agencies/professions?
- o In what ways may story influenced by legislation/policy?
- o Is practitioner telling me what they think a 'professional' <u>should</u> be saying?
- o Is practitioner telling me how they want it to be, or how they want me to think it is?

- **Positioning processes;**
- o Institutional positioning eg how practitioner should be & do?
- o 'modular' positioning eg risk management?
- o How does practitioner position self in story eg expert, confident etc?
- o What is the 'discursive' positioning? Eg narrative structures, use of rationalisation, such as but...
- o How does practitioner position others in story?
- o What are the positions statements;
  - Eg. Choice, victim etc?
  - Use of grammar (eg. Passive/active, repetitions)?
- o How are the influences of societal structures accounted for?
- o How does practitioner use different identities in position self in story (eg daughter, carer, professional)?
- o How is professional self constructed?
- o Does this performance of self 'identify' with professional discourse of self?
- o What 'culturally available' identity scripts are 'mobilised'?
- o How is this performed?
- o *'whose voice do we hear'* (practitioner or institution)?
- o Are there *shifts in position,* eg. Verbal preface; *alternatively, with a different hat on*?

<u>Ways of talking about that we draw on; interpretative repertoires</u>

- Use of language in a particular social & cultural context (close links with concept of discourse, but smaller & more fragmented than Foucauldian DA in next stage)

o What are the shared patterns of meanings?

o How does this try to making sense of everyday life?

o What repertoires are 'at play'?

o Are there different ways of talking about the same phenomenon/ process?

o Who is implied?

o What does it say about that person?

o Politics of representation; who is empowered?

o What are the dilemmatic themes?

o How are ideological dilemmas accounted for eg rights & risks?

o How may stories be connected to that of others?

• Locate the discourse phenomena in a particular historical/ institutional/ societal context

R&L 5; DISCOURSE ANALYSIS (includes WHAT, WHY & HOW?)

Useful to consider both 'micro' interactions and 'macro' contextual factors (not either/or)

Foucauldian; interest in power, discourse & constructions of institutions eg psychiatry.

Emphasis on **content (what;** themes, interpersonal context & discourse) **over structure**

• Interpretations; discursive considerations; use of words. Authority & representation. Narrative identity, pluralistic identity;

• **What lies beyond the self evident?**

• **Ideational:** what?

• **Discursive;** how, the way in which?

• **Action & social conditions;** relationships & structures?

o How do accounts link into discourses (may be unintentional)?

o What is the effect of linking the account to discourses?

o **'question the text & speculative interpretations';** what is a critical commonsense understanding;

o Re **general knowledge** of situation; eg what does the account express about dementia, risk assessment etc?

o Re **person;** eg what does the account express about the practitioner & their relationship to risk management?

Conforming or challenging grand narratives and dominant ideologies ;

Ideological dilemmas. Billig, (1988) questions marxist notion of ideology & suggests additional alternative of 'lived' ideologies. Fragmented & inconsistent, not

integrated or coherent; ways of life, beliefs, values & practices of a society / culture; contradictions & dilemmas.

- o   What are the important elements, eg;
- ▪   Content?
- ▪   Implicit debates?
- ▪   Interpersonal?
- o   Does account support and/or challenge the grand narrative/ dominant discourse?
- o   What are the 'ruling' discourses?
- ▪   What versions of reality do they construct/sustain?
- ▪   How do discourses work together to sustain particular realities?
- ▪   What are the explicit/implicit assumptions in the use of these discourses?
- ▪   How are dominant discourses maintained?
- ▪   How do they produce understandings?
- ▪   How does discourse position self, others & organization?
- o   Do contesting discourses exist?
- ▪   Different world views?
- ▪   Power imbalances?
- o   What are the 'competing' discourses?
- ▪   What are the oppositions & contradictions between discourses?
- ▪   Professional autonomy/institutional control?
- ▪   How do some discourses oppose/resist power?
- o   Are oppositional subject positions constructed eg good/bad?
- o   Which economic/political/cultural discourses 'gain weight' in this story? Who stands to benefit? Whose interest is served?
- o   Who is disadvantaged by such accounts?
- o   Can story be located within an institution/ structure? What social, cultural, political & historical factors underpin such accounts?
- o   What accounts are provided of decision making in risk management?
- o   What views do discourses permit or inhibit?
- ▪   How do they confine-what is left out?
- ▪   What is 'alien'? What is not said ?
- ●   Foucault; **panopticism & governance**
- o   Is certain knowledge valued & reinforced?
- o   Is certain knowledge marginalised & excluded?
- o   Does this narrative support the dominant discourse / grand narrative of dementia, EBP, NICE etc...eg?
- ▪   Is one way of assessing promoted over others?

- What about professional judgement? Eg gathering info but not using (Sainsbury RA?)
  - Do accounts of adherence refer to unnamed others ('they')?
- What are the 'moral tales'?
- How does account construct what is 'right' & 'wrong'?

DERRIDA, 1978;Consideration of DECONSTRUCTIONS & RE-CONSTRUCTIONS Challenging / erasing the boundaries of binary opposition (eg safe/unsafe, mind/body);

- Dichotomies as ideological assumptions not social actualities
- Is account constructed around dichotomous, oppositional worlds?
- **Warning note;** Kikuchi, 2006 the problem is not the binary but our misuse of binaries. The problem is more with sophism; telling people what they want to hear, persuasion & verbal manipulation & defending the argument
  - What are the hierarchical binaries upon which the account relies eg reason/emotion, objective/subjective?
  - Read 'against the grain', consider **re-constructions** of timing, structure & form; what is the impact? Are there alternatives?
  - Locate & consider the 'promising margins' of the account eg unguarded comments, metaphors, 'turns' in the account
  - Expose, reverse, then remove hierarchical binaries
- Play with the text';
  - Dismantle the dichotomy
  - Examine the silences
  - Attend to contradictions
  - Focus on most alien/peculiar
  - Interpret metaphors
  - Use careful substitution to reconstruct (eg Zephania);
  - Use limitations of reconstructions to explore status quo
  - consider dualisms either/or , to both/and
  - Consider representing dualisms as a continuum eg reason/cognition & emotion, risky & safe, compliant & uncooperative

R&L 6; REFLEXIVE ANALYSIS *throughout* (what, why, how & what about me?)

Reflexivity (knowledge of self or other) is always partial & temporary

Impossible to separate researcher from research

Finlay, 1998; **personal, social & methodological**

- o Consider my reflexive notes pre/during/post int. People I know & feeling like …being an insider?
- o How do I feel about my 'dual' role?
- o How did my researcher role influence my interactions?
- o How do I feel re-reading my words in transcript?
- o Did I experience any dissonance?
- o Expectations re previous relationships & shared identities?
  - • Why am I reading it in this way?
  - • What is the relevance of my identity to the process of this research?
  - • Subjective/objective as continuum;
- o What is my culturally gained 'positioning' eg gender, class, sexuality?
- o What about my values (gained from these positions?)?
- o What have been dominant influences on my choices & understandings in practice & research?
- o What is my social position?
- o What is my theoretical position?
  - ▪ What is the nature & assumptions of the knowledge i am producing?
  - ▪ Who am I producing the knowledge for?
- o What are my pre-conceived ideas, exclusions, inclusions & prejudices?
- o How did I negotiate power relations with practitioners eg claims for identities, confidentiality, space…?
- o Governmentality (Foucault); in what ways am I a 'self-governing researcher'?
- o Is it possible to 'know' how my connections with practitioners influenced constructions? (No?)
  - • **Interactions; in what ways have I shaped the story?**
- o Personal; identities, power, approach, values etc
- o Structure; interactions, turn taking etc
- o My questions; when do I prompt?
- o How does practitioner attempt to 'position' me?
- o How do I attempt to 'position' the practitioner?
- o How do I attempt to 'position' self?
- o Are attempts made to resist positions?
- o How are central characters or minor role(s) constructed?
- o Who shifts topics?
- o Who determines which messages 'get through'?
  - • **My responses;**
- o How does practitioner monitor who they are in relation to me & vice versa?

o When & how do I 'pick' up/ validate or pay no attention to a topic raised by the practitioner?

o Are my questions/clarifications based on my assumptions &/or interests as 'insider'?

o Being a listener; was I active, passive, intrusive... did I feel there was a 'correct' way?

o In what ways do I share/ identify with practitioner?

o Am I steering or supporting?

o Do I stand by or stand back?

o Do I go along with assumptions?

o Did I agree with assumptions that I do not share?

o What was my response to sharing my views?

o What about boundaries, distance & avoidance?

o How do I create 'slots' for narratives in the Q&A?

o How do I encourage narrative through use of NV & utterances?

o Consider use of laughter

o In what ways do we monitoring each others exchanges?

o Is practitioner just saying the 'right' thing?

o In what ways are participant & myself 'artful'; 'borrowing' from different available narratives?

o Questioning; what questions do I return to –eg from a different angle, reframing, using different words- and why?

o In what ways do I control the content eg what is said, how long the participant talks for...?

• Kvale (1996) warning p226; the implicit or unconscious meanings attributed to practitioner by me , may be my theories;

o Do I see myself as expert?

o Did I already have a story in mind that I wanted to tell?

o Be aware of when I am narrative finder & narrative creator

o Do I only notice discourse that supports my arguments/ narrative? What about other stories?

o *Perspective subjectivity;* consider questions from a different perspective & make this perspective & questions explicit– does this construct different interpretations/ meanings of same story?

o Power & relations; what did the practitioner say about the relationship & roles, eg an academic, my approval...?

o Access & use different metaphors to help reflexion; use them to resist being 'stuck' eg, detective, traveller, gardener, miner, potter....

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o   Listen to my feelings & process them

o   What did I feel in the interview re situation/ content?

o   Did I hesitate to ask certain questions?

o   What do I feel now about my tone etc?

o   What surprises me?

o   Are there contradictions?

o   Are there 'dissenting discourses'?

o   In what ways & why do I maintain/ promote professional/ institutional discourse?

o   In what ways & why do I disrupt professional/institutional discourse?

o   Are there ethical issues arising /risks for participants in the interview, such as *'getting thinking', unsettling'?*

o   What about issues relating to limits of confidentiality (also see tutorial notes)?

o   What power relations are at work in the interview?

o   How did I use probing questions?

o   Did I ask invasive questions eg re beliefs, values etc?

o   Did I intrude on time / space…?

o   Who stands to benefit from participation in interviews?

o   Did I ask questions about 'delicate' subjects?

o   Were strategies used to avoid invasive/'delicate' subjects?

o   What kind of research relationship did I try to establish?

o   What alternatives were there?

o   How do I think this may have influenced the stories?

o   How did I negotiate research relationship?

o   Where there explicit & implicit agreements about the way i undertook the research?

o   Am I prohibiting some of story for ethical reasons?

REMINDER; considering next stages in coding & analysis Implications of reflective discussions re using paper AND 'NVIVO' for analysis RE narrative context & coding

NVIVO: Stanford, 2007 (p122) Banks & Williams, 2005, Bazeley, (Ch 5 *Making Connections*) 2007, Aajawi, 2006 p165-9 Bringer et al, 2004, Furner &Steadman, 2004, Gibbs, 2002, Hill, 2009, Johnston, 2005)

R&L 7; CONTINUING CYCLICAL PROCESS; Move away from readings; MOVING between CODINGS & ANALYSIS

COLLATE OPEN CODES into CATEGORIES & NETWORKS ACROSS ALL transcripts

Continue to move from coding, grouping & grouping content towards analysis; further exploration of transcripts using *nvivo*; check through all 'annotations' & undertake 'queries' using info constructed in interview; key theoretical, methodological & analytical concepts & words.

- Positioning, different' readings & contested meanings
- **Search/questions texts from different layers of** 'contextual understandings';
- Self; practitioner accounts of understandings & meaning
- 'critical common sense'; from a 'wider frame' of general / practice knowledge
- Theoretical; building on NA, DA, RA
- Sorting & linking; how words/phrases are linked at level of discourse (eg medical)
- Phenomenological immediacy/distance; meanings for/beyond individual
- Effect of language; effects of 'chains of meanings' in discourses
- **Question texts for patterns of language use;**
- **Organisational;** differences & similarities in **content (use 'tree nodes')**
- Hypotheses & connections re **purpose & function** of accounts **(analyse patterns of associations in 'nodes'; 'relationships' & 'models')**
- **Look through** *nvivo* **'free nodes';**
- Group as 'descriptive' (about) or interpretative (suggest)?
- Being to move from 'descriptive' to interpretative
- What is the **relationship between the 'free nodes'?**
- Develop **'tree nodes'** & print out reports **and** continue to work with complete transcripts for context
- Develop **pattern 'matrices' & 'models' & reports**
- Organise information using networks / modelling (use 'nvivo' software & paper systems) use web like representations to assist in exploration at different levels & to enable systematic developments of 'groupings'

R&L 8; TEXTS FROM CASE RECORDS, POLICY, MEDIA & REFLECTIONS ANALYSED AS SECONDARY/ CONTEXTUAL/ EXTRA DISCURSIVE DATA (all data that is not interview transcripts).

- In *Nvivo*, BUT different **level** of analysis (material contexts of interviews)
- Secondary/contextual texts (non interview)

Arranged into 4 groups for analysis of;

- **Case records;**

- **Policy docs;** national and trust legislation & guidance (grand narratives)
- **Media representations;**
- **My reflexive documents & accounts;**
  - What does the reader need to know about (not indulgent)?
  - Consider what may 'trouble the reader', eg;
    - being an insider
    - 'tenuous' links; between accounts and practice ...therefore how much use is this project?
    - Not linking case notes to interviews –why?...questions for later (post doctoral triangulation of interview data and case notes?)
  - My impact on the research process
    - See assessments
    - Before, during and after the interviews
    - The co-construction of the interview
  - Instances of differences & being an insider –clarifications of how this occurred, agreements & disagreements (eg being 'rejected' (pt), ethics, confidentiality....)
  - Space & time to think
  - Feelings
  - Nvivo; me and judgements and accountability, and my control
    - 'extra discursive analysis & literature search?
    - What about links with wider patterns /wider contexts?....<u>blurs into eda</u>
    - Work contexts and 'material conditions'
    - Ideology & grand narratives?
  - Discursive environments
  - Biography, cultural, personal &folk narratives
  - Ethnomethodological impulses what's & how's;
    - What is the narrative? <u>And</u>
    - How does what is said relate to daily lives of the practitioners?
  - Multiple footings
    - Examining the ideological character of institutional processes;
  - How are practitioners; conceptualised & categorised?

o How are practitioners coordinated & controlled through use of these categories?

o Narrative accounts embedded in social relations/contexts, & cultural resources

o Figure ground' perceptions; individual & context

o Material context. Micro & macro in daily lives

o Weaving contexts, institutional ethnography & significance of context

o Context list; 'associated surroundings' what is the context & what is the connection?

• What is the standardised discourse of this setting?

• Psychology, extra-discursive content, experience, scripts & schema
Work contexts, material & social conditions da, risk & mh
Sims–Schout et al (2007) p108 (Carey 2008, Griffiths, 2001, Harrison & Smith, 2004, Hui & Stickley, 2007, and Opie, 1997). Grime & Ong, 2007, Hamilton & Manias, 2006, Hammell, 2009, Harper, 2004, Hastings, 1998, Heartfield, 1996, Hui & Stickley, 2007, Huntington & Gilmour, 2001, Janks, 2005, Rapley & Flick, 2007, Stanely, 2005, Taylor, 2008, Tilley, 2000 and Wilson, 2007). Gubrium and Holstein, 2003b

STEP 9. Keep analytical notes throughout (anonymised reflective diary notes about project – include notes about my decisions, intentions, experiences, feelings)

Appendix XII: *'Nvivo'* Reports (3 Examples)

1. Free Node List 270210

Type	Name	Sources	References	Created On	Modified On
Free Node	**DECISION MAKING**	12	544	06/02/2010 17:53	26/02/2010 17:35
Free Node	**DEMENTIA**	11	78	06/02/2010 17:59	26/02/2010 15:22
Free Node	**DISCOURSE**	11	633	07/02/2010 12:53	26/02/2010 20:51
Free Node	**METAPHORS**	11	130	06/02/2010 18:20	26/02/2010 18:07
Free Node	**NARR EMPHASIS**	11	97	06/02/2010 18:12	26/02/2010 11:07
Free Node	**NARR OWNERSHIP**	11	89	06/02/2010 18:18	26/02/2010 12:32
Free Node	**NARR STRUCTURE**	11	57	06/02/2010 18:09	26/02/2010 12:21
Free Node	**NARR THEME**	11	352	20/02/2010 12:37	26/02/2010 14:26
Free Node	**POLICY**	12	128	06/02/2010 18:04	26/02/2010 20:14
Free Node	**REFLEXIVE**	11	87	24/02/2010 17:51	26/02/2010 20:50
Free Node	**RISK MANAGEMENT**	11	627	06/02/2010 17:57	26/02/2010 18:41
Free Node	**SELF**	11	382	07/02/2010 12:58	26/02/2010 20:48
Free Node	**WELLBEING & QOL**	10	71	06/02/2010 18:01	26/02/2010 17:25

Type	Name	Sources	References	Created By	Created On	Modified On
Tree Node	NARRATIVE	0	0	SUE	02/03/2010 09:39	04/03/2010 16:33
Tree Node	PEOPLE	0	0	SUE	02/03/2010 09:42	04/03/2010 17:06
Tree Node	REFLEXIVE	22	149	SUE	02/03/2010 09:08	04/03/2010 09:27
Tree Node	RISK DECISIONS & PRACTICE	0	0	SUE	04/03/2010 15:37	04/03/2010 18:15
Tree Node	RISK MATTERS DISCOURSE	21	221	SUE	04/03/2010 18:38	04/03/2010 18:59
Tree Node	SAVED ARCHIVE	0	0	SUE	02/03/2010 09:38	04/03/2010 19:22

3 Matrix query; (Risk Matters Discourse, Dualisms, metaphors, Self) x (Assessment, Thresholds, Home, Homecare) x (QOL, Wellbeing , 'PCA')

RISK MATTERS DISCOURSE (PARENT)(11)

<Internals\INTERVIEWS\ISOBEL> - § 2 references coded [0.44% Coverage]
Reference 1 - 0.22% Coverage
I feel as though wellbeing is like … I wouldn't say its above risk I wouldn't say its above safety but I think its very very parallel

Reference 2 - 0.22% Coverage
for me that cross over between risk and wellbeing was really really significant that

Mmm

So I did a bit of a reflection about it and ……

<Internals\INTERVIEWS\NAOMI> - § 3 references coded [1.46% Coverage]
Reference 1 - 0.46% Coverage
helping them hold on to who they are

Mmm

And the skills they have and maintaining that quality of life so that it isn't just an existence even though they're safe

Mmm

Its taking risks to maintain that quality and that sense of enjoyment …

Reference 2 - 0.68% Coverage

 increased disorientation and distress because a new environment and communal living risk of falling

Mmm

They all go up if you move into 24 hour accommodation

Mmm

There isn't the risk of wandering out the door

Yeah

15.00

And getting lost but there are the other risks the effect on mood when they suddenly get bereaved of everything that makes them them

Reference 3 - 0.31% Coverage

 risk is a daily thing isn't it we all manage risk daily suddenly when people get a label … we take away that responsibility of risky living or people will try to …

<Internals\INTERVIEWS\NEIL> - § 4 references coded [1.37% Coverage]

Reference 1 - 0.41% Coverage

she was willing to put up with that cos she said oh he likes to walk he always comes back often he did sometimes he didn't …but you know all the rules in the book would say no no no ((laughs)) you shouldn't do that

Reference 2 - 0.43% Coverage

peoples safety and wellbeing is paramount

mmm

But there are different ways of looking at that

mmm

You know as to the values you give to certain things

13.00

For example

Well dignity independence

yeah

Choice

Reference 3 - 0.38% Coverage

you can apply the wellbeing ill being to certain conditions and assess what people's need are rather than impose well this is how they should live and that's the level of risk they should accept or not

Reference 4 - 0.15% Coverage

personally I think its better to make mistakes and give people the chance than

<Internals\INTERVIEWS\ORLA> - § 1 reference coded [0.17% Coverage]

Reference 1 - 0.17% Coverage

I think that its worth for the wellbeing really looking and exploring the positive risk taking

- § 1 reference coded [0.14% Coverage]
Reference 1 - 0.14% Coverage
the tablets have made a big difference she feels she's got some of her life back

DUALISM (7)

- § 1 reference coded [1.25% Coverage]
Reference 1 - 1.25% Coverage
I saw glimmers of her mood and depression and just apathy setting in and she's not then the lady she is for the rest of her life

Mmm

She's very different very with drawn very quiet doesn't want to eat much just sits all day ... and when she's on her feet she'll chat to people they don't know she's chatting to them because they don't know they've equally got dementia she doesn't know ... but she's happy she's chatting away and it's a very different presentation so I'm convinced that if that were the case that she would deteriorate emotionally dementia wise maybe depression on the top you know physically sitting there in one place isn't good for the body

- § 1 reference coded [0.19% Coverage]
Reference 1 - 0.19% Coverage
being good all the time is not necessarily a good thing people should be allowed to express themselves you know

- § 2 references coded [0.48% Coverage]
Reference 1 - 0.22% Coverage

I feel as though wellbeing is like ... I wouldn't say its above risk I wouldn't say its above safety but I think its very very parallel

Reference 2 - 0.26% Coverage
Because that meant a lot her

Mmm

So for me ... its getting that balance between wellbeing and safety

Mmm

... And that for me can be really really difficult

- § 1 reference coded [0.29% Coverage]
Reference 1 - 0.29% Coverage
In relation to looking at a person's quality of life and trying to find that balance there's no happy medium

No

We're just trying to find that balance

- § 1 reference coded [0.16% Coverage]
Reference 1 - 0.16% Coverage
its looking for the wellbeing looking for the skills its looking for the empowerment

- § 1 reference coded [0.25% Coverage]
Reference 1 - 0.25% Coverage

but **I suppose its this old culture that's been maintained because people think that's what you do and nobody's ever challenged it before**

METAPHORS(14)

<Internals\INTERVIEWS\DANIEL> - § 1 reference coded [0.21% Coverage]
Reference 1 - 0.21% Coverage
So therefore the lesser of 3 evils is to keep her walking even though there's an associated risk of her falling

<Internals\INTERVIEWS\ISOBEL> - § 7 references coded [1.38% Coverage]
Reference 1 - 0.22% Coverage
 I feel as though wellbeing is like … I wouldn't say its above risk I wouldn't say its above safety but I think its very very parallel

Reference 2 - 0.13% Coverage
And to her to take that away from her was a big … a big chunk out of her wellbeing

Reference 3 - 0.14% Coverage
for me that cross over between risk and wellbeing was really really significant that

Reference 4 - 0.20% Coverage
So for me … its getting that balance between wellbeing and safety

Mmm

… And that for me can be really really difficult

Reference 5 - 0.19% Coverage
 those first hand experiences of doing homecare I know how it was

Mmm

To take someone's wellbeing away from them …

Reference 6 - 0.21% Coverage
 I feel really upset because oh my gosh they're going to go into this home and that's it feels very much like that's it for them

Reference 7 - 0.28% Coverage
I feel they need to take some of that dignity with them they need to take some of that person what makes them them

Mmm

With them so they can carry on being that [person]

<Internals\INTERVIEWS\KARL> - § 1 reference coded [0.29% Coverage]
Reference 1 - 0.29% Coverage
In relation to looking at a person's quality of life and trying to find that balance there's no happy medium

No

We're just trying to find that balance

<Internals\INTERVIEWS\NAOMI> - § 4 references coded [0.46% Coverage]
Reference 1 - 0.07% Coverage
helping them hold on to who they are

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Reference 2 - 0.11% Coverage
suddenly get bereaved of everything that makes them them

Reference 3 - 0.23% Coverage
the bereavement of their whole lifestyle and who they are and what they are which is defined by place for a lot of people

Reference 4 - 0.05% Coverage
They sit there and be dusted

<Internals\INTERVIEWS\ORLA> - § 1 reference coded [0.18% Coverage]
Reference 1 - 0.18% Coverage
I have to keep that in the back of my mind because that's the culture that we're chipping away at

SELF (26)

<Internals\INTERVIEWS\DANIEL> - § 1 reference coded [0.23% Coverage]
Reference 1 - 0.23% Coverage
… and I agree with that yeah I think yeah its right … she's happy doing that even though there's a risk attached to it

<Internals\INTERVIEWS\HANNAH> - § 2 references coded [0.37% Coverage]
Reference 1 - 0.17% Coverage
 imagine if it was you ((laughs)) you'd want to be able to do what you can for as long as you can

Reference 2 - 0.19% Coverage
being good all the time is not necessarily a good thing people should be allowed to express themselves you know

<Internals\INTERVIEWS\ISOBEL> - § 7 references coded [3.53% Coverage]
Reference 1 - 0.22% Coverage

I feel as though wellbeing is like … I wouldn't say its above risk I wouldn't say its above safety but I think its very very parallel

Reference 2 - 1.25% Coverage
 but the fact is what my point was … this lady she gets a lot of … you know satisfaction from going for this little walk and it meant a lot to her and she every time I went she'd often speak about I've been for me walk this morning she'd do it every single day
30.00

Mmm

And to her to take that away from her was a big … a big chunk out of her wellbeing you know a big impact on her wellbeing and my … it got quite heated between me and the family because that's what I was saying to her there were ways that we would be able to try and look at her maybe shutting the door or but lets not rule those out

Mmm

For now … and for me that cross over between risk and wellbeing was really really significant that

Mmm

So I did a bit of a reflection about it and ......

but why should she get used to it because that meant so much to her life
31.00

Mmm

And so much to her the meaning of her life

those first hand experiences of doing homecare I know how it was

Mmm

To take someone's wellbeing away from them ...

... but I do think that the safety the risk and managing and maintaining someone's wellbeing is a fine line

Mmm

And sometimes I ... I struggle with that

Mmm ...mmm...

I really do and I think many people do

For smeone's personhood for someone's wellbeing for them ... because that is such a life changing event to go into a home
40.00

Yeah

And I don't think people realise ... they just ... I hear so many ... she's got dementia therefore it doesn't matter anyway ... and it ... and it ... sometimes I go home and I when I've been to do assessments and I feel really upset because oh my gosh they're going to go into this home and that's it feels very much like that's it for them

I think well what would it what for me if I went there

Mmm

I would no longer be able to see my husband I would no longer have my car I would no longer have all the things that have meaning in my life

Mmm

And that's gonna effect my mental health I'm going to feel depressed I'm going to feel emotional I'm gonna be angry at everybody

it empowers them and improves their quality of life so that's what the jobs about in my book

I always I try emphasis that I'm there to learn I'm there to gather information about how memory is affecting their quality of life and how they function and what risks there arc in relation to that

I think that for me anyway has got to be one of the most difficult questions to answer ... because it's so subjective because its very much how the person that I'm with how they perceive their quality of life ... I don't feel that its my place to make a judgment on that I can only ... learn from them where they feel that they ... are having issues with their quality of life

In relation to looking at a person's quality of life and trying to find that balance there's no happy medium

No

We're just trying to find that balance

as an OT I'm looking for purpose and activity and purpose and wellbeing

having places to go its alright having people coming in and working with people in their own homes but a lot of people need that social interaction even if they have dementia

sometimes people they're not just carers they're companions and its loosing their companionship

I didn't know what title it was it was just that people's needs people's life history was accepted and acknowledged and accommodated

for me its very much about the old culture the malignant social psychology

Mmm

that ......what I tend to find ... and maybe this comes from the asylums having never worked in the asylums

what troubles me is that nobody ever thinks that that person may not like it there

I suppose its this old culture that's been maintained because people think that's what you do and nobody's ever challenged it before

... I have to keep that in the back of my mind because that's the culture that we're chipping away at

completely and then to look at the work of Kitwood and realise that well actually this is what I had always believed in but just didn't know what it was called

Reference 7 - 0.39% Coverage
being a dementia care mapping trainer because I guess its just always affirmed that that's what I believe in and what I believe in is the right thing

Mmm

And I get such a sense of satisfaction from sharing that

<Internals\INTERVIEWS\SUE> - § 2 references coded [1.33% Coverage]
Reference 1 - 0.64% Coverage
it its not just a risk assessment I do no no

Yeah

I think a big part of it is looking at you know the persons self perception and what their own hopes and aspirations are and what their own goals are for their life really that would be a big part of … that might not be about risk that just might be about their own desires and hopes

Reference 2 - 0.69% Coverage
I hope that somebody would begin to trust me enough to actually share their own concerns about where they're living and share their own emotions and feelings about the situation and just be more open with me it's a real it's the only way you can get a true picture of someone is to encourage them to actually share with you and feel comfortable enough to trust you

ASSESSMENT (4)
<Internals\INTERVIEWS\KARL> - § 1 reference coded [0.38% Coverage]
Reference 1 - 0.38% Coverage
I always I try emphasis that I'm there to learn I'm there to gather information about how memory is affecting their quality of life and how they function and what risks there are in relation to that

<Internals\INTERVIEWS\SUE> - § 3 references coded [1.61% Coverage]
Reference 1 - 0.25% Coverage
……It's about understanding the individual really and trying to … I think understanding the family's feelings as well with that person

Reference 2 - 0.67% Coverage
risk is a part of it its not just a risk assessment I do no no

Yeah

I think a big part of it is looking at you know the persons self perception and what their own hopes and aspirations are and what their own goals are for their life really that would be a big part of … that might not be about risk that just might be about their own desires and hopes

Reference 3 - 0.69% Coverage
I hope that somebody would begin to trust me enough to actually share their own concerns about where they're living and share their own emotions and feelings about the situation and just be more open with me it's a real it's the only way you can get a true picture of someone is to encourage them to actually share with you and feel comfortable enough to trust you

THRESHOLDS (2)

<Internals\INTERVIEWS\ISOBEL> - § 1 reference coded [0.83% Coverage]

Reference 1 - 0.83% Coverage

I've got if they were taken away from one of those tasks that they do on a daily basis that has meaning if that's taken away their wellbeing is … has been effected in someway

Mmm

33.00

But for everybody you know the definition of wellbeing or what wellbeing means is different to everybody

Mmm

And … but I do think that the safety the risk and managing and maintaining someone's wellbeing is a fine line

Mmm

And sometimes I … I struggle with that

Mmm …mmm…

I really do and I think many people do

<Internals\INTERVIEWS\KARL> - § 1 reference coded [0.94% Coverage]

Reference 1 - 0.94% Coverage

the thing was is that we had to balance that and say well look if we change her environment is that going to effect her mental health even further so therefore she just gives up and dies

Yes

Which would have been absolutely tragic

Mmm

But as it turned out it did turn out well but those are always the risks that we take

Yes

1.08.00

In relation to looking at a person's quality of life and trying to find that balance there's no happy medium

No

We're just trying to find that balance

HOME (14)

<Internals\INTERVIEWS\HANNAH> - § 3 references coded [1.81% Coverage]

Reference 1 - 0.80% Coverage

I think they might be physically more well cared for

Yeas

And more reassured as well less anxious perhaps … but it depends I suppose it depends on the stage they're at whether they … because if its too early if

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they're still not ready to accept it then they're gonna be just thoroughly miserable

Mmm

So even though they might be better fed if they're gonna be miserable all the time that they're there its not necessarily a better thing is it I suppose

Reference 2 - 0.35% Coverage
… I certainly think depression a risk

Mmm mmm

That people with some insight into the fact that they're in care and

Mmm

They didn't want to be there I think depression's probably quite a major risk

Reference 3 - 0.66% Coverage
I suppose it can be quite traumatising in a way

Yes

And if they are less physically able and there are people who are wandering round and perhaps aggressive you know it needs to be the right place

Yeah

Somebody that will sit quietly and spend a lot of time sleeping perhaps its less of a … a worry

Mmm

In that sense and they're certainly easier to care for aren't they

<Internals\INTERVIEWS\KARL> - § 1 reference coded [0.30% Coverage]
Reference 1 - 0.30% Coverage
we can try to support people and keep people at home if that seems to be the best for them

Yeah

For their quality of life

Yeah

And their mental health

<Internals\INTERVIEWS\NAOMI> - § 4 references coded [1.97% Coverage]
Reference 1 - 0.16% Coverage
its looking for the wellbeing looking for the skills its looking for the empowerment

Reference 2 - 0.33% Coverage
having places to go its alright having people coming in and working with people in their own homes but a lot of people need that social interaction even if they have dementia

Reference 3 - 0.68% Coverage
increased disorientation and distress because a new environment and communal living risk of falling

295

Mmm

They all go up if you move into 24 hour accommodation

Mmm

There isn't the risk of wandering out the door

Yeah

15.00
And getting lost but there are the other risks the effect on mood when they suddenly get bereaved of everything that makes them them

Reference 4 - 0.79% Coverage
the bereavement of their whole lifestyle and who they are and what they are which is defined by place for a lot of people

Yes yeah …

It's a bereavement from their … they cant do they cant potter in and put the kettle on or make a cup of tea or even make get themselves a glass of water often when they want to

Mmm

They sit there and be dusted I'm sorry maybe I'm …… maybe its just the homes I've seen recently

<Internals\INTERVIEWS\ORLA> - § 4 references coded [2.11% Coverage]
Reference 1 - 0.38% Coverage
if that makes them if it makes them happy to go back in their own home and the risks are balanced and manageable then I don't see why we shouldn't challenge and let that person at least try being at home

Reference 2 - 0.97% Coverage
if somebody is discharged home

Yes

And they're going back to an environment where they've perhaps lived happily for 20 30 40 years an environment that's familiar to them that they feel comfortable and safe in and if 4 times a day home care and family support is enough to maintain that for however long or short period of time then the chances are that persons wellbeing that person with dementia will achieve a much greater level of wellbeing

Mmm

By being in their own home

Mmm

… versus going into a care establishment

Reference 3 - 0.61% Coverage
They might be used to pegging washing out or pottering about in their garden and that sense of being included the whole you know psychological needs

mmm

… and I think in general I think we underestimate and again I use the term we very broadly we underestimate the damage it can cause somebody psychologically going into a care home

Reference 4 - 0.15% Coverage
what troubles me is that nobody ever thinks that that person may not like it there

<Internals\INTERVIEWS\RACHEL> - § 1 reference coded [1.34% Coverage]
Reference 1 - 1.34% Coverage
 had a nice married life there its their possession its their ownership it defines who they are their house often its got their own furnishings in and their own take on it and to move somebody our of that into a … what is going to be a small room that they don't own that doesn't have their own things in and if it does its only very few of their own things
36.00

Mmm

You know to sit around with people at breakfast dinner and lunch that you don't know … you don't always want to know … it's a huge decision it must be horrendous absolutely horrendous and if you've got … so its like you say you've got dementia and then you're there and you just never seem to leave that must be very confusing

Mmm

And upsetting and if you cant express that as well …it must be very traumatic

<Internals\INTERVIEWS\SUE> - § 1 reference coded [0.55% Coverage]
Reference 1 - 0.55% Coverage
Just the loss of independence and the loss of their own home and being able to make the choices about their everyday life is taken away from them and go in to basically institutionalised care
25.00

Mmm

And all the problems that come with that really of adjustment

Mmm

And loss of freedom

HOMECARE (5)
<Internals\INTERVIEWS\ISOBEL> - § 3 references coded [0.96% Coverage]
Reference 1 - 0.20% Coverage
So for me … its getting that balance between wellbeing and safety

Mmm

… And that for me can be really really difficult

Reference 2 - 0.57% Coverage
we often go see people to determine you know do they need homecare

Mmm

To help them get washed and dressed

Mmm

Do they need homecare to and for that person … putting their shoes on in a morning getting dressed might have a big impact on their wellbeing if somebody was going and doing it for them and lets be honest that's what homecare do

Reference 3 - 0.19% Coverage
 those first hand experiences of doing homecare I know how it was

Mmm

To take someone's wellbeing away from them …

<Internals\INTERVIEWS\SUE> - § 2 references coded [1.53% Coverage]
Reference 1 - 0.29% Coverage
there's no real opportunity for that person to carry on with any skills they have and actually work alongside them

Mmm

In reality that's not happening

Reference 2 - 1.24% Coverage
I think a homecare service goes in and will go into someone's home and provide a meal will put a plate in front of someone

Mmm

I think an engaging service would actually work go into someone's home and actually work alongside them to help them prepare a meal themselves so they would retain skills for longer

Mmm

37.00
And I think that would be and it would also be about how the person felt themselves it would increase their self worth their feeling of achievement and feeling of retaining their independence and give them a sense of autonomy which I think as soon as we start putting services into someone's home we take that away we deskill them

Appendix XIII: Dissemination Performance Emails

A short selection of emails following COT conference seminar

From: MJB
Sent: 28 June 2009 11:41
To: Bower Sue
Subject: conference presentation
Dear Sue
I was wondering whether I could have a copy of your presentation from the conference. I found it very thought provoking and reassuring as an fairly newly qualified OT working with people with dementia. Would I be able to share with colleauges also?
Many thanks
Kind regards
M

From: ZT
Sent: 30 June 2009 13:18
To: Bower Sue
Subject: re Ot Conference
Hi Sue
Thank you for your informative presentation at the conference. I would be grateful if you could email me a copy of your presentation as this will help me pass the information onto my colleagues in the office. We are a community based team specialising in aids and adaptations. We are receiving an increase in referrals for people with dementia living in the community and risk is very high on our agenda when considering how best we can help.
Kind regards
ZT

From: JLD
Sent: 30 June 2009 16:53
To: Bower Sue
Subject: OT conference
Dear Sue,
I attended your presentation at conference last week and would be very interested in a copy of your presentation. I currently work in the acute elderly medicine setting and discharge planning/ taking risks is a big part of our daily workload!
I found your presentation extremely interesting so Thank you!
JLD

From: MPD **Sent:** 30 June 2009 12:47 **To:** Bower Sue
Subject: Re: COT 33rd Conference Seminar 160
Dear Sue,
Many thanks for sharing the presentation! Thank you for inviting our interaction. Do you have a blog?
Anyways, I feel your presentation stimulates alot of self-reflection and your philosophical approach to research and practice. Risk assessments etc have always been emphased on placements, but academically there is a gap to further understand how we come to making these decisions that ultimately impacts our work- perhaps its an 'occupational science' thing we still need to develop. I know psychological studies etc..have discussed decision making in cognitive etc terms....but to be able to relate directly to OT would be beneficial.
As you were saying about being aware of applying our own moral values into risk decision making etc...it made me think it would be useful for our uni to provide a session to investigate whether there is a universal OT way of approaching this. I

think perhaps because discussing ethical issues may be less straightforward for some....it is often overlooked.

I also think the OT has a slight ethical slant in the definition of its profession. Whilst some are defined by the specialist knowledge that can be used for many purpose. OT on the other hand, seems to be defined by what could be considered as a 'positive purpose' which is to 'empowering/benefiting self &community'...using participation and a compilation of different disciplines/areas of knowledge. Im still trying to grasp the whole OT as a student...and I feel that the society still have a strong reductionist approach, whilst I think the philosophy of OT doesnt, which is why it struggles in the current political, culture climate.....sorry for the blabbling!!

So yeh...your presentation makes me think quite abit, which is why I enjoyed the session!

Re: email - I found it from the online abstract that was sent to me before the conference.

All the best,

M

FROM: Bower Sue   SENT:2009/6/30
Hi M
–good to hear from you and thank's for your comments –I have attached my presentation (if you access the notes pages this includes related references) I would be very interested in why you feel so positive about my presentation. I am happy for you to get in touch if you would like to ask any questions/discuss further.
regards
Sue bower

From: MJB **Sent:** 26 June 2009 22:03
To: Bower Sue
Subject: COT 33rd Conference Seminar 160

Dear Sue,

I am an OT student from XXXXXXXX who attended your session on taking risks with dementia. Many thanks for the informative talk that made me think ! I would be very grateful if it was possible for you could send me a copy of your brilliant presentation? I think itll definately help me with my practice when I graduate!

Many thanks for your time,

MJB

From: JMM
Sent: 15 July 2009 21:33
To: Bower Sue
Subject: Taking risks with dementia

Hi Sue,

Wanted to say thank you for your session at COT conference and to request a copy of your slides. You seem to have become a researcher and academic and managed to keep your feet firmly on the ground as a clinician - how refreshing that is and it made for a great presentation. It was one of those that you could have sat down with a cup of coffee and continued to discuss / debate for the rest of the day.

Lots of food for thought that I want to share with my colleagues and think the slides will help me recall some of the points more readily.

Thanks again,

Regards,

JMM