

VOLUME I: RESEARCH COMPONENT
THE EXPERIENCES OF CARERS OF PEOPLE WITH
DOWN SYNDROME WHO DEVELOP DEMENTIA

BY
ANGELA FOSTER

A thesis submitted to
The University of Birmingham
For the Degree of
DOCTOR OF CLINICAL PSYCHOLOGY

School of Psychology
University of Birmingham

June 2012

UNIVERSITY OF
BIRMINGHAM

University of Birmingham Research Archive

e-theses repository

This unpublished thesis/dissertation is copyright of the author and/or third parties. The intellectual property rights of the author or third parties in respect of this work are as defined by The Copyright Designs and Patents Act 1988 or as modified by any successor legislation.

Any use made of information contained in this thesis/dissertation must be in accordance with that legislation and must be properly acknowledged. Further distribution or reproduction in any format is prohibited without the permission of the copyright holder.

Thesis Overview

Volume I is divided into two papers. The first paper is a literature review that draws on research relating to diagnoses of, and living with, learning disability and dementia and draws out the implications for having a relative with both Down syndrome and dementia. The review demonstrates that more research is needed into the experiences of people who care for adults with Down syndrome and dementia. The second paper is a qualitative study exploring family member and professional carer perspectives on caring for adults with Down syndrome and dementia. Data was analysed using interpretative phenomenological analysis (IPA) looking at professional carer and family member experiences separately. For family members four themes emerged; dementia and understanding; emotional containment; relationships and difficulties endured. For professional carers four themes emerged; dementia meaning; containment; witnessing others suffering and person-centred.

Volume II consists of five reports. The first describes the assessment of Peter, a 54 year-old man who has intrusive sexual thoughts and compulsively stares at people. The report formulates Peter's problems from a cognitive and psychodynamic perspective. The second report is a service evaluation of a Community Mental Health Team, using a client satisfaction survey. The third describes David, a 79-year-old man with dementia, who presented with 'challenging behaviours'. A person-centred formulation and intervention are outlined and a single-case experimental design is used to evaluate the impact.

The fourth is a case study of Paul, a 56-year-old man with learning disabilities who was referred for compulsive behaviours and the work undertaken with Paul and his mother, which was informed by systemic ways of thinking. The final report is an oral presentation of Emily, a 22-year-old female who was referred to psychotherapy services for difficulties with anxiety, depression and borderline personality traits. Psychodynamic ways of thinking were used to discuss her difficulties.

Acknowledgements

I would like to thank all of the family members and paid staff carers who took part in this research. Without their time and commitment in telling their stories this work would not have been possible. The stories conveyed were both painful and inspirational and I was very moved by what many people had to say. I would like to thank Dr David Rose for recruiting all of the participants and his continued support of both the research and myself. I would also like to thank my academic research supervisors Dr Jan Oyebode and Dr Liz Kent. Both gave a huge amount of time to helping me draw my research together and helping me think about all aspects of the thesis. The thinking space that was provided was invaluable in allowing the work to come together. Jan, Liz and David were extremely supportive and containing when the ethics application became difficult and helped me to see that it was not the end of the world. And last, but by no means least, I would like to thank Martin Ball for providing many cups of tea and generally putting up with me.

CONTENTS

VOLUME I: RESEARCH COMPONENT

Literature Review

Exploring the dementia and learning disability literature to support an understanding of the experiences of caring for someone with Down syndrome who develops dementia	Page number
Abstract	2
Introduction	3
Aims	3
Method	4
Search Strategy	4
Family response to a learning disability	7
Breaking the news	8
Benefits and difficulties of having a child with a disability in the family	11
Early on-set dementia	13
Dementia diagnosis	14
Carers' experiences of negotiating the system	18
Relationships within the system	18
Barriers to accessing care	21
Decision making	22
The experience of caring for someone with dementia	23
Carers of adults with Down syndrome and dementia	27
End of life issues	29

Communication and information giving	33
Conclusion	33
References	37

Empirical paper

Family member and professional carer perspectives on caring for adults with Down syndrome and dementia

Page
number

Abstract	47
Introduction	49
Aim	52
Method	52
Design	52
Procedure	53
Interview schedules	54
Participants	55
Data analysis	57
Self-reflexivity	58
Results- Family member themes	58
Dementia and understanding	60
The meaning of dementia	61
Struggle to understand	63
Emotional containment	64

Difficult emotions	64
Containment	66
Relationships	68
Person-centred	68
Reciprocity	69
Systemic difficulties	70
Difficulties endured	73
Loss	73
Sacrifices	74
Unjust suffering	75
Fear of things to come	76
Results- Paid staff carer themes	78
Dementia meaning	78
Meaning	78
Understanding inner world	79
Containment	80
Awareness of dementia in own life	80
Difficult emotions	81
Emotional attachment v emotional distance	82
Do the best job you can	83
Witness others suffering	84
Unfair suffering	84
Bleak future	85
Loss	86

Person-centred care	86
Discussion	88
Limitations	92
Research implications	93
Clinical implications	93
References	95

Public Dissemination Document

The experiences of carers of people with Down syndrome who develop dementia	102
--	-----

Appendices

Appendix 1: The Journal of Policy and Practice in Intellectual Disabilities- Author Guidelines	109
Appendix 2: Journal of Applied Research in Intellectual Disabilities- Author Guidelines	114
Appendix 3: Social Care Research Ethics Committee letter	123
Appendix 4: Participant information sheet	128
Appendix 5: Consent form	131
Appendix 6: Interview schedule	133
Appendix 7: Worked example of IPA process	133
Interview transcript	135
Emergent themes	157
Super-ordinate themes	167

Appendix 8: Self-reflexivity and the positions the researcher has
brought to the research

169

List of Figures

	Page number
Figure 1. Map of the literature reviewed	7

List of Tables

	Page number
Table 1: Search strategy	6
Table 2: Main areas covered by semi-structured topic guide	55
Table 3: Participant demographics	56
Table 4: Analysis using accepted IPA protocol	57
Table 5: Family carers contribution to sub-ordinate themes	59
Table 6: Paid staff carers contribution to sub-ordinate themes	60

CONTENTS

VOLUME II: CLINICAL COMPONENTS

Clinical Practice Report 1: A cognitive and psychodynamic formulation of a man with obsessive thoughts	Page number
Abstract	2
Presenting difficulties	3
Background	4
Family history	4
Mental health history	5
Assessment	6
Formulation one: Cognitive model	9
Peter's three stage model of obsessions	11
Formulation two: Psychodynamic model	15
Malan's triangle's	15
Peter's triangle of conflict	17
Peter's triangle of the person	22
Reflections	25
Personal reflections	27
References	28
Clinical Practice Report 2: An evaluation of a community mental health team	Page number
Abstract	31

Introduction	32
New Horizons	33
Employment and voluntary work	33
Physical health	34
Recovery- Care programme approach	34
Personalisation and choice	35
Client satisfaction surveys	36
Service user involvement	37
Aim of this evaluation	37
Method	38
Design	38
Client satisfaction questionnaire	38
Participants	39
Procedure	41
Data analysis	41
Results	42
Discussion	56
Interpretation of results	56
Limitations	61
Recommendations	63
Reflections	65
References	66

Clinical Practice Report 3: Single-case experimental design:

David, a 79 year-old man with dementia presenting with 'challenging behaviour'	Page number
Abstract	70
Introduction	71
Reason for referral	71
Presenting difficulties	71
Background information	71
Overview of Alzheimer's dementia and vascular dementia	74
Assessment	75
Formulation	77
Kitwood- Person-centred care	77
Newcastle model	78
Experimental design	83
Phase A- Baseline	83
Phase B- Intended intervention	84
Results	86
Analysis	88
Auto-correlation	88
Discussion	91
Limitations of intervention	91
Limitations of data collection	92
Limitations of design	92

Effectiveness of treatment in light of limitations	93
Alternative design	94
Reflections	94
References	96

Clinical Practice Report 4: Case study: Paul, a 56 year-old man referred for 'compulsive behaviour'	Page number
Abstract	100
Introduction	101
Reason for referral	101
Assessment	102
Initial meeting	102
Paul and Rachel tell their stories- a 'problem saturated description'	102
Background information	103
Second meeting- externalising the problem	105
Formulation	107
Intervention	112
Solution-focused questioning	112
Preferred future	113
Scaling	114
Goals	115
Externalising conversation	116
Evaluation	118

Reflection	120
References	123
<hr/>	
Clinical Practice Report 5: “I don’t know when she’s coming back”: The process of rupture repair after a break	Page number
<hr/>	
Abstract	126
References	127
Appendices	
Appendix 1: Client satisfaction questionnaire	128
Appendix 2: Community mental health team service evaluation summary	135
Appendix 3: Behavioural charts	138
Appendix 4: Getting to know you form	139

List of Figures

	Page number
Figure 1. Genogram of Peter's family relationships	4
Figure 2. Cycle of staring and sexual thoughts	8
Figure 3. Diagram of cognitive control theory of obsessions	14
Figure 4. The interaction of Malan's two triangles	16
Figure 5. Peter's triangle of conflict and triangle of person	21
Figure 6. Genogram to show David's family	73
Figure 7. Newcastle Model formulation	80
Figure 8. Frequency of David's aggressive behaviours by week across baseline and intervention	86
Figure 9. Frequency of hours David spent in his room unoccupied across baseline and intervention	86
Figure 10. Frequency of hours David spent occupied and interactive across baseline and intervention	87
Figure 11. Frequency of hours David spent purposefully wandering	87
Figure 12. Genogram of Paul's family	104
Figure 13. Co-ordinated management of meaning formulation	109

List of Tables

	Page number
Table 1: Gender of Clients receiving a service from the CMHT	40
Table 2: Ethnicity of clients receiving a service from the CMHT	40
Table 3: Frequency and responses to quality of service questions	43
Table 4: Frequency and percentage of responses to employment, training and voluntary work questions	45
Table 5: Frequency and percentage of responses to physical health questions	46
Table 6: Frequency and percentage of responses to Care Programme Approach questions	47
Table 7. Frequency and percentage of responses to questions about choice	48
Table 8. Frequency and percentage of responses to questions about medication	49
Table 9. Results of Fischers Exact Test for gender differences	50
Table 10. Results of Fischers Exact Test for ethnicity differences	51
Table 11. Summary of correlations for Lag-1	89
Table 12. Summary scores from double bootstrap analysis for frequency of physical aggression	89
Table 13. Summary scores from double bootstrap analysis for frequency of time spent unoccupied in his room	90
Table 14. Summary scores from double bootstrap analysis for	

frequency of time spent occupied and interactive 90

Table 15. Summary scores from double bootstrap analysis for

frequency of time spent purposefully wandering 90

LITERATURE REVIEW

Exploring the dementia and learning disability literature to support an understanding of the experiences of caring for someone with Down syndrome who develops dementia.

Word Count: 6770 (excluding Tables, Figures, References and Appendices)

To be prepared for submission to The Journal of Policy and Practice in Intellectual Disabilities

Abstract

This conceptual review is a synthesis of the literature relevant to carers of people with Down syndrome and dementia. It draws on research relating to diagnoses of, and living with, learning disability and dementia and highlights the implications for having a relative with both Down syndrome and dementia. A search of electronic databases identified both quantitative and qualitative studies and these were assessed as to whether they would add breadth to the knowledge base and the quality of the paper. Fifty-eight relevant papers were identified and clustered into a narrative strand that takes the reader through the life course. The review identifies that families may not have had a positive experience of receiving a diagnosis of their child's learning disability, but may be better able to cope with a subsequent diagnosis of dementia, due to their long-term caring experiences. The needs of family members and the people with dementia are identified as different and therefore should be assessed separately. Differences between carers are also highlighted and cultural differences are acknowledged as impacting on the needs of both carers and those with dementia. For paid staff carers, support and training is highlighted as a requirement to support them in managing their clients changing needs. The review also demonstrates that more research is needed into the experiences of people who care for adults with Down syndrome and dementia.

Keywords: 'intellectual disabilities'; 'dementia'; 'carer'; 'Down syndrome'; 'diagnosis'; 'end of life'

INTRODUCTION

This paper draws together, reviews and evaluates studies that may help us understand carers' responses to having a relative with Down syndrome who develops dementia. There is very little published research directly exploring the experiences of carers of adults with Down syndrome and dementia, therefore the review will draw on research relating to diagnoses of, and living with, learning disability and dementia and draw out the implications for having a relative with both Down syndrome and dementia.

AIMS

The review aims to examine what we can learn about the experiences of carers of people with Down syndrome and dementia. It aims to do this by examining wide areas of research that investigate the experiences of carers of people with learning disabilities and carers of people dementia across the life span. In exploring wide areas of research it aims to address the following questions:

- What are the similarities/ differences between the experiences of carers of people with Down syndrome and dementia and those with dementia alone?
- Does having the experience of an initial diagnosis and subsequent caring experience, make the further diagnosis of dementia easier

to manage for carers of people with Down syndrome and dementia, than those who care for people with dementia alone?

- Would this have implications for the carer's ability to access support systems?
- Would this have implications for end of life issues?
- Are there differences for different family members?
- Are there differences for paid staff carers?

METHOD

This conceptual review synthesises literature relevant to the experience of carers of this population. It is not a systematic review, so papers within an area may be missing, but the aim is to draw on key papers across a wide range of disparate pockets of knowledge in order to present a narrative account of research into relevant experiences.

Search Strategy

Searches were conducted to address the question: 'What can we draw from research on receiving a diagnosis, caregiving or having a relative with dementia or a learning disability that will shed light on the experience of caring for someone with Down syndrome who develops dementia?'

Electronic databases were searched for papers published up until August 2011. The main groups of search terms related to carers of people with learning disabilities, carers of people with dementia and carers of people

with Down syndrome and dementia and details are shown in Table 1. The search terms aimed to capture the main terminology used within each group, both within the UK, internationally, currently and historically. The search terms were exploded to include other terms within the category, e.g. intellectual disabilities within learning disabilities. The articles retrieved were reviewed to establish their relevance to the question being proposed. They were selected based on whether they added breadth to the knowledge base and the quality of the paper. Case studies were omitted due to not meeting either of these criteria. Fifty-eight were found to be relevant and were clustered to form the structure of the review (see Figure 1). A number of relevant literature reviews were included. Papers that were within these literature reviews are not discussed separately but have contributed to the reviews' conclusions, which are included in the present review. A discussion regarding the quality of the papers is given at the end of the each section.

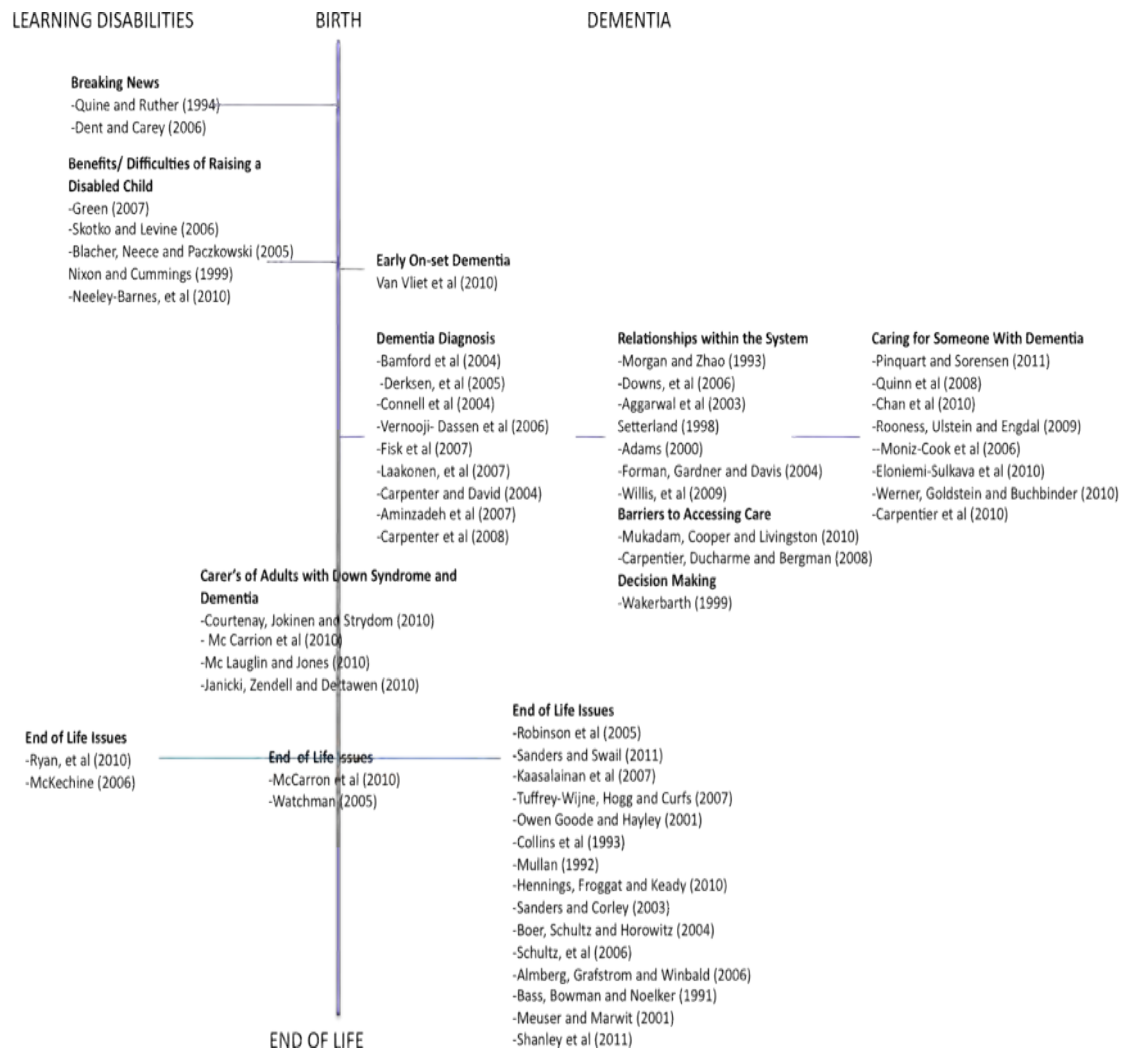
Table 1- Search strategy

Electronic databases searched:
Psycinfo 1806 to August 2011
Medline 1948 to August 2011
Embase 1980 to August 2011
Web of Science 1898 to August 2011

Search terms used in all databases:

1. learning disabilities/
2. mental retardation/ or down's syndrome/ or home reared mentally retarded/ or institutionalized mentally retarded/ or mild mental retardation/ or moderate mental retardation/ or profound mental retardation/ or severe mental retardation/
3. dementia/ or dementia with Lewy bodies/ or exp presenile dementia/ or semantic dementia/ or exp senile dementia/ or vascular dementia/
4. caregivers/
5. social services/
6. health personnel attitudes/
7. emotional responses/

Figure 1. Map of the literature reviewed



Family response to a learning disability diagnosis

Carers would have experienced many transition points along the life course of the person with Down syndrome and have had a lot of information and events to come to terms with and adapt to; the first event being disclosure that their child/ sibling had Down syndrome.

Understanding how carers were able to negotiate this news, and how the

early diagnosis influenced the life course, attachment to the child and the negotiation of early disappointment, may help us understand how well prepared or not relatives might be for later crises, disappointment and losses, such as a subsequent diagnosis of dementia.

Breaking the news

This section begins with a consideration of research on parents' responses and needs on receiving difficult news about a child's medical diagnosis or disability, before going on to review research, which specifically addresses reactions to the disclosure of Down syndrome.

Examination of the literature revealed that almost 50% of parents were unhappy with the way news of diagnosis was disclosed (Quine & Ruther 1994). Quine and Ruther (1994) concluded there were three main components that appeared to increase satisfaction: When the diagnosis was delivered as soon as possible; when the person delivering the news had a sympathetic approach and when they were given information on the disorder. These conclusions were supported by findings of other studies (Gayton, Walker & Rochester, 1974; Cunningham, Morgan & McGucken, 1984). Quine and Ruther (1994) used two models to understand the dissatisfaction, Ley's (1977) cognitive model, which suggested parents do not understand what they were being told and Korsch et al's (1968) affective model, which suggested affect and social interaction explain the dissatisfaction. It was found Korsch et al's affect scale was a much stronger predictor of parental satisfaction than Ley's

cognitive model, suggesting it was not what was said, but how it was delivered that was important.

This was supported by Dent and Carey (2006) who reviewed a wide body of literature in an attempt to understand how best to deliver the diagnosis of Down syndrome. Within the review, Sharp, Strauss and Lorch (1992) found parents wanted a display of feeling from the person delivering the news of the child's disability; more time to discuss the diagnosis and ask questions and greater confidence in the physician's ability to deliver the news. Ptack and Eberhardt (1996) and Girgis and Sanson-Fisher (1995) came to similar conclusions when they consolidated themes from the research literature on oncology and disability settings.

Parents were satisfied with diagnosis delivery when the news was delivered by appropriate professionals as soon as possible and the family were told together, preferably with the baby present, in a private place where they were able to stay after the news had been delivered; the family could ask as many questions as they wished and a follow-up interview was arranged for 24 hours after disclosure of diagnosis (Cunningham, Morgan & McGucken, 1984).

Within his review, Skotko (2005) draws on literature and his own clinical experience to develop a framework to support thinking around breaking difficult news. This starts by considering variables relating to pregnancy; then the birth of a child with a genetic defect and ends with the reaction sequence at the point at which parents are informed of the

genetic issues. The paper highlighted parent's preference to have positive aspects of diagnoses explained to them. However, Partington (2002) found positive aspects of a diagnosis were not given causing parents to go through a cycle of bereavement.

Some of the papers within Quine and Ruther's (1994) review date back to the 1960's, so could not be said to reflect the current situation. However, they were relevant to the population being considered here, as many contemporary parents of people with Down syndrome and dementia would have received the diagnosis of learning disability within the decades examined. The findings, of a wish for diagnosis to be given as early as possible, in a sympathetic manner and with full information, were consistent across studies and time, suggesting that findings were reliable and satisfaction has not improved. There was also support for Korsch et al's (1968) affective model, suggesting that it was not the information given, but the way it was delivered.

Parents' dissatisfaction with the way the news of their child's disability was communicated to them could have implications regarding families' relationships with health professionals throughout the course of the person with Down syndrome's life and also how they may respond to any future diagnosis. If parents were initially dissatisfied with the way in which the diagnosis was delivered this may impact negatively on their expectations of future support and could influence their willingness to engage with available services.

Benefits and difficulties of having a child with a disability in the family

When a child is diagnosed with a disability the whole family has to adjust to the news. The research examined here explores the perspectives of different family members and the benefits and difficulties of having a child with a disability within their families.

It has been found that mothers experience many benefits from raising a child with a disability, such as becoming more assertive; slowing down to enjoy life; and improving existing family bonds (Green, 2007). Green (2007) describes how mothers were mainly affected by objective burdens, such as financial difficulties and increased workload, rather than subjective emotional burden. In their review, Blacher, Neece and Paczkowski (2005) found a shift in the literature from examining family well-being to looking at positive aspects of having a child with an intellectual disability.

Sibling experiences were explored by Skotko and Levine (2006) through examination of sibling workshops for the brothers and sisters of children with Down syndrome. They highlighted how children in this position often had a greater respect for diversity, but also experienced greater responsibility, moments of embarrassment and a sense they were not being acknowledged in the same way as their sibling with a disability. Supporting these findings, Nixon and Cummings (1999) found in their paper comparing 30 siblings with a disabled brother or sister and 30 without, that those with a disabled sibling reported higher levels of

distress to recorded vignettes of family arguments, which they suggested shows higher sensitisation to family conflict due to family stresses.

Skotko and Levine (2006) highlighted discrimination experienced outside the family and how this can cause distress to family members. Neely-Barnes, Graff, Roberts, Hall and Hankins (2010) reported comparable findings when they used interpretative analysis to explore parents' understanding of community perceptions of their child. Themes that emerged were, support from external sources versus lack of support; inclusion in wider social systems versus exclusion and the role of parents and siblings, which were summarised as advocating, educating, informing, ignoring and hiding, with the first three seen as empowering and the last two seen as disempowering for the child and family. This paper suggested parents experienced others perceptions in different ways depending on whether they were confronted with support or discrimination and reacted to discrimination in different ways, but felt discrimination acutely.

The papers in this area covered a range of methodologies and give some interesting and thought provoking perspectives on living with a disabled child. Appropriate sample sizes were recruited and where measures were used these were standardised (Green, 2007). Some of the research was more anecdotal in nature (Skotko & Levine, 2006), but added modestly to the developing knowledge base.

Even though disclosure of a disability appeared to be a difficult time for families, the realities of living with a child who had been

diagnosed with Down syndrome did not appear to have been wholly negative. People within a family had different relationships to the child, so had different needs. Any negative perceptions of their circumstances were exacerbated by discrimination but mitigated by positive external support.

Early on-set dementia

Adults with Down syndrome who develop dementia have an earlier on-set than the majority of people who develop dementia in the non-disabled population. It may therefore be helpful to draw upon research undertaken with carers of adults with early onset dementia within the non-disabled population to help us to think about carers of adults with Down syndrome.

In a review of research on the impact of early on-set dementia on caregiving, van Vliet, de Vught, Bakker, Koopmans, and Verhey (2010) identified 17 articles, including one randomised controlled trial, ten cross-sectional studies, two qualitative studies and four case reports. Van Vliet et al (2010) concluded caregivers of people with early on-set dementia expressed higher levels of burden and depression, although this was only statistically significant in one study (Freyne, Kidd, Coen & Lawlor, 1999). Difficulties such as work problems, financial problems and problems with children were found to be higher for this group than for those with later on-set (Luscombe, Brodaty & Freeth, 1998). There was also higher distress caused by difficulties in receiving a diagnosis (Sampson, Warren

& Rossor, 2004; Mendez, 2006) and perceived lower levels of social support (Freyne, Kidd, Coen & Lawlor, 1999; Arai, Matsumoto, Ikeda, Arai, 2007). Van Vliet et al (2010) highlighted there were few high quality papers in this area, so felt that firm conclusions could not be drawn.

Extrapolating these findings to carers of adults with Down syndrome and dementia, it is probable that issues relating to the stage in the life course may not be as much of a concern, as it is unlikely someone with Down syndrome will have been in paid employment or have children. For family carers however onset of dementia may mean they have to change life plans for retirement or alter the way they have been living up to that point. They may also experience lower perceived levels of social support, as networks for carers of people with Down syndrome and dementia are not well established.

Dementia diagnosis

There has been a lot of research into the reaction of carers to a dementia diagnosis although little of this is within the Down syndrome population. In this section the literature will be examined and then related to adults with Down syndrome and dementia.

In a systematic review of research examining disclosure of dementia diagnosis Bamford, Lamont, Eccles, Robinson, May and Bond (2004) identified 59 papers. They found wide variability in positive and negative beliefs, attitudes and consequences to the diagnosis of

dementia. They also highlighted that the voices of people with dementia themselves were largely ignored.

In a qualitative case analysis from patient and carer perspectives, Derksen, Vernooji-Dassen, Gillissen, Olde-Rikkert and Scheltens (2005) found diagnosis confirmed carers' suspicions; helped carers understand their relatives' behaviour and gave carers a greater understanding of the capabilities of the client. The importance of disclosure to help carers understand their relatives' behaviour was also highlighted by Connell, Boise, Stuckey, Holmes and Hudson (2004) and physicians felt it was important to disclose early, so that families could make plans.

The experiences of carers and people with dementia have been found to be different. Vernooji-Dassen, Derksen, Scheltens and Moniz-Cook (2006) compared weeks 2 and 12 following diagnosis and found subtle differences over time. It was found that after 3 months the person with dementia used strategies such as minimisation and distraction to cope, whereas carers accepted the change in relationship. They observed there was continued mutual reciprocity. Both parties felt a sense of loss, yet some carers were able to adapt to safeguard their relatives' autonomy. During the 3 months some carers began to make concrete plans about how best to support their relative, which suggests the importance of early diagnosis and disclosure. This study shows the importance of carers within the process, but also how it is important to assess patient and client needs independently.

In a review of literature around the ethics of disclosure of a dementia diagnosis, Fisk, Beattie, Donnelly, Byszewski and Molnar (2007) concluded disclosure was an ongoing process of information and education for both the person with dementia and family members/ carers, from the point when a cognitive impairment is first suspected. They also highlighted the need for a person-centred approach, suggesting all disclosures should be tailored to the needs of the patient and carer. Laakkonen, et al (2011) highlighted that elderly carers were satisfied with the information given to them about dementia, but were not satisfied with the after-care. Carpenter and Dave (2004) completed a literature review that highlighted that process issues in disclosure, such as who is told and how, are generally poorly understood.

The diagnosis of dementia has an emotional impact on carers and persons with dementia. Aminzadeh, Byszewski, Molnar and Eisner (2007) identified that people went through a process where they initially deny symptoms and had little insight into what was happening; then they had a grief response, which would then lead into a positive coping response. This process suggested carers and people with dementia can get to a point of positive coping.

This is supported by Carpenter, et al. (2008) who measured anxiety and depression in patients and a significant other before and after diagnosis and found that mood and anxiety levels improved after diagnosis for both. This suggested understanding what is happening

when cognitive impairments are suspected, can help both carers and people with dementia.

This area of research is firmly established with literature reviews covering recent papers, however the reviews do state that the literature is of variable quality and the results often contradictory. Where qualitative methods were used the authors gave greater strength to their findings through triangulation of themes, making them more robust in quality. On the opposing side, the measures used within some studies were not always appropriate for the population examined (Carpenter, et al, 2008).

There is a wide body of literature examining the beliefs and consequences of a diagnosis of dementia. There has been a shift from the papers that Bamford, et al. (2004) reviewed focusing on whether carers thought it was appropriate to inform the person with dementia, to later papers looking at the psychological consequences for both the carer and person with dementia. The difference for carers of people with Down syndrome and dementia, particularly family carers, is that this will not be the first diagnosis they have received, so it is interesting to wonder what this would mean psychologically for their preparedness for the diagnosis and their ability to adapt. The papers demonstrated the importance of carers being able to understand the diagnosis. They also highlighted the importance of an assessment of needs being undertaken independently of the person with Down syndrome and dementia. As Bamford et al (2004) highlighted, the voice of the person with dementia is not heard

within research and this is probably more true for people with Down syndrome and dementia.

Carers' experiences of negotiating the system

To receive a diagnosis of dementia, health services must be accessed. People may also encounter social care services and other providers. This is at a time when their relatives are experiencing cognitive changes; and they may be unsure what the changes mean. To help understand the experiences of carers of people with Down syndrome and dementia in negotiating these complex systems the review now turns to examine dementia caregivers' experiences of engaging with services.

Relationships within the system

This section examines the literature around relationships with people within the care system to try and understand what works well and what barriers there may be.

In a qualitative analysis of focus groups with carers, Morgan and Zhao (1993), found, overall, people had negative experiences of their doctor's attitude and care. They stated the relationship with their GP was particularly negative and they had more positive experiences with specialist doctors.

In contrast, Downs et al (2006) used qualitative and quantitative methods to evaluate 122 carers' experiences of GP contacts at the

beginning of help seeking behaviour. The majority of GPs were rated as at least good. Higher ratings were related to the GP showing concern, responding quickly, providing good access to the service, being thorough, appearing knowledgeable and taking the initiative. Lower ratings were related to a lack of acknowledgement, a lack of action, poor interpersonal skills and lack of empathy. This may suggest that GPs are becoming better at building relationships with people with dementia, as this research is more recent than that of Morgan and Zhao (1993).

However, the experiences of the person with dementia and carer are different. Aggarwal, Vass, Minardi, Ward, Garfield and Cybyk (2003) interviewed 27 people with dementia and their relatives about personal experiences of Alzheimer's and provision of care. The views of relatives were found to be more positive than those of the person with Alzheimer's. The positive views of carers were noted by Setterland (1998), who investigated the relationship between dementia care staff and family carers, in Australia, from staff carers' perspective. Staff described family members' gratitude for the care provided and experienced them as undemanding. They also saw family members as uninvolved in the care of their relatives and appeared critical of this, but were able to express an understanding of why it may be. However, Adams (2000) highlighted many family carers were given a prominent or active position, thus leaving the person with dementia in a more passive role.

Many people who have been suspected of/ or have developed dementia, go to a memory clinic. Foreman, Gardner and Davis (2004)

used the Dementia Care Satisfaction Questionnaire (van Hout et al., 2001) to evaluate 13 memory clinics within Australia. Data were obtained from 193 carers and 45 people with dementia. Overall, both groups were satisfied. This was also found to be the case in Willis, Chan, Murray, Matthews and Banerjee's (2009) qualitative evaluation of an English memory service. Some service-users found members of staff patronising and others found seeing people in more advanced stages of dementia distressing. The gaps in service were identified including not meeting the needs of those with early on-set dementia or the needs of those with mild cognitive impairment.

These papers often had high numbers of participants and have multi-modal methodology, using multiple sites. However, one of the papers cited (Willis, et al, 2009) was a service evaluation and is therefore only applicable to the site discussed.

When entering the system many people's initial point of contact is their GP and it appeared GPs struggle to build relationships with people with dementia. Therefore it may be harder for them to build relationships with someone who already had a cognitive impairment who then developed dementia. Research also suggested families may not always be fully involved in the care of their relative. Therefore, family carers' views on the provision of care may not be accurate and the different positions of family carer, staff carer and the person with Down syndrome and dementia need to be held in mind.

Barriers to accessing care

When looking at the care system it is important to understand what barriers there may be to people with dementia or possible dementia, accessing services, as these may also prevent carers of people with Down syndrome and dementia accessing the system.

Within a systematic review of ethnicity and pathways to care in dementia, Mukadam, Cooper and Livingstone (2010) identified 13 papers from the USA or UK. The studies revealed most groups had difficulty attributing symptoms to dementia, with many believing they were a normal part of ageing, or attributing symptoms to different spiritual beliefs or psychological causes such as stress. Those that did not see the symptoms as an illness were less likely to seek help from health services. Cultural pressure for family members to care for the person was also a barrier to help-seeking behaviour. Healthcare related barriers included experiences of discrimination, language barriers, a lack of clarity about where to seek help and a belief that nothing can be done. Knowledge of dementia appeared to be a positive factor towards help-seeking behaviour. The studies also highlighted that BME carers were more likely to only access services when they were in crisis. Carpentier, Ducharme, Kergoat and Bergman (2008) also found that those not in BME communities delayed accessing support because of carers' lack of knowledge of support available and responses developed by family and friend networks.

Mukadam et al's review examines the literature in a systematic way, however only 2 of the studies were from UK populations, so the results may not be wholly applicable. There was also large theoretical variation between studies and many had very small numbers of participants. However, the review still gives us an understanding of the BME communities' perspective and barriers to care.

These papers suggested familial and cultural scripts might influence a person's willingness or ability to access services and support. With a person with Down syndrome and dementia there would be further ideas around the learning disability, which may impact on families' desire to approach services.

Decision making

Throughout their lives, family members have made decisions and supported the adult with Down syndrome in making decisions about their life. When it is discovered a person has dementia further decisions have to be made about the person's care. The following paper examines the challenges of decision-making for carers of people with dementia.

Wackerbarth (1999) used a survey approach to ask 80 family caregivers what decisions they faced; which decisions were challenging and to describe their decision-making questions. The decisions were categorised according to their purpose. One-off decisions, such as obtaining guardianship, were considered less stressful, as they were generally less complex. Caregivers tended to implement small changes in

caregiving practices before implementing large changes, such as moving the person with dementia into care. Decisions considered challenging were day-to-day decisions to improve their ability to provide care (92.3%) and relocation decisions, whether that was into a nursing home (87.5%) or into the community (80.4%). Difficulties in making the decisions involved timing (67%), the superiority of alternatives (63%) and how to carry out the decisions (56%).

This study had a large sample, but used a non-standardised survey methodology. However, it is still a useful study to help us think about the decisions that need to be made.

Carers of adults with Down syndrome and dementia may have had to make many more decisions for the person throughout their life, so many of the decisions, such as financial ones, may have been made many years before the onset of dementia. However, carers will have to make day-to-day decisions and possibly decisions around relocation, which were found to be the most challenging.

The experience of caring for someone with dementia

Adults who have Down syndrome will in most cases already be cared for in some way, but as they develop dementia this care may need to change. Looking at the experiences of people caring for adults with dementia within the non-disabled population may help us understand the experiences of those within the Down syndrome population.

In a meta-analytic comparison of 168 empirical papers, Pinquart and Sorensen (2011) examined differences in burden related to the relationship with the care recipient. They identified that spousal carers experience higher depressive symptoms, higher financial and physical burden and lower levels of psychological well-being. This can partly be explained by higher levels of care provision, due to living with the care recipient. There was found to be little difference between children and child-in-law carers, other than children-in-law carers reporting a lower quality of relationship.

The relationship with spousal carer has been explored extensively. Quinn, Clare, Pearce and van Dijkhuizen (2008) used interpretative phenomenological analysis to examine 34 spousal carers' experiences of the early stages of dementia. They found four main themes: Difficulty in understanding the diagnosis and dementia; changes in the relationship; problems and challenges and the development of ways of coping. This shows that people need to have support in understanding dementia from the beginning. Chan, Mok, Wong, Pang and Chiu (2010) also highlighted carers' many unmet needs and social role conflicts, which impede their well-being.

Similarly, Rooness, Ulstein and Engedal (2009) examined the burden of spousal carers who were accessing a memory clinic for the first time. Two hundred and seventy six of those being cared for were diagnosed with cognitive impairment with no dementia (CIND) and 137 had a dementia diagnosis. High levels of impaired activities of daily living

and high depression in the people with memory impairment and being a female carer, were high predictors of stress for carers. The diagnosis of dementia had no impact on stress levels. The results suggest that it was disruption to life rather than the diagnosis that causes spousal carers' stress.

Furthermore, Moniz-Cook, Manthorpe, Carr, Gibson and Vernooji-Dassen (2006) in a semi-structured interview of 48 people with dementia and their carers about their appraisals of 'health threat', identified loss as a major concern. Fear of loss of control of bodily function, loss of personality factors and loss of pleasure over time were identified themes. Families were concerned about the prospect of a care home and wanted reassurances and information on what to do for their relative.

When caregiving ended Eloniemi-Sulkava, Rahkonen, Suihkonen, Halonen, Hentinen and Sulkava (2002) demonstrated spouses were at higher risk for loneliness, depressive feelings and sorrow than carers who were not spouses. They identified community support was a protective factor against these difficulties. Non-spouses appeared to experience relief when caregiving had ended.

Stigma is something that has been identified as a risk for carers. Werner, Goldstein and Buchbinder (2010) looked at the subjective experience of family stigma, as reported by 10 children of people with Alzheimer's dementia. They used semi-structured interviews to interview the relatives and used content analysis to examine the data. They found that carers had stigmatised attributions themselves; experienced others

as stigmatising and considered the health service to be flawed. This led to reduced involvement with their parent. However, there were some carers who reported increased closeness to their parent because of perceived external stigma.

Carers of people with Down syndrome and dementia may manage the onset of dementia better than those caring for someone without a disability. Carpentier, Bernard, Grenier and Guberman (2010) identified those with previous experience of caring for people with either a physical or mental health problem before the onset of dementia had an easier transition into the caring role. It was also found that the people they were caring for were more likely to be diagnosed within the first 12 months of onset.

Limitations of these studies are that some of the findings may not be generalisable due to concentrating on specific groups, locations or having a small sample size (Eloiem- Sulkava, et al, 2002, Werner, et al, 2010, Quinn et al, 2008, & Moniz- Cook et al, 2006).

The research suggests it is easier to care for someone with dementia if the carer was caring for them already, which would be the position of many carers of adults with Down syndrome and dementia. However, it also highlighted the importance of understanding the diagnosis and how as impairment of activities of daily living increased carer stress increased. However, being a spouse was a risk factor for more depressive feelings when caring ended and many carers would not be in a spousal relationship, so this may be mitigated. The stigma

reported within the research may be something carers of people with Down syndrome and dementia have had to manage for many years. This may make it easier to cope with or it may be compounded by the development of dementia.

Carers of adults with Down syndrome and dementia

Whilst the research is limited one review and three studies were located on the experiences of people who care for adults with Down's syndrome and dementia.

A systematic review was conducted by Courtenay, Jokinen and Strydom (2010) and 21 papers identified that related to social-psychological aspects of caregiving. They identified little research into family carers experiences, but noted the importance of the development of the Caregiving Difficulty Scale- Intellectual Disability (CDS-ID) (McCallion, McCarron & Force, 2005) and the Caregiver Activity Scale (CAS-ID) (McCarron, Gill, Lawlor & Begley, 2002) in the development of research into caregiver burden. It was found that mid and end-stage dementia; those with co-morbid conditions and the presence of challenging behaviour increased staff burden. It was also identified that staff react, rather than plan for changes in need. The burden can be reduced via education, training and support groups for staff, or interventions with the person with dementia.

The training needs of staff were evident in McCarron, McCallion, Fahey-McCarthy, Connaire and Dunn-Lane's (2010) examination of advanced dementia care. Staff described anxiety, as clients came towards end of life. The majority of staff wanted residents to age in place, but did not feel equipped to support their needs.

McLaughlin and Jones (2010) identified change as an overarching theme, within a thematic analysis of interviews with 4 siblings and 2 paid carers. Change involved trying to make sense of the change and change in ability and character. Previous experience of caring for someone with dementia was helpful preparation and having the diagnosis was seen as helping end uncertainty. Post-diagnosis was seen as a time of adjustment to a role of full-time carer and as the symptoms increased the carers need for support increased, but there was also a lack of awareness of how this support could be provided.

Many of the family carers of people with Down syndrome and dementia will be older adults themselves. Janicki, Zendell and DeHaven. (2010) examined the impact of caring on older carers. The study included 17 carers who were either elderly mothers or siblings living within the USA and did not find any significant detriment to the well-being of participants. This was explained as a result of the participants being long-term carers who had made a commitment early on to care for their relative and were seen as 'adaptive copers'.

There is not much evidence to draw upon within this area. The research there is gives some interesting insights into the experiences of

carers of people with Down syndrome and dementia. However, the studies discussed have low participant numbers. Those using qualitative methodology did not separate different types of carers, e.g., paid staff, parental, sibling (McLaughlin & Jones, 2010), but were still able to highlight carer experience.

This research suggests that there is no significant impact on the carers' well-being of caring for a person with Down syndrome and dementia and that, as they have experience of caring for the person throughout their lives, they are able to adapt to the changing situation. It also highlighted that paid staff carers may need more support in working with someone if they do develop dementia, as they may not feel equipped for the increased needs.

End of life issues

End of life is something that both carers of adults with Down syndrome and dementia and those with dementia or a learning disability have to face, so it may be helpful to draw upon the literature from all of these sources to examine how carers cope with this.

Within a review of the general dementia literature, Robinson, Hughes, Daley, Keady, Ballard and Volicer (2005) highlighted that paid staff carers did not associate dementia with end of life. They also struggled to manage the associated health, psychological and behavioural difficulties. Sanders and Swail (2011) attributed the

difficulties experienced by 43 hospice social workers, working with people with dementia, to finding the work un-stimulating and a lack of understanding and training about dementia (Kaasalainan, Brazil, Ploeg & Martin, 2007, Tuffrey-Wijne, Hogg & Curfs, 2007). This was counter-balanced by a desire to provide a 'good death' for clients (Tuffrey-Wijne, Hogg & Curfs, 2007) and finding meaning in their work through working in a person-centred way (Sanders & Swail, 2011).

Within learning disability literature it was found paid staff carers felt there was not enough support and they were not given enough time to mourn after the death of the person with a learning disability (Ryan, Guerin, Dodd & McEvoy, 2010). McKeniche's (2006) review of the literature suggested that problems involved lack of education, communication difficulties and a lack of involvement of the individual and their families in decision-making.

Anticipatory grief was discussed by Robinson, et al (2005). The concept of 'anticipatory grief' (Sweeting & Gilhooly, 1990; Sweeting & Gilhooly, 1997) involved grieving before the death of the relative. Anticipatory grief has been found to reduce grieving after death and the death may be seen as a relief (Owen, Goode & Haley, 2001; Collins, Liken, King & Kokinakis, 1993; Mullan, 1992). However, anticipatory grief can add to the difficulties of decision-making regarding their relative's care, thus increasing the carer's need for support (Hennings, Froggat & Keady, 2010). Sanders and Corley (2003) identified that some people did

not experience anticipatory grief and still valued the relationship they had with their relative.

Valuing the relationship and gaining satisfaction from caregiving were found to be risk factors associated with complex grief (Boerner, Schultz & Horowitz, 2004; Schultz, Boerner, Shear, Zhang & Gitlin, 2006). Other risk factors identified were: having higher levels of pre-death depression; caring for someone with more severe dementia; higher levels of burden; having poor perceived support when caring; being unsatisfied with external care provisions; not being able to say goodbye; being unable to recall positive memories and being a spouse rather than a child caregiver (Almberg, Grafstrom & Winbald, 2000; Bass, Bowman & Noelker, 1991; Boerner et al, 2004; Meuser & Marwit, 2001; Schultz et al, 2006; Shanley, Russell, Middleton & Simpson-Young, 2011). Owen, Goode and Haley (2001) also found African-American families were more likely to refuse to withhold treatment at the end of life; more likely to have their relative die at home; be less accepting of their relative's death and experience a greater sense of loss.

There were two studies that look specifically at caring for adults with Down syndrome and dementia at the end of life (McCarron, McCallion, Fahey-McCarthy & Connaire, Dunn-Lane, 2010; Watchman, (2005). They echo the findings of the research within general dementia care, in that, staff struggle to provide for the changing needs of the client as their health deteriorates (McCarron et al, 2010; Watchman, 2005). McCarron et al (2010) identified service systems create a barrier to carers

implementing changes to provide better care. Challenges staff faced included people not being allowed to age in place, not being able to provide person-centred care and difficulties enabling liaison with other services. It was also identified that staff wanted to provide their clients with a 'good death' (McCarron et al, 2010).

The research reviewed appears to be consistent across studies, thus increasing the strength of what is being expressed. Schultz et al (2006) conducted a randomised controlled trial, which demonstrates good quality, but other quantitative studies appear to have relatively low numbers and no control groups. The majority of papers are qualitative in methodology and often struggle to clearly define their method of analysis. There are three literature reviews within this research, one of which is a systematic review (Hennings, Froggat & Keady, 2010), which stresses the insufficient research in the area and that what research there is, is of variable quality.

These studies highlight that staff need support and training to enable them to support those with Down syndrome and dementia at the end of their life. The literature also suggests that higher levels of impairment, which would be found in the Down syndrome population, can contribute to increased likelihood of complex grief. We also have to be mindful of differences between groups of carers both in terms of their relationship to the adult with Down syndrome and their cultural background.

Communication and Information Giving

Throughout the review one aspect that has pervaded all areas is that people would like clear communication and information about the difficulties that they are facing. This is when they are receiving a diagnosis of their child's disability (Sharp, Strauss, Lorch, 1992, & Skotko, 2005), when they are navigating the system (Foreman, Gardner & Davis, 2004, & Aggarwal, et al, 2003) and when they are caring for someone (Moniz-Cook, et al, 2006, McLaughlin & Jones, 2010). It is highlighted that carers do not feel that the information is being adequately provided.

CONCLUSIONS

This review aimed to draw on wide ranging areas of research to attempt to understand the experiences of carers of adults with Down syndrome and dementia. It went through the life course, examining family member's experiences of the initial diagnosis of learning disability; the diagnosis of dementia and through to end of life, taking staff carers experiences into account.

The synthesis of research aimed to draw out similarities and differences between the experiences of those caring for Down syndrome and dementia and those caring for people with dementia alone. The similarities highlighted were that carers are important within the process and the process can be made easier if they understand the diagnosis and

its implications. It was demonstrated that caring for someone with dementia is a difficult job and if they also have Down syndrome this may be even harder. Many carers of people within the non-disabled population are spousal carers, which is unlikely to be the same for people with learning disabilities, but if they are parental carers they are likely to be the same age as spousal carers and therefore elderly themselves. This may result in them having to make major life changes, such as changing their plans for retirement or considering residential care for their child. At all points carers felt that receiving appropriate and timely information was important in helping them manage, but felt they were not always provided with this. Differences between the experiences were that it was unlikely that the people with Down syndrome were supporting a family or have a job, so the financial burden of the diagnosis is unlikely to have the same impact on the families of those without a disability.

The review also aimed to investigate if the experience of receiving an initial diagnosis of a learning disability made it easier for family members to manage the further diagnosis of dementia. We know parents caring for children with Down syndrome and dementia now, would probably not have had a positive experience of receiving a diagnosis of their child's disability. However, not all carers are parents, so other relationships, and how these impact on carer needs, should to be considered. The research suggested that despite the initial negative experience of receiving a diagnosis, carers of people with Down syndrome and dementia were able to cope with the additional diagnosis

of dementia, as they have been in the role of carer throughout the person's life, but the research was limited and based on very small samples.

It was highlighted that the difference between the needs of carers and the needs of the person with Down syndrome and dementia need to be assessed separately, as the literature suggested the needs and opinions were different. It also needs to be highlighted that the voice of people with Down syndrome and dementia were not to be found within the literature and this needs to be addressed in future research.

The review suggested that carers of people with dementia had difficulty in accessing the system. However, people who have Down syndrome are more likely to be in the system already, so therefore it may be easier for them access necessary supports. Acknowledging difference in terms of cultural background was also important, as it appeared to influence people's help-seeking behaviour. As there was little research in the area of carers of people with Down syndrome and dementia, there was no research on the impact on carers from BME populations.

The review highlighted differences in the experience of carer burden between different family members, with siblings and parental carers experiencing carer burden differently. Staff carers were found to experience most carer burden towards the mid to end stages of dementia; if there was a co-morbid condition and if there was challenging behaviour. It was also found that staff reacted to changing situations

rather than planning ahead, which suggests that staff need support with understanding future needs.

For paid staff carers end-of-life issues were difficult, as they did not feel equipped with the training, understanding or support to deal with the deaths of people either with learning disabilities or with dementia. This is an issue that can be resolved through offering staff what they think they need and hopefully with the application of the Dementia Strategy (DoH, 2009) these issues will be addressed. The issues for family carers at end-of-life were that caring for adults with both Down syndrome and dementia meant that they were at higher risk for experiencing complex grief, which may mean that support needs to be put in place for family members after the death of their relative.

This synthesis of literature demonstrated that more research is needed into the experiences of people who care for adults with Down syndrome and dementia, as the current research is limited and of variable quality.

REFERENCES

- Adams, T. (2000). The discursive construction of identity by community psychiatric nurses and family members caring for people with dementia. *Journal of Advanced Nursing*, 32, 791-798.
- Aggarwal, N., Vass, A. A., Minardi, H. A., Ward, R., Garfield, C. & Cybyk, B. (2003). People with dementia and their relatives: Personal experiences of Alzheimer's and of the provision of care. *Journal of Psychiatric and Mental Health Nursing*, 10, 187-197.
- Almberg, B. E., Grafstrom, M. & Winbald, B. (2000). Caregivers of relatives with dementia: Experiences encompassing social support and bereavement. *Aging and Mental Health*, 4, 82-89.
- Aminzadeh, F., Byszewski, A., Molnar, F. J. & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers perspective. *Aging and Mental Health*, 11, 281- 290.
- Arai, A., Matsumoto, T., Ikeda, M., & Arai, Y. (2007). Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia? *International Journal of Geriatric Psychiatry*, 22, 1255-1261.
- Bamford, C., Lamont, S., Eccles, M., Robinson, L., May, C. & Bond, J. (2004). Disclosing a diagnosis of dementia: A systematic review. *International Journal of Geriatric Psychiatry*, 19, 151-169.
- Bass, D., Bowman, K. & Noelker, L. (1991). The influence of caregiving and bereavement support on adjusting to an older relative's death. *The Gerontologist*, 31, 32-42.
- Blacher, J., Neece, C. L. & Paczkowski, E. (2005). Families and intellectual disabilities. *Current Opinion in Psychiatry*, 18, 507-513.
- Boerner, K., Schultz, R. & Horowitz, A. (2004). Positive aspects of caregiving and adaptation after bereavement. *Psychology and Aging*, 19, 668-675.

- Carpenter, B. & Dave, J. (2004). Disclosing a dementia diagnosis: A review of opinion and practice, and a proposed research agenda. *The Gerontologist*, 44, 149-157.
- Carpenter, B. D., Xiang, C., Porensky, E. K., Lee, M. M., Brown, P. J., Coats, M., Johnson, D. & Morris, J. C. (2008). Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment. *Journal of the American Geriatrics Society*, 56, 405-412.
- Carpentier, N., Bernard, P., Grenier, A. & Guberman, N. (2010). Using the life course trajectory to study the entry into the illness trajectory: The perspectives of caregivers of people with Alzheimer's disease. *Social Science and Medicine*, 70, 1501-1508.
- Carpentier, N., Ducharme, F., Kergoat, M. & Bergman, H. (2008). Social representations of barriers to care early in the careers of caregivers of persons with Alzheimer's disease. *Research on Aging*, 30, 334-357.
- Chan, W. C., Mok, C. C. M., Wong, F. L. F., Pang, S. L. & Chiu, H. F. K. (2010). Lived experience of caregivers of persons with Dementia in Hong Kong: A qualitative study. *East Asian Archive of Psychiatry*, 20, 163-168.
- Collins, C., Liken, M., King, S. & Kokinakis, C. (1993). Loss and grief among family caregivers of relatives with dementia. *Qualitative Health Research*, 3, 236-253.
- Connell, C. M., Boise, L., Stuckey, J. C., Holmes, S. B. & Hudson, M. L. (2004). Attitudes towards the diagnosis and disclosure of dementia among family caregivers and primary physicians. *The Gerontologist*. 44, 500-507.
- Courtenay, K., Jokinen, N. S. & Strydom, A. (2010). Caregiving and adults with intellectual disabilities affected by dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 7, 26-33.

- Cunningham, C. C., Morgan, P. A. & McGucken, R. B. (1984). Down's syndrome: Is dissatisfaction with disclosure of diagnosis inevitable? *Developmental Medicine and Child Neurology*, 26, 33-39.
- Dent, K. M. & Carey, J. C. (2006). Breaking difficult news in a newborn setting: Down syndrome as a paradigm. *American Journal of Medical Genetics Part C (Seminars in Medical Genetics)*, 142C, 173-179.
- Department of Health. (2009). *Living well with dementia: A National Dementia Strategy*. London: Department of Health.
- Derksen, E., Vernooji-Dassen, M., Gillissen, F., Olde-Rikkert, M. & Scheltens, P. (2005). The impact of diagnostic disclosure in dementia: A qualitative case analysis. *International Psychogeriatrics*, 17, 319-326.
- Downs, M., Ariss, S. M. B., Grant, E., Keady, J., Turner, S., Bryans, M., Wilcock, J., Levin, E., O'Carroll, R. & Iliffe, S. (2006). Family carers' accounts of general practice contacts for their relatives with early signs of dementia. *Dementia*, 5, 353-373.
- Eloniemi-Sulkava, U., Rahkonen, T., Suihkonen, M., Halonen, P., Hentinen, M. & Sulkava, R. (2002). Emotional reactions and life changes of caregivers of demented patients when home caregiving ends. *Aging and Mental Health*, 6, 343-349.
- Fisk, J. D., Beattie, B. L., Donnelly, M., Byszewski, A. & Molnar, F. J. (2007). Disclosure of the diagnosis of dementia. *Alzheimer's and dementia*, 3, 404-410.
- Foreman, P., Gardner, I.L., & Davis, S. (2004). Multidisciplinary memory clinics: what is important to caregivers and clients? *International Journal of Geriatric Psychiatry*, 19, 588-589.
- Freyne, A., Kidd, N., Coen, R. & Lawlor, B. A. (1999). Burden in carers of dementia patients: higher levels in carers of younger sufferers. *Geriatric Psychiatry*, 14, 784-788.

- Gayton, W. F., Walker, L. & Rochester, M. S. W. (1974). Down syndrome: Informing the parents. *American Journal of the Disabled Child*, 127, 510-512.
- Girgis, A. & Sanson-Fisher, R. W. (1995). Breaking bad news: Consensus guidelines for medical practitioners. *Journal of Clinical Oncology*, 13, 2449-2456.
- Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science and Medicine*, 64, 150-163.
- Hennings, J., Froggatt, K. & Keady, J. (2010). Approaching the end of life and dying with dementia in care homes: The accounts of family carers. *Reviews in Clinical Gerontology*, 20, 114-127.
- Janicki, M. P., Zendell, A. & DeHaven, K. (2010). Coping with dementia and older families of adults with Down syndrome and dementia. *Dementia*, 9, 391-407.
- Kaasalainen, S., Brazil, K., Ploeg, J. & Martin, L. S. (2007). Nurses' perceptions around providing care for long-term care residents with dementia. *Journal of Palliative Care*, 23, 173-180.
- Korsch, B., Gozzi, E. & Francis, V. (1968). Gaps in doctor-patient communication. I: Doctor-patient interaction and patient satisfaction. *Pediatrics*, 42, 855-871.
- Laakkonen, M. L., Raivio, M. M., Eloniemi-Sulkava, U., Saaenheimo, M., Pietila, M., Tilvis, R. S. & Pitkala, K. H. (2011). How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care? *Journal of Medical Ethics*, 34, 427-430.
- Ley, P. (1977). Psychological studies of doctor-patient communication. In S. Rachman (eds) *Contributions to Medical Psychology, Vol. 1*. Oxford: Pergamon Press.

- Luscombe, G., Brodaty, H. & Freeth, S. (1998) Younger people with dementia: diagnostic issues, effects on carers and use of services. *International Journal of Geriatric Psychiatry*, 13, 1-7.
- McCallion, P., McCarron, M. & Force, L. T. (2005). A measure of subjective burden for dementia care: the Caregiving Difficulty Scale- Intellectual Disability. *Journal of Intellectual Disability Research*, 49, 365-371.
- McCarron, M., Gill, M., Lawlor, & Begley, C. (2002). Time spent caregiving for persons with the dual disability of Down's syndrome and Alzheimer's dementia: Preliminary findings. *Journal of Intellectual Disabilities*, 6, 263-279.
- McCarron, M., McCallion, P., Fahey-McCarthy, E., Connaire, K. (2010). Staff perceptions of essential prerequisites underpinning end-of-life care for persons with intellectual disabilities and advanced dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 7, 143-152.
- McCarron, M., McCallion, P., Fahey-McCarthy, E., Connaire, K. & Dunn-Lane, J. (2010). Supporting persons with Down syndrome and advanced dementia: Challenges and care concerns. *Dementia*, 9, 285-298.
- McKechine, R. C. (2006). What does the literature tell us about death, dying and palliative care for people with intellectual disabilities. *Progress in Palliative Care*, 14, 255-259.
- McLaughlin, K. & Jones, A. (2010). 'It's all changed:' Carers' experiences of caring for adults who have Down's syndrome and dementia. *British Journal of Learning Disabilities*, 39, 57-63.
- Mendez, M. F. (2006). The accurate diagnosis of early-onset dementia. *International Journal of Psychiatric Medicine*, 36, 401-412.
- Meuser, T. M. & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist*, 41, 658-670.

- Moniz-Cook, E., Manthorpe, J., Carr, I., Gibson, G. & Vernooji-Dassen, M. (2006). Facing the future: A qualitative study of older people referred to a memory clinic prior to assessment and diagnosis. *Dementia*, 5, 375-395.
- Morgan, D. L. & Zhao, P. Z. (1993). The doctor-caregiver relationship: Managing the care of family members with Alzheimer's disease. *Qualitative Health Research*, 3, 133-164.
- Mukadam, N., Cooper, C. & Livingstone, G. (2010). A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry*, 26, 12-20.
- Mullan, J. (1992). The bereaved caregiver: A prospective study of changes in well-being. *The Gerontologist*, 5, 673-683.
- Neely-Barnes, S. L., Graff, C., Roberts, R. J., Hall, H. R. & Hankins, J. S. (2010). "It's our job": Qualitative study of family responses to ableism. *Intellectual and Developmental Disabilities*, 48, 245-258.
- Nixon, C. L. & Cummings, M. (1999). Sibling disability and children's reactivity to conflicts involving family members. *Journal of Family Psychology*, 13, 274-285.
- Owen, J. E., Goode, K. T. & Haley, W. E. (2001). End of life care and Reactions to death in African-American and White family caregivers of relatives with Alzheimer's disease. *Omega*, 43, 349-361.
- Partington, K. J. (2002). Maternal responses to the diagnosis of learning disabilities in children: A qualitative study using a focus group approach. *Journal of Learning Disabilities*, 6, 163-173.
- Pinquart, M. & Sorensen, S. (2011). Spouses, adult children and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*, 26, 1-14.

- Ptack, J. T. & Eberhardt, T. L. (1996). Breaking bad news: A review of literature. *Journal of the American Medical Association*, 276, 496-502.
- Quine, L. & Ruther, D. R. (1994). First diagnosis of severe mental and physical disability: A study of doctor- parent communication. *Journal of Child Psychology and Psychiatry*, 35, 1273-1287.
- Quinn, C., Clare, L., Pearce, A. & van Dijkhuizen, M. (2008). The experience of providing care in the early stages of dementia: An interpretative phenomenological analysis. *Aging and Mental Health*, 12, 769-778.
- Robinson, L., Hughes, J., Daley, S., Keady, J., Ballard, C. & Volicer, L. (2005). End-of-life care and dementia. *Reviews in Clinical Gerontology*, 15, 135-148.
- Roones, T. A., Ulstein, I. & Engedal, K. (2009). Stress affects carers before patient's first visit to a memory clinic. *International journal of Geriatric Psychiatry*, 24, 1143-1150.
- Ryan, K., Guerin, S., Dodd, P. & McEvoy, J. (2010). End-of-life care for people with intellectual disabilities: Paid carer perspectives. *Journal of Applied Research in Intellectual Disabilities*, 24, 199-207.
- Sampson, E. L., Warren, J. D. & Rossor, M. N. (2004). Young onset dementia. *Postgraduate Medical Journal*, 80, 125-139.
- Sanders, S. & Corley, C. S. (2003). Are they grieving? A qualitative analysis examining grief in caregiving of individuals with Alzheimer's disease. *Social Work in Health Care*, 37, 35-53.
- Sanders, S. & Swail, P. (2011). A quest for meaning: Hospice social workers and patients with end-stage dementia. *Social Work*, 56, 129-139.
- Schulz, R., Boerner, k., Shear, K., Zhang, S. & Gitlin, L. N. (2006). Predictors of complicated grief among dementia caregivers: A

prospective study of bereavement. *The American Journal of Geriatric Psychiatry*, 14, 650-658.

Setterland, D. S. (1998). Dementia care staff and family carers: Their relationship in the context of care. *Australian Journal on Aging*, 17, 135-139.

Shanley, C., Russell, C., Middleton, H. & Simpson-Young, V. (2011). Living through end-stage dementia: The experiences and expressed needs of family carers. *Dementia*, 10, 325-340.

Sharp, M. C., Strauss, R. P. & Lorch, S. C. (1992). Communicating medical bad news: Parents' experiences and preferences. *Journal of Pediatrics*, 121, 539-546.

Skotko, B. G. (2005). Mothers of children with Down syndrome reflect on their postnatal support. *Pediatrics*, 115, 64-77.

Skotko, B. G. & Levine, S. P. (2006). What the other children are thinking: Brothers and sisters of persons with Down syndrome. *American Journal of American Genetics Part C (Seminars in Medical Genetics)*, 142 C, 180-186.

Sweeting, H. N. & Gilhooly, M. L. (1990). Anticipatory grief: A review. *Social Science and Medicine*, 30, 1073-1080.

Sweeting, H. N. & Gilhooly, M. L. (1997). Dementia and the phenomenon of social death. *Sociology of Health and Illness*, 19, 93-117.

Tuffrey-Wijne, I., Hogg, J. & Curfs, L. (2007). End-of-life and palliative care for people with intellectual disabilities who have cancer or other life-limiting illness: A review of the literature and available resources. *Journal of Applied Research in Intellectual Disabilities*, 20, 331-344.

van Hout, H. P. J., Vernooij-Dassen, M. J. F. J., Hoef-Nagels, W. H. L. & Grol, R. P. T. M. (2001). Measuring the opinions of memory clinic users: patients, relatives and general practitioners. *International Journal of Geriatric Psychiatry*, 16, 846-851.

- van Vliet, D., de Vugt, M. E., Bakker, C., Koopmans, R. T. C. M. & Verhey, F. R. J. (2010). Impact of early onset dementia on caregivers: A review. *Geriatric Psychiatry*, 25, 1091-1100.
- Vernooji-Dassen, M., Derksen, E., Scheltens, P. & Moniz-Cook, E. (2006). Receiving a dementia diagnosis. *Dementia*, 5, 397-410.
- Wackerbarth, S. (1999). What decisions are made by family caregivers? *American Journal of Alzheimer's Disease*, 14, 111-119.
- Watchman, K. (2005). Practitioner-raised issues and end-of-life care for adults with Down syndrome and dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 2, 156-162.
- Werner, P., Goldstein, D. & Buchbinder, E. (2010). Subjective experience of family stigma as reported by children of Alzheimer's disease patients. *Qualitative Health Research*, 20, 159-169.
- Willis, R., Chan, J., Murray, J., Matthews, D. & Banerjee, S. (2009). People with dementia and their family carers' satisfaction with a memory service: A qualitative evaluation generating quality indicators for dementia. *Journal of Mental Health*, 18, 26-37.

EMPIRICAL PAPER

Family member and professional carer perspectives on caring for adults
with Down syndrome and dementia

Word Count: 8086 (excluding Tables, Figures, References, Indented
Quotes and Appendices)

To be prepared for submission to The Journal of Applied Research in
Intellectual Disabilities

Abstract

To date, little research has investigated what carers understand about the diagnosis of dementia and what their thoughts and feelings are about caring for a person with this diagnosis. This research explored paid staff carers' and family carers' experiences around caring for an individual with Down syndrome and dementia and looked for convergences and differences in their subjective accounts. Semi-structured interviews were conducted and interpretative phenomenological analysis (IPA) was employed for comprehensive and systematic exploration of how events, processes and relationships were understood by the participants and the researcher. Family member and paid staff carer accounts were examined separately. For family members four themes emerged; dementia and understanding; emotional containment; relationships and difficulties endured. For professional carers four themes emerged; dementia meaning; containment; witnessing others suffering and person-centred.

Similar themes emerged for family members and paid staff carers. The main differences were the emotional content. Family members were immersed in the experiences and it was a painful part of their lives, whereas staff carers talked about the experiences from an observer position. Possible reasons for the differences were discussed in terms of psychological defences and attachment theory. The differences described need to be explored further to understand the reasons for them. The importance of emotional containment for both groups was also

highlighted and how these can be developed further within service delivery to help prevent distress.

Keywords: 'intellectual disabilities'; 'Down syndrome'; 'dementia'; 'staff'; 'carer'; 'qualitative research'

INTRODUCTION

The Alzheimer's Society (2012) estimated there are 800,000 people living with dementia in the UK and the Down Syndrome Association (2012) estimated there are 60,000 people living with Down syndrome. It has been recognised that adults who have Down's syndrome are more likely to develop dementia than the general population (Nieuwenhuis-Mark, 2009), and this is particularly true for those who are over the age of 35 years (Tyrell, et al., 2001, Zigman, Silverman & Wisniewski, 1996). The prevalence data for dementia in adults with Down syndrome varies between 7% and 50% depending on measures used and the age of the sample (Zigman, Schupf, Sersen & Silverman, 1995). Nieuwenhuis-Mark (2009) states average prevalence rates appear to be around 15% and increase with age.

Within the UK, due to higher prevalence, the National Dementia Strategy (Department of Health, 2009) highlighted the needs of people with Down syndrome and their carers and outlined objectives aimed at improving all areas of the care system. The Dementia Strategy emphasised the importance of carers and Valuing People (Department of Health, 2001), a key White Paper in the development of learning disability services, acknowledged that supporting carers was central to supporting people with learning disabilities. As such, guidance was developed on how to implement the Carer's Strategy (Department of Health, 1999) within this population. The needs of carers within both the dementia and

learning disability populations has long been acknowledged and it may be those caring for adults with both Down syndrome and dementia have greater needs.

Studies have investigated whether there is an increase in behavioural disturbance after a person with Down syndrome has been diagnosed with dementia (Prasher & Filer, 1995; Cooper & Prasher, 1998; Millichap, Oliver, McQuillan, Kalsy, Lloyd & Hall, 2003; Adams, et al, 2007), which may impact on a carer's life, but there have been inconsistent findings. However, Donaldson (2002) and Lloyd, Kalsy and Gatherer (2008) highlighted that decrease in perceived staff well-being after a dementia diagnosis was not related to increases in challenging behaviours. McCarron, Gill, Lawlor, and Beagly (2005), McCarron, Gill, Lawlor and Beagly (2002), McCallion, McCarron and Force (2005) and McCarron, Gill, McCallion, and Begley (2005) demonstrated that caregiver activity increased after the diagnosis of dementia, but were inconclusive as to whether this increased subjective burden. Janicki, Zendell and DeHaven (2010) found there was no detrimental impact to carers' well-being. A case study by Soliman and Hawkins (1998) highlighted the gaps in service provision. The staff within the study struggled to meet the clients' needs, suggesting there were issues to be addressed by services and commissioners (Watchman, 2003; Watchman, 2008). Kalsy, Heath, Adams and Oliver (2007) found that training staff who work with people with Down syndrome and dementia, about dementia, influenced the attributions that they made about the

controllability of behaviours. Anxiety was found to increase in staff as clients came towards the end of life (McCarron, McCallion, Fahey-McCarthy, Connaire & Dunn-Lane, 2010) and carers were found to need increased support as symptoms of dementia increased (McLaughlin & Jones, 2010).

However, to date, little research has investigated what carers understand about the diagnosis of dementia and what their thoughts and feelings are about caring for a person with this diagnosis. The majority of the research has been quantitative and not directly about the effect that caring has on the carer, but looks at issues that may impact upon them, such as increases in behavioural disturbance. The research does not often make the distinction between those who are employed carers and those who are family carers and the difference this has on the emotional impact of caring for the person and the way carers view the person.

The diagnosis of dementia may have a major impact on carers emotionally, as they watch someone they have worked with or who is a family member, lose cognitive functioning and develop different behaviours. If we are able to understand what carers are aware of, and improve our understanding of the processes that are occurring, we will be better able to support them in coping with the issues raised, and this will hopefully improve the quality of life for adults with Down's syndrome and dementia.

Aim

There is limited research about caring for someone with Down syndrome and dementia. This research explored paid staff carers' and family carers' experiences around caring for an individual with Down syndrome and dementia and looked for convergences and differences in their subjective accounts.

METHOD

Design

The qualitative methodology interpretative phenomenological analysis, IPA (Smith, Flowers, Larkin, 2009) was employed, as the researcher was interested in the professional carers' and family members' experience of caring for those with Down syndrome and dementia. IPA is underpinned by the philosophical concepts of phenomenology (Husserl, 1927; Heidegger, 1962; Merleau-Ponty, 1962 and Sartre, 1948), hermeneutics (Schleiermacher, 1998; Heidegger 1962; and Gadamer, 1960) and idiography. This means that IPA is employed to attempt to understand how others experience their existence, acknowledging an interpretative position, as the researcher tries to make sense of their experiences, whilst also taking into account the person's individual context and life experiences.

Thus IPA is ideal for comprehensive and systematic exploration of how events, processes or relationships are understood by the participant and the researcher (Smith, Flowers & Larkin, 2009). IPA is helpful in eliciting individual stories and provides a way of exploring the possibility of individual differences in how people experience and understand caring for a person with Down's syndrome and dementia. IPA involved the researcher trying to make sense of a person's world through a process of interpretative engagement with the transcript of an individual's interview. The process was iterative and involved identifying themes that were clustered and labelled to try and capture the essence of what was being conveyed.

Procedure

The research outline was presented at the 'Age Well Conference' at the University of Birmingham to consult with older adults interested in research, on the methodology and ethics. Ethical approval was obtained from the Social Care Research Ethics Committee (Appendix 3).

Participants were recruited through private sector and third sector care homes within the West Midlands. Recruitment was purposive. Participants needed to be professional carers or family members of adults who had a diagnosis of Down's syndrome and dementia. The care home managers were approached by a clinical psychologist, working for a Community Learning Disability Dementia Service, to secure the homes' agreement for staff members to participate. Once management

agreement was obtained, the clinical psychologist approached family members and paid staff carers to invite them to discuss their experiences. The psychologist used a participant information sheet (Appendix 4) to help explain the research and ensure that participants were aware that if they did not wish to take part there would be no implications for the person with Down's syndrome and dementia and no implications from the organisation that they worked for. The psychologist then forwarded the person's contact details to the researcher who contacted them to discuss the research further. Informed consent was then obtained (Appendix 5).

Interviews of family members took place in their homes. Interviews of staff members either took place in their workplace or within the NHS Community Learning Disability Service. Interviews ranged from 30 to 100 minutes. All interviews were audio taped to allow for accurate transcription and for the researcher to focus on the interview and participant rather than on taking notes. The interviews were transcribed by the researcher and all identifying information removed.

After the interviews, copies of the transcripts were sent to participants and any text they wished to be excluded from the analysis was removed.

Interview Schedules

Interviews were conducted using a semi-structured topic guide (Appendix 6) (see brief outline below) based on broad questions about the person's experiences of caring for someone with Down syndrome and

dementia. The topic guide acted as an aid for the researcher to cover various areas during the interview, but also gave the participants the opportunity to reflect on their experiences.

Table 2: Main Areas Covered by Semi-Structured Topic Guide

Understanding dementia
Experiences of diagnosis
Effects of dementia on life
Life before and after dementia
What the future holds
Coping day-to-day

Participants

A total of ten participants took part, over the course of 8 interviews. A sole staff member was interviewed regarding their experiences with each person with Down syndrome, and corresponding family members were either interviewed alone or in couples. Demographic information is provided in Table 3.

Table 3: Participant demographics

Person with Down Syndrome and dementia	Family Members		Paid staff carer	
Laura Lives at home with her parents and attends a day centre 5 days a week.	Name*	Harry and Joyce (white Irish)	Name	Heather (white UK)
	Relationship	Parents-caring for Laura at home.	Relationship	Key worker-caring for Laura 5 days a week at a learning disability day centre
Matthew Lives in a group home and his most significant relationship is with his sister.	Name	Margaret (white UK)	Name	Janet (white UK)
	Relationship	Sister-previous home carer	Relationship	Senior carer-learning disability care home
Alex Has lived in a group home for many years. Prior to this lived with his parents.	Name	John and Claire (white UK)	Name	Tracey (white UK)
	Relationship	Brother and sister-in-law-occasional visits to home	Relationship	Senior carer-learning disability care home
Craig Lives in a group home. Craig is one of seven siblings and has a close relationship with his mother and two of his sisters.	Name	Jean (white UK)	Name	Sharon (white UK)
	Relationship	Sister-weekly visits to home	Relationship	Key worker-learning disability care home

**All names have been changed to protect confidentiality.*

Data Analysis

When analysing the participants' transcripts it was ensured that accepted IPA protocol was adhered to.

Table 4: Analysis using accepted IPA protocol (Smith, Flowers & Larkin, 2009):

Step 1:	Reading and Re-reading of the transcripts.
Step 2:	Initial Noting (Identifying descriptive, linguistic and conceptual comments).
Step 3:	Development of emergent themes (identifying emergent themes through connections and patterns between initial notes).
Step 4:	Searching for connections across emergent themes (looking for interrelationship between emergent themes).
Step 5:	Moving to the next case.
Step 6:	Looking for patterns across cases. The last step involved looking for patterns amongst group experiences, in terms of paid staff carer's experiences and family member experiences.

As a means of minimising the effect of any single researcher's interpretation bias, the analysis and coding process was completed by the chief researcher, but was discussed with two research supervisors at each stage. All themes required agreement/consensus from the whole research team to be accepted. This served to minimise idiosyncratic codes or interpretations and promote greater plausibility. All analysis was completed manually. To aid transparency, a worked example has been provided (Appendix 7).

Self-reflexivity

The hermeneutic underpinning of IPA acknowledges the interpretative role of the researcher and thus the preconceptions the researcher brings to the study, which may influence data collection and analysis. Of particular note in this study is the researcher's position as the daughter of a paid staff carer and the grand-daughter of a family carer of older adults with dementia. I am also currently working within a psychotherapy service, which colours the way I view the world (see appendix 8 for further details of the researcher's position).

Results

The results were analysed in two groups, family carers and paid staff carers. For both groups four super-ordinate themes emerged. For the family carers the themes were Dementia and Understanding; Emotional Containment; Relationships and Difficulties Endured (Table 5). For the staff carers the themes were Dementia Meaning; Containment; Witnessing Others Suffer and Person-centred care (Table 6). Each super-ordinate theme comprises sub-ordinate themes that will be explored in more detail.

Table 5: Family carers contribution to sub-ordinate themes

Super-ordinate theme	Sub-ordinate theme	Participants contributing to the sub-ordinate theme
Dementia and understanding	The meaning of dementia	<ul style="list-style-type: none"> • Jean • Harry and Joyce • John and Claire
	Struggle to understand	<ul style="list-style-type: none"> • All
Emotional Containment	Difficult emotions	<ul style="list-style-type: none"> • All
	Containment	<ul style="list-style-type: none"> • All
Relationships	Person-centred	<ul style="list-style-type: none"> • Jean • Harry and Joyce • John and Claire
	Reciprocity	<ul style="list-style-type: none"> • Jean • Harry and Joyce • Margaret
	Systemic difficulties	<ul style="list-style-type: none"> • All
Difficulties Endured	Loss	<ul style="list-style-type: none"> • All
	Sacrifices	<ul style="list-style-type: none"> • Jean • Harry and Joyce • Margaret
	Unjust suffering	<ul style="list-style-type: none"> • Jean • Harry and Joyce • Margaret
	Fear of things to come	<ul style="list-style-type: none"> • All

Table 6: Paid staff carers contribution to sub-ordinate themes

Super-ordinate themes	Sub-ordinate themes	Participants contributing to the sub-ordinate themes
Dementia meaning	Understanding inner world	<ul style="list-style-type: none"> • Janet • Heather • Sharon
	Meaning	<ul style="list-style-type: none"> • All
Containment	Awareness of dementia in own life	<ul style="list-style-type: none"> • Tracey • Janet
	Difficult emotions	<ul style="list-style-type: none"> • Tracey • Heather
	Emotional attachment v Distance	<ul style="list-style-type: none"> • All
	Do the best job we can	<ul style="list-style-type: none"> • All
Witnessing others suffering	Unjust suffering	<ul style="list-style-type: none"> • Heather • Sharon
	Bleak future	<ul style="list-style-type: none"> • All
	Loss	<ul style="list-style-type: none"> • All
Person-centred	Person-centred	<ul style="list-style-type: none"> • All

FAMILY MEMBER THEMES

Dementia and Understanding

The families all had different experiences of dementia. They all had views on what dementia meant, but some had a greater understanding of the diagnosis whilst others seemed lost and confused by dementia and what it actually meant for their relative. Within the concept of understanding are two sub-ordinate themes: 'The meaning of dementia' and 'Struggle to understand'.

The Meaning of dementia: All participants conceptualised dementia as 'memory loss', with this being described by many families as the prevailing narrative within society and the understanding that they had had of dementia before their relative developed it.

Some families said it was a gradual process, which Harry described as not noticing at first:

It's obviously, er, er. What happens it doesn't over night, because there's just gradual, very gradual and when you're living with a person on a day to day basis, er, er, it doesn't hit you so much as, er, er like when someone hadn't seen that person for weeks or months. Like our son hadn't and he could see there was something happening. We knew there was something wrong, but we obviously didn't think it was something as drastic as dementia. (Harry, line 157-165)

Harry and Joyce also described it as a developing process, with an insidious quality, where "it's problems on top of problems". It is described as 'building up', suggesting a movement away from understanding dementia as memory loss, to a complex understanding of a multi-layered difficulty, affecting many aspects of the person's life. This gives a sense the 'building up' is weighing Harry and Joyce down and as time moves forward they have to constantly adjust to Laura's changing needs, giving them little time to process what is happening or get used to the differences in their lives.

John, along with Jean, "noticed a big change very quickly." (John, line 28) The sudden nature of the change did not appear to be less

distressing for families and may have contributed towards a feeling of confusion about what was happening.

The process of getting a diagnosis was found to be long, but Harry and Joyce felt it was thorough, ensuring all possibilities were examined:

They checked all her medication; he checked all her records; all her history. Everything like that. What medication she was on, to try and see if it was. Cause obviously they can't just pin it down to that at the time. So after all the research, they then decided then, that there was no doubt about it then, she had dementia. (Harry, line 115-120)

Jean felt that getting a diagnosis helped her to feel in control and able to be proactive in response to Craig's difficulties. However, she also struggled with the idea of Craig having a diagnosis of dementia:

No, I think if they hadn't have diagnosed with dementia and they'd said, it's just how Craig is he's getting old, I think I'd have probably looked at it in a different way. But I think this dementia's got a stigma to it, like a, you here, well, like I said I work, we've got residents with dementia and I can see how bad they get and it is frightening when you look at it really. I think if they'd just said it's just how Craig's got with his Downs and he's gradually going to get worse, it probably wouldn't have sounded so frightening, but because we know it's dementia, he could just suddenly get really bad and he could just forget who we are. (Jean, line 1534-1550)

Jean felt dementia had a 'stigma' to it and the label brought with it some unknown fear. The idea of Craig deteriorating because of a learning disability seemed easier to manage emotionally and suggests the word 'dementia' has a huge amount of power to elicit both negative meaning and feeling.

Struggle to understand: All participants had difficulty conceptualising dementia. None was able to recognise initially that dementia was the cause of the difficulties their relative was having and they appeared unaware of the higher prevalence of dementia amongst people with Down syndrome, which left them unprepared for the possibility of this happening:

But we're finding out more and more, like, ya know. Erm, I think, everybody's finding more and more now, because it's associated, Down's with dementia. The percentage is much higher....when your Down's. We weren't aware of that.... So when I read into it and [the psychologist] put us in the picture and I read into it. Where in the past they thought Down's was probably like what I thought, what we thought, erm is it because she's aging. (Joyce, line 1386-1396)

Joyce and Jean went through a similar process of "denial" and when Jean was told it was dementia she stated: "No it can't be". The idea of dementia was difficult for families to accept and they defended against the pain of what dementia meant to them through denial.

Jean, as well as John and Claire, experienced confusion around the diagnosis and John struggled to understand when explanations were offered:

John: I think they have explained that. They was talking about that.

Claire: It must have been one meeting when I couldn't go.

John: They have explained things to me, but half the time, you say, yeah, yeah and you forget, or you just don't quite understand it. It ain't very nice is it.

(John and Claire, line 440-445).

This demonstrates difficulties families had understanding, due to the complexity of unfamiliar language used and how this served to mystify dementia, leaving families confused about what was happening. There seemed to be a barrier to asking for clarification, as John asserts that “we’re not ignorant, we just don’t understand”, suggesting he may have been made to feel “ignorant” by a system that has its own language that he felt unable to access.

These two sub-themes demonstrate families trying to make sense of what is happening to their relative. Dementia was thought about in different ways with families struggling with various aspects.

Emotional Containment

Families found their relative having dementia created difficult emotions that needed to be contained, leading to two sub-themes of: ‘Difficult Emotions’ and ‘Containment’.

Difficult Emotions: For all families, difficult feelings were aroused by their relative having dementia. Margaret expressed a sense of being “hopeless” and “helpless” and had thoughts that: “There’s nothing” she could do to help Matthew. She also described an emptiness as they used to spend: “Everyday, 24 hours a day” together and he was “company” for her, but now she was left on her own and she felt things weren’t getting any easier for her:

You know, it's hard for me to sorta. Although he's been in there five or six years, it's still as painful as the first day [crying]. And people think it gets better, but not for me. And, er, I found it hard to express, I mean I find it hard to express myself to me children or me husband. (Margaret, line 554-559)

Things seemed incredibly painful for Margaret. She described her feelings as "raw" and the language she used evoked images of a person lost, whose emotions were spilling out. It felt as if she could not imagine the pain stopping. Margaret appeared to relate to physical pain in the way she described her emotions, embodying her experiences, and this was echoed by Harry who described his emotions as a "body blow" and how it "hurt us so much".

John was "more concerned" for Alex since he had developed dementia and this led him to "see him more than I used to". However, he stated that one reason for this was "probably guilt". John conveyed that if he did not visit Alex "the staff think his brother don't come and see him", so there was a sense of obligation and a desire not to be judged by others.

Margaret disclosed strong feelings of guilt due to thoughts she had let both her father and brother down:

Margaret: I can't explain to anybody what it's like. And it's like, I always said to me dad I'd look after him and I feel as though I've let him down.

Interviewer: You feel as if you've let your father down?

Margaret: Yes, because I said I'd always look after him as long as I was well enough. You know. Because I've had him in a home, it always gets me worked sorta thing. Everybody always says you've

done a marv..., but at the end of the day, I had health, you know, and I want him here with me, but I know it's impossible. (Margaret, line 194-204)

Jean and Margaret struggled to feel expressing emotions was acceptable. Margaret felt her emotions were "private" and struggled to "express myself to me children or husband". From Margaret's interview it is hard to imagine how she kept such strong emotions suppressed, but she described herself as almost stoical, which is in contrast to how she presented. Jean felt that emotions showed weakness and she should try harder to "be more in control." This led Jean to judge herself harshly for expressing her feelings.

Containment: Whilst all families had some emotional difficulties, they found ways of supporting the containment of emotions. They found good external support was helpful. Margaret described the home Matthew lived in as a good place:

But it's a really good place where he is. A really good place. So there's a bit of comfort in that. And the staff are really nice. And I speak to the more or less.... Yeah, them really good. I ask them questions about his personal care. (Margaret, line 521-529)

For Margaret, not looking after her brother was a source of guilt, but she was able to get relief from knowing he was being cared for. John saw the home as Alex's family:

Twenty-five years. It's his home. [name of home] is his family. I mean, I know he's my brother, but them at [name of home] and everybody, they'm more his family, than, than I am. Er, so, I don't know. I am concerned about him, but my biggest concern and you, and you know it, is I don't want him to leave [name of home]. (John, line 117-121)

This helped John with feelings of guilt at not being close to his brother. He felt they looked after his brother well and cared for him like a family, taking away the emphasis of family responsibility from him.

Harry and Joyce, along with Jean and her family, thought of ways to solve problems as they came up and worked as a team, which helped them manage. Harry and Joyce felt the experience had "probably bonded us more together", but it was felt they needed to be together to manage:

I think it would just be too much for me. So, so, while we've got each other, we can draw on each other's strengths, so to speak, ya know. And support each other. But if you've only got one person, you can't get that kinda support. Laura can't give you support. You've got to give it to her and you've got no one else there to give it to us. (Harry, line 1048-1055)

Working together seemed a containing experience allowing the families to manage both emotionally and physically. However, Joyce and Harry, particularly, felt if they were not together they would not manage.

Jean felt "the more information we can get from professional people, I think that's going to be beneficial" and felt support from people who were experiencing something similar would be helpful:

Yeah, I think sometimes you just. You see it with other disabilities don't you or other illnesses that people have and they have groups

don't they where they can meet up and talk about what they're going through. I think personally maybe that would do me good. (Jean, line 1202-1211)

Jean highlighted the little support for families who have a member with Down syndrome and dementia. This left her feeling on her own, that others could not understand and that she was not coping, but she felt a group might contain this.

The sub-themes highlight families' difficult feelings, but demonstrate carers' ability to contain the feelings and carry on.

Relationships

Families perceived relationships as positive or as denying them what they felt they needed. There are three sub-ordinate themes within this section- 'Person-centred', 'Reciprocity' and 'Systemic difficulties'.

Person-centred: Most families felt they were able to understand things from the perspective of the person with Down syndrome and dementia. Harry describes how he understands why his daughter refused to go to the toilet on a journey out, due to changes in her visual perception:

She wouldn't go onto the toilet and she, she probably saw a great big hole there that we couldn't see and what she sees is different to what we see, and she refused to go, so we had had to take her further on. (Harry, line 252-255)

Harry learnt about changes in perception within dementia and recognised what was happening with Laura and responded in a thoughtful and helpful way to help her to manage the difficulties.

John and Jean felt that their brothers might be “frustrated” due to being unable to communicate their needs. Both were able to understand the reasons behind their brother’s behaviours.

Harry and Joyce and Jean were very proud of their relative. Harry and Joyce talked a lot about Laura’s achievements and abilities before she developed dementia. How she got “literally hundreds of medals” for swimming and running:

That’s how, how, how, ya know, how well she done for a Downs, ya know, like. She achieved such a lot. Ya know, she really has achieved such a lot. And it was such a lovely stage. I mean, it was hard work for the first few years and that, but it was very rewarding. Yeah, very rewarding. What she’d done. (Joyce, line 2043-2049)

This shows how families looked past the disability and dementia and took intense pride in their relative. They had supported their relative in achieving a great deal and they were still enabling them to do as much as they could even though things were becoming more difficult for them all.

Reciprocity: Most families felt they gave to their relative, but also received a lot back. Joyce described: “The rewards are lovely...when you get her smiling” and that these moments let her and Harry know she was still there.

Margaret felt Matthew had been there for her. When she had cancer she described him as “a shoulder to cry on” and how they had many “really fun times, really good times” and tried “to draw on them” to help her through. Margaret seemed to get a lot of pleasure from talking about the happier times with Matthew and felt he was still able to give her something even though he was so unwell.

By contrast, Jean struggled on occasions to maintain reciprocal roles and felt she had to keep information about the diagnosis from others, as she: “Couldn’t really explain it to Craig what’s going on”. She also said she needed to protect her mother against the diagnosis:

And obviously that’s an issue as well, because mom has just put all her trust in us to take over looking after Craig now. All the responsibility. Because she’s 88 and we don’t worry her with any issues and really we haven’t involved mom in a lot of the discussions and issues that we’ve had, because really I don’t think she’d cope with it too good. (Jean, line 619-628)

It felt Jean was attempting to protect her relatives from news she felt they were unable to manage. It appears perhaps it was difficult for her to think of them knowing and being in pain.

Systemic difficulties: All families perceived the system involved in the care of their relative to have let them down or not adequately provided for their relative’s needs. Margaret, as well as John and Claire felt people within the wider health care system were unable to deal with a person

with Down syndrome. John describes a time when Alex was taken to a general hospital within which Claire worked:

John: ..then they moved him onto the EAU and all they could do was call you down from upstairs, because, because they're not used to dealing with Down syndrome. And, o, what's the matter with him, what's the matter with him?

Claire: Why's he shouting? Why's he doing this, you know. Cause, cause they're not used to dealing with them. (John and Claire, line 555-560)

Margaret felt let down by organisations in general and felt :“At the end of the day you still have to do it yourself”. In particular, Margaret displayed mistrust of “more medical” people and thought care should be more “hands on”, so she preferred to talk to the less senior staff. It appeared she believed the more theoretical and intellectualised care became, the less caring it was, although she did express a trust in the psychologist, who provided the most theoretically driven care. There was a general sense she felt that “no one can look after him how I did”. This may be a projection of guilt relating to being unable to look after Matthew herself.

Jean was concerned about the home Craig lived in, as she supported them to manage Craig's incontinence:

We thought the home should be able to cope with that type of thing, so we were a bit, erm. Not let down by the home, but we just felt that. Well especially me. I was questioning, have they had enough training, do they know what they're doing. (Jean, line 569-576)

Jean also thought sometimes they only saw dementia “like he just had a label stuck on him.” For Jean having “outside people coming in” was relatively new and she was not yet comfortable with it. Also her employment as a care assistant may have placed her in an oppositional role with the home, as she felt they should be doing things differently; whereas John and Claire’s “biggest concern” was if Alex was unable to age in place.

Harry and Joyce were angry about service cuts meaning Laura had fewer days at her daycentre:

That’s why it makes me angry, that when the government makes, when he makes these cuts, does, does he, er, realise, what, what impact it’s having on, er, vulnerable people? It’s really scary, because people don’t..... We’ve all got problems, but some have got bigger problems than others and, and, that will have a huge impact on us and on her. (Harry, line 1872-1878)

This had the potential to have a huge impact on their lives. The anger seemed to come from the fear and acknowledgement that they had no control over what was going to happen.

From these sub-ordinate themes it appears the families were able to see things from the perspective of the person with dementia and felt proud of their relative’s achievements. They also felt that they received a lot from the relationship they had developed with this person and some felt that this continued despite the dementia. However, all the families felt let down by some part of the external system, whether it was the home the person lived in or wider society.

Difficulties Endured

The aim of this theme is to convey an impression of the difficulties that the families went through and endured. It includes four sub-ordinate themes- "Loss", "Sacrifices", "Unfair suffering" and "Fear of things to come".

Loss: Loss was a theme for all the families, both in terms of watching their relative lose their cognitive functioning and the personal loss they experienced. All families described their relatives as previously very able and commented on now watching the person with dementia losing their independence.

There was a great sense of loss when the person with Down syndrome and dementia stopped being able to recognize them. For Jean, this was a fear for the future, expressed in the hope that he doesn't "completely forget us". Margaret described it as like a bereavement "like somebody's died, but they haven't". It was as if they were experiencing anticipatory grief and mourning the loss of the person before they had actually died. The loss for Margaret seemed quite significant, as she had given a large part of her life to caring for Matthew and the loss she experienced felt worse because he had a disability:

Er, but Matthew because of the disability it's been hard. But a normal brother would just get married, have a family and we'd just see him now and again or family occasions, but with him it's been intense all the time. That's what it's like. That's why I say he ain't

like my brother, he's like my child with a disability. (Margaret, line 1015-1021)

Margaret did not just see her role as a caring one, but also as maternal as she "took my mother's place with him". She felt Matthew "needed me more than... me own children". Margaret was attempting to "keep a bit of distance and try and get on with my own life a bit" and she was trying to find a new role and things to do, such as buying "myself a laptop and practice on that a bit." It felt that she was attempting to create a life away from Matthew, but she was still struggling to think what this could look like.

Sacrifices: The majority of families talked about sacrificing parts of their lives or future plans for their relative. Harry and Joyce, for example, were making sacrifices to accommodate Laura's changing needs. They described how they had all been going to bed as early as 8.30pm, so that Laura could get more sleep. They spoke about how Laura having dementia had "affected our lives terribly" and is "having an impact on everything" and they do not feel they are doing the things in life they had been expecting to do when they reached retirement:

Your plans you actually make during the course of your life, I mean, I dare say you've made plans about when you want to retire, what you would like to do, where you want to go to retire, will you have enough funds to get everything in place? And we've been doing that for most of our lives. Trying to get into pension schemes and, and, say. I think everybody's dream is retire and maybe buy a house down in Cornwall or somewhere like that, er, er, up Scotland or down Wales. Nine times out of ten they don't materialise, but all our

plans, our hopes, our dreams have all changed dramatically. And er, er, what we planned for will not happen, so we just make the, we do the best with what we got and hope for the best. (Harry, line 1926-1940)

They had had ideas about what they were going to do in their retirement when they had expected to have their workload reduce, not increase. They seemed unprepared for this eventuality, which added to the loss of the fantasy they had.

Unjust suffering: All families felt they had endured a lot both in terms of what they had been through and what their relative had been through and conveyed a sense of how unfair this was:

She's been, we've been faced with this problem since birth and why is she still being punished and why are we being punished? And I'm thinking has she not suffered enough, have we not suffered enough? Ya, ya know, and it does question your belief. It does. This is not right, this not fair, this is, this is, horrible. (Harry, line 633-638)

They had watched someone suffer enough through the course of their life, but to watch them get worse was heartbreaking. There was also a sense of unfairness as they had been so capable before the diagnosis:

So I think that's why he learnt so much, because we did things with him, which was good, it was really good. Which is why I think if he does get this dementia really bad, it's going to be hard, because he's been so good at doing everything. So that's going to be a big shock really, cause he's always been so independent. (Jean, line 1147-1155)

There seemed to be a prevailing idea that bad things should not happen to good people, which created a sense of injustice. This can be conceptualised in Harry's case as stemming from religious belief, which he began to question due to the suffering he has endured. Others did not express any religious ideology, but the core of what they were expressing seemed similar.

Fear of things to come: For all of the families the idea of the future was a frightening one. Part of Jean wanted to deny what will happen through a "hope that he doesn't get worse", but part accepted things were going to be hard and she could plan for the future:

I think it's mainly if problems arrive how to cope with them. You know like cause at the moment I'm quite relaxed about it I can think about it, the dementia and how we're going to cope with it and things we're putting into plan and you start making lists of what you need to do. (Jean, line 1411-1418)

Other families, who were further on in their dementia journey felt they could not plan ahead, because they did not know what would happen in the future. Harry and Joyce, along with Margaret, conveyed a fear of their own vulnerabilities and a realisation that they themselves were getting older; it was implied they wanted to out live Laura to ensure that she was looked after:

Course, our, our big worry is how long will it go on for. Er, we're getting older. We're obviously reasonably fit people. Obviously

Joyce's got her problems with her. I got a knee replacement in April, so I can't run like I used to be able to run. (Harry, line 1185- 1189)

Most families believed their relative was close to death. For John it had got to a point where he thought Alex's life was not worth living and "Alex's got no quality of life. Not now." John felt that death "would be a positive thing for Alex." This belief meant John had stopped trying to stimulate Alex and the home also told him they had stopped, as there was a belief he was gaining nothing positive from it.

Margaret expressed that, even though she could see the difficulties he was having, it was hard for her to let go:

It don't matter how much I want him to be like he was, it ain't gonna happen [crying]. And it don't matter how many people say or how many doctors say it's going to affect this and that, until it happens I still want him to keep carrying on. (Margaret, line 483-488)

These themes communicate the difficult journey the families had been through since the person with Down syndrome was born. Watching the person deteriorate, after they had supported them to achieve so much within the context of a disability, was heartbreaking for many of them. They felt both they and their relative had suffered enough and struggled to see why they were suffering more, with the possibility of worse to come.

PAID STAFF CARER THEMES

Dementia Meaning

For staff carers 'dementia meaning' was not about struggling to understand the dementia diagnosis, as it was in the families, as many of the staff had received dementia training and had worked with people with dementia for many years. It was more about how they conceptualised dementia and their desire to understand an inaccessible inner world. From this emerged the themes- 'dementia meaning' and 'understanding inner world'.

Meaning: All the staff had views on what dementia was, seeing it as "a general deterioration". Sharon described Craig's decline as "gradual", which was in contrast to the "sudden" deterioration Jean had described. A similar disparity was observed between Tracey and Alex's family. The staff spent more time with Craig and Alex than did their families, so change may have been less perceptible, as they saw them day-to-day.

Sharon described Craig's dementia as involving him "getting very, very confused over details" and his behaviour as "stroppy" and "awkward". Janet saw dementia as "a lot more complex than what you think" and Heather struggled to understand whether the presentation was "with everyone in dementia or just learning disabilities". Heather also felt that it was "more difficult working with someone who's got dementia than someone who hasn't got it".

Understanding inner world: When talking about Matthew, Janet

wondered what was happening in his mind:

...we often sit there and go, I'd love to know what's he's thinking, but he'll have moments when he just sits there and he just laughs or he chuckles, he's got a big smile. I'd love to know what he's thinking, but he's not able to tell us. (Janet, line 119-122)

This felt as if it left staff with some feelings of impotence, which Heather described, as she worried about whether she was doing the right thing:

...cause you think, you might be looking at her and you think she might want something or need something, but you don't know because she can't tell you. You have to keep doing all these things with her and she's doing things many times a day, and she might not want it, but she might want it. (Heather, line 124-129)

It seems that Heather was doing "things" with Laura and did not always feel this was the right approach to take. This felt disempowering for Heather and brought with it a fear that she was doing harm.

Sharon, similarly to Jean, felt that Matthew could not understand, but there was also a real hope that he did not understand:

I hope he doesn't realise, because that would be worse. If he could tell, remember, not what he's done, but his capabilities. If he could remember and now he can't do it, that would be worse for him, because he was quite outgoing, well very outgoing. (Sharon, line 362-367)

From these sub-themes we can see that dementia is seen as complex and involving many different aspects. Dementia is conceptualised as referring to more behavioural aspects and as having implications for their work. There was also a desire to know what was happening within the person's mind and being unable to know this made staff feel powerless. Combined with the level of deterioration within the people they cared for, this made staff wish that the person did not understand.

Containment

Staff carers felt they needed to do their job and to enable them to do that, it seemed that they needed to defend against difficult feelings or thoughts that might arise. This led to the sub-ordinate themes of 'awareness of dementia in own life', 'difficult emotions', 'emotional attachment v distance' and 'do the best job we can'.

Awareness of dementia in own life: Both Sharon and Janet talked about the possibility of dementia in their own lives. Sharon described how she had a brother with learning disabilities and how "it frightens me to think this could happen to him" and how "it could happen to anyone of us at any point" and how that was "a frightening thought". Tracey felt that working within care meant that she had a greater awareness of dementia and that "sometimes too much info cannot necessarily always be a good thing". The thought of dementia occurring in their own lives appeared

frightening to them, but there was no discussion about how these thoughts were managed within the work environment.

Difficult Emotions: Not all the staff had personal difficult feelings, but there was a sense it was difficult to watch someone suffer; Tracey and Heather gave accounts of how difficult it was. For Tracey the word “frustrating” kept being repeated and referred to her frustration at knowing that “sometimes he could be frustrated” and that it is “difficult...to understand Alex and what he wants and what he needs”. The word frustration may describe the impotence she felt when attempting to provide for someone who was unable to communicate his needs. She also described how she went home feeling “physically and mentally drained” and how she had some somatic symptoms, including “a lot of headaches”. It felt as if Tracey was defended against most of the difficult feelings, but was able to recognise they might be manifesting in the form of headaches.

Heather stated that “if you notice she’s lost something again, it is a bit sad” and that she felt it was “going to get even more sadder” and she also said that when you noticed the decline “it’s upsetting”. There were feelings of empathy for Laura’s family and that as “they’re a lovely family...you feel awful for them”. Heather was the only staff member who became openly tearful during the interviews and it felt that she was genuinely distressed by what was happening to Laura.

Emotional attachment v emotional distance: Most of the carers saw it as necessary to keep an emotional distance. However, Heather said since she had been working one-to-one with Laura she had developed an emotional attachment, even though she was told in her training that “you’re not supposed to get attached to people you work with”. Due to this emotional attachment it was hard to watch Laura’s deterioration and it felt harder to manage “than it did with my Nan”. Heather felt she was doing something wrong in developing an emotional attachment to her client, which may have furthered her distress.

The other carers, who were older than Heather and had worked in care for longer, did not have the same emotional attachment. Sharon stated that she had “others to look after”, which was not the case for Heather. She also said that she was “paid to look after him” [Alex] and deal with any event that comes up” and she had been working at the home for “26 years”. She also described her home life where she has a disabled husband and feels that you “virtually have to cut one off from the other in order to cope”. This was echoed in the accounts of Tracey and Janet.

It appeared that length of time within a service supported the building of psychological defences, allowing staff to be emotionally detached at work and psychologically compartmentalise work from home; consequently protecting them from developing difficult emotional feelings.

Do the best job you can: All staff said that they wanted to do a good job for the people they worked with and this helped them to manage difficulties and gave them a sense of satisfaction. All the carers conveyed that they needed to get on with the job and as Janet said; “You wanna help and make a difference” and “It’s about making sure we make the best of what we can”.

Many of the carers said that training and gaining knowledge supported them in doing a good job. Janet said: “That’s why I’m happy to do anything like this, any training courses that could help anybody in the future”. This may have supported them with their feelings of impotence when they were unsure of what those with dementia wanted and needed.

Supportive colleagues were felt to be important. Tracey stated “we have a good staff team here and we release by talking to each other”. This appeared to serve the function of containing difficult feelings as they arose allowing staff members to continue to function within their roles. Staff also emphasised the importance of working with clients’ families, with Heather saying “they’re very good with communicating with us, which makes it a lot easier”.

From these sub-themes we can see that staff do experience some difficult emotions, but the majority are able to psychologically defend against them and continue to stay motivated and gain satisfaction from their jobs.

Witness others suffering

Within staff accounts there was a sense that it could be difficult for them to witness the clients and families suffer. The staff members took on an observer position, which detached them from the personal feelings that they might experience, unlike the families who were consumed with emotion. There are three sub-ordinate themes within this section: 'Unfair suffering', 'bleak future' and 'loss'.

Unfair suffering: In the same way that the families felt that they and their relative had been through enough already, Sharon and Heather felt that Matthew and Laura had suffered enough, with Sharon stating how she felt it was unfair:

Er, yeah. Terrible thing. You wonder why it happened as well. He's got enough to put up with being, having learning difficulties. That on top. It just seems so unfair really... I wonder why? Why did it have to happen? (Sharon, line 244-250)

Heather appeared to communicate that it was so difficult, "cause she's such a nice girl", suggesting that bad things should not happen to nice people. This appears to be a similar position to that of the family members, using superstitious thinking to try and make sense of the world, but finding that reality does not fit with these ideas, leaving them feeling confused.

Bleak future: All the care staff saw the future as bleak for both the people with Down syndrome and their family members. Sharon was quite fatalistic about the future stating that: “Well, it’s life really, erm. I think it’s a cross that they have to bear really. There’s nothing, there’s no prevention. There’s medication that can help, but they can’t cure it.” (Sharon, line 253-256). The use of the idiom ‘cross to bear’ is suggestive of having to bear the suffering entailed in an unwanted destiny. It was almost a counter-point to the superstitious thinking, taking an existential perspective that unpleasant situations occur and that is life.

There was an acknowledgement that things would only get worse, with Tracey recognising that Alex “could deteriorate more”. These descriptions came with a sense of detachment and did not have the same emotional resonance that was felt from family members.

However, Heather was concerned about any change for Laura, as she felt that changes contributed to Laura’s deterioration:

Yeah, if you break her routine it’s like over the two weeks holiday she has and Christmas she always goes home and always goes down after those, cause her routines broke and that’s why. [psychologist] said she’s best to have a routine. (Heather, line 437-441)

Heather felt that routine was important for Laura and “if you stick to routine she’s fine”, but there was an acknowledgement that this was not always something she could control and this appeared to cause Heather some concern.

Loss: The loss experienced by the staff was not the same as the loss experienced by the relatives. For the staff carers it was more an observation of what the people were losing, rather than a loss for themselves. All of the carers noticed the loss of skills:

You know puzzles that you put the pieces in, you'd do those sorts of things with him, but you couldn't do that now. You know he can't walk and it's just transferring and that side of it. Erm, he used to feed himself his tea, sandwiches or whatever he'd be able to pick up himself, but he can't do that now. If it wasn't for us feeding him, he wouldn't eat. (Janet, line 205-209)

This suggests that the loss in skills meant there was an increase in work for the staff, but it did not appear to be viewed in a negative light and was taken as just another thing to do at work.

Due to the attachment Heather had to Laura, she described a more personal and emotional loss as Laura's abilities deteriorated, as she "was changing from someone, from who I knew".

The sub-ordinate themes appear to show how the staff see and feel the difficulties of the people they work with, but mostly do so with a sense of distant detachment.

Person-centred care

All the staff expressed some kind of person-centred attitude towards the people they worked with, within which there was a tension between being person-centred by doing something for someone's own good and being person-centred by empathising with a person. An

example of this is when Janet describes not being able to give Matthew chocolate, because he can't swallow it:

He can't feed himself [cough] and he's got other health issues so he can't, he has to have all his food blended. Well why can't he have a bit of chocolate, you know what I mean, but you've got to do what's right for him and his safety and his health side of it, so you have to keep a clear head of what's right for him sorta thing. (Janet, line 100-105)

Janet felt it was more important to protect someone's physical safety than give that person what they want.

Staff were also able to see things from the perspective of the person with Down syndrome and dementia. Janet and Tracey acknowledged the "frustration" that the clients must feel.

The majority of the staff mentioned seeing the person and not the dementia. There was also discussion about not labelling people with the term "dementia". When Tracey was talking about Alex, she said "I don't kind of label him and look at him in that sense". The quality of person-centredness felt different to that expressed by the families, as staff members appeared to draw upon training to describe person-centred working, whereas it felt more natural from families.

From this section we can see staff want to do what is right for the clients and try to imagine the world from their perspective. Heather was particularly invested in the relationship and enjoyed Laura's company, but as was discussed earlier this may have been at an emotional cost.

DISCUSSION

Similar themes emerged for paid staff carers and family members. All attempted to understand the meaning of dementia, expressed some difficult emotions, attempted to contain these, expressed loss, felt people were suffering unjustly, saw the future as negative and tried to take a person-centred approach. However, the way these themes were expressed was different. Families were very emotional in their language and the struggles related to what they and their relative were experiencing. It felt as if they were immersed in their experiences and it was very much part of their lives. Even John, who was not as close to Alex as other families were to their relatives, spoke from an emotional position.

Paid staff carers talked about the difficulties mostly from an observer position. Sometimes they struggled to hold in mind the client they were talking about and would talk about dementia and clients in general. Heather expressed some painful emotions, but felt she was not entitled to, as she should not have become attached. Heather may have been experiencing 'disenfranchised grief' (Doka, 1989), where the societal rules mean she feels she should not have a grief reaction, as the relationship is not viewed as significant, leaving her feeling alone with her difficulties. It may also be possible that Margaret was experiencing something similar, as she felt she had to align herself with a maternal

role to explain the pain she was in, as a sibling might not be expected to have such a strong reaction.

Much of the loss experienced by families is 'ambiguous loss' (Boss, 1999), as the person is still physically present, but different, leaving families uncertain about what they have lost. The grief expressed by Margaret was partly 'anticipatory grief' (Sweeting & Gilhooly, 1990), as she was grieving before death. However, they were also experiencing actual bereavement as they mourned the loss of the relationship they once had (Oyebode, 2009); and the continuing cumulative losses that Joyce and Harry experienced seemed to provoke 'chronic sorrow' (Olshansky, 1962) as they went on and on by layer. This is different to the loss experienced by the paid staff carers, as they felt bad for the other's loss, but experienced no personal reaction.

Highlighted throughout is the difference in the emotional reaction between the staff and family members. The attachment bond between a parent and a child is brought about by the interplay of evolutionary, biological and psychological factors to ensure the child is cared for (Rubin & Malkinson, 2002) making it a very powerful bond. Cicirelli (1982) reported that the most enduring relationship throughout a person's lifespan is that of the sibling relationship. Given the strength of these relationships it is understandable that family members experienced more distress. It has been found that siblings with brothers and sisters with an intellectual disability have stronger emotional ties (Orsmond & Seltzer, 2000; Pruchno, Patrick & Burant, 1996). Also, females have more

intimate relationships than males (Dolgin & Lindsay, 1999; Pulakos, 1987), which was displayed in the sibling relationships explored here.

The expression of grief was described by Bowlby (1980) as having four stages, initially 'numbing', which can be seen as a form of denial, as Joyce and Jean described. The next is 'yearning, searching and anger'. This was expressed in the description of the unjust nature of what was happening to their relative and the anger Harry articulated. However, this could be conceptualised as 'splitting' off some the more difficult emotions through expressing anger towards external systems (Bateman & Holmes, 1995). The last two stages are 'disorganisation and despair' and 'reorganisation'. Despair was communicated by all family members and confusion felt by some. There were some efforts to reorganise and adapt to losses and look at life outside of the relationship but it may be that this cannot be tackled until the life of the person with dementia has ended.

The lower level of emotional involvement in the majority of staff may be because family members had a lifetime with the person, but in some cases the staff spent more time with the person with Down syndrome and dementia than the family member, so strong emotional ties might be expected. It could be that staff are attempting to defend against emotions that are too painful or threatening to acknowledge (Obhozer & Roberts, 1994). Speck (1994) described how working with people who are dying could elicit feelings about loss in the lives of care staff. Some staff acknowledged the resonance with their own

circumstances, which they stated frightened them and also described a sense of their impotence at not being able to restore the clients to health. However, most of the staff described their difficulties in terms of the position of the person and family, which could be a denial of their own feelings through projection (Bateman & Holmes, 1995). There was also evidence of rationalisation by Sharon, as she philosophically described the 'cross that they have to bear' and a general repression of feeling.

On the other hand, it could be that staff's feelings were being contained. Douglas (2007) describes containment as when one person receives an emotional communication from another and is able to think about and give it back to that person in a more manageable form. Staff described how they "released pressure" by talking to each other, thus containing the emotional difficulties. Families also described how they sought containment from each other and external sources to support them in managing the difficult feelings, so containment was important for all participants.

For both groups person-centred ideas were identified. Kitwood (1997) described how dementia was not just a neurological process, but the effect of neurological impairment; physical health; biography and malignant social psychologies. Personhood is the idea that we are all unique and have an ethical right to be treated with respect. For people with dementia who cannot recall their own identity, others can sustain their personhood through supportive person-centred interaction that takes their individuality into account. We can see this clearly from family

members who saw the person very much as an individual who led a full and rich life, and who understood many of their difficulties through the context of personal understanding. This perhaps, was more difficult for staff, as they had not known the person all their lives, but there were efforts made to think about the person's perspective and promote 'personhood'.

Throughout, families were able to identify things they thought services could do to improve. Staff training to give further understanding of the difficulties encountered in dementia; a commitment to supporting ageing in place and the need for groups to be available for carers of people with Down syndrome and dementia were all suggested by participants. The system seems to be struggling to meet the needs of these families and adding to their distress. However, families did find some of the external support systems helpful, although it was not conveyed why this was and this may need to be explored further.

Limitations

The data gathered in this study has not been triangulated with the research participants, thus threatening its validity. However, all work has been developed through the collaboration of the researcher with two research supervisors, a clinical supervisor and a peer-based group. The researcher intends to seek participant feedback in the future.

Another factor to consider is that three of the people with Down syndrome and dementia lived in the same care home, so three of the staff

came from the same organisation producing a sample bias. However, it is not claimed that the results of IPA studies can be generalised across populations, but assist in the gradual development of a knowledge base (Smith, Flowers & Larkin, 2009). The research may therefore show a heavy bias towards highlighting the staff experience within that home.

Research Implications

Interest in carers of people with Down syndrome and dementia has recently increased, but there is still little research. Contrasting the experiences of staff and family carers has highlighted some differences. Particularly of note was the emotional difference between staff and family members, so it may be interesting to explore the process of how staff become distanced and whether this is positive, in being a protective factor, or negative in leading to them being uncaring. It would be interesting to investigate further how relatives react when the person dies, how easily they are able to re-establish their lives and if they have a prolonged grief experience.

Clinical Implications

A key implication emerged with the idea of a need for containment. Participants managed with containment and were able to identify things that both supported and hindered it. Having the support of others appeared key for both families and staff. One family member identified how she felt her

feelings could have been contained by a support group for carers of people with Down syndrome and dementia. This would be a relatively simple service to develop and implement and could be run solely by carers themselves. External agencies were not always helpful for families and could increase relatives' worries. Some of the difficulties may reflect the current financial climate and consequent massive structural changes in services. Staff sought support from each other, but was on an informal basis and it did not appear that they received formal supervision. The work the staff did was difficult and stressful and therefore offering an opportunity to share difficulties may help to prevent distress.

REFERENCES

- Adams, D., Oliver, C., Kalsy, S., Peters, S., Broquard, M., Basra, T., Konstandinidi, E. & McQuillan, S. (2007). Behavioural characteristics associated with dementia assessment referrals in adults with Down syndrome. *Journal of Intellectual Disability Research*, 52, 358-368.
- Alzheimer's Society. (2012). *Dementia 2012: A national challenge*. London: Alzheimer's Society.
- Bateman, A. & Holmes, J. (1995). *Introduction to psychoanalysis: Contemporary theory and practice*. London: Routledge.
- Boss, P. (1999). *Ambiguous Loss: Learning to live with unresolved grief*. Massachusetts: Harvard University Press.
- Bowlby, J. (1980). *Attachment and Loss, vol. 3: Sadness and Depression*. London: Hogarth Press
- Cicirelli, V. G. (1982). Sibling influence throughout the lifespan. In Lamb, m. E. & Sutton-Smith, B (eds) *Sibling relationships: Their nature and significance across the lifespan*. New Jersey: Erlbaum.
- Cooper, S. A. & Prasher, V. P. (1998). Maladaptive behaviours and symptoms of dementia in adults with Down's syndrome compared with adults with intellectual disability of other aetiologies. *Journal of Intellectual Disability Research*, 42, 293-300.
- Department of Health. (1999). *Caring about carers: A National Strategy for Carers*. London: Department of Health.
- Department of Health. (2009). *Living well with dementia: A National Dementia Strategy*. London: Department of Health.

- Department of Health. (2001). *Valuing People: A new strategy for learning disability for the 21st century*. London: Department of Health.
- Doka, K. J. (1989). *Disenfranchised Grief: Recognising the hidden sorrow*. New York: Lexington Books.
- Dolgin, K. G., & Lindsay, K. R. (1999). Disclosure between college students and their siblings. *Journal of Family Psychology*, 13, 393–400.
- Donaldson, S. (2002). Work stress and people with Down syndrome and dementia. *Down Syndrome Research and Practices*, 8, 74-78.
- Douglas, H. (2007). *Containment and Reciprocity: Integrating psychoanalytic theory and child development research for work with children*. London: Routledge.
- Down Syndrome Association. (2012). *People With Down Syndrome: Your questions answered*. Middlesex: Down Syndrome Association.
- Gadamer, H. (1960). *Truth and Method*. New York: Crossroad.
- Heidegger, M. (1962). *Being and Time*. Oxford: Blackwell.
- Husserl, E. (1927). Phenomenology. For *Encyclopaedia Britannica* (R. Palmer, Trans. And revised). Available at: <http://www.hfu.edu.tw/~huangkm/phenom/husserl-britannica.htm>
- Janicki, M. P., Zendell, A. & DeHaven, K. (2010). Coping with dementia and older families of adults with Down syndrome and dementia. *Dementia*, 9, 391-407.
- Kalsy, S., Heath, R., Adams, D. & Oliver, C. (2007). Effects of training on controllability attributions of behavioural excesses and deficits

shown by adults with Down syndrome and dementia. *Journal of Applied Research in Intellectual Disabilities*, 20, 64-68.

Kitwood, T. (1997). *Dementia Reconsidered: The person comes first*. Buckingham: Open University Press.

Lloyd, V., Kalsy, S. & Gatherer, A. (2008). Impact of dementia upon residential care for individuals with Down syndrome. *Journal of Policy and Practice in Intellectual Disabilities*, 5, 33-38.

McCallion, P., McCarron, M. & Force, L. T. (2005). A measure of subjective burden for dementia care: The Caregiving Difficulty Scale- Intellectual Disability. *Journal of Intellectual Disability Research*, 49, 363-371.

McCarron, M., Gill, M., Lawlor, B. & Begley, C. (2002). A pilot study of the reliability and validity of the Caregiving Activity Survey-Intellectual Disability (CAS-ID). *Journal of Intellectual Disability Research*, 46, 605-612.

McCarron, M., Gill, M., Lawlor, B. & Begley, C. (2005). Alzheimer's dementia in persons with Down's syndrome: Predicting time spent on day-to-day caregiving. *Dementia*, 4, 521-538.

McCarron, M., Gill, M., McCallion, P. & Begley, C. (2005). Health comorbidities in ageing persons with Down syndrome and Alzheimer's dementia. *Journal of Intellectual Disability Research*, 49, 560-566.

McCarron, M., McCallion, P., Fahey-McCarthy, E., Connaire, K. & Dunn-Lane, J. (2010). Supporting persons with Down syndrome and advanced dementia: Challenges and care concerns. *Dementia*, 9, 285-298.

McLaughlin, K. & Jones, A. (2010). 'It's all changed:' Carers' experiences of caring for adults who have Down's syndrome and dementia. *British Journal of Learning Disabilities*, 39, 57-63.

- Merleau-Ponty, M. (1962). *Phenomenology of Perception*. London: Routledge.
- Millichap, D., Oliver, C., McQuillan, S., Kalsy, S., Lloyd, V. & Hall, S. (2003). Descriptive functional analysis of behavioural excesses shown by adults with Down syndrome and dementia. *International Journal of Geriatric Psychiatry*, 18, 844-854.
- Nieuwenhuis- Mark, R. E. (2009). Diagnosing Alzheimer's dementia in Down Syndrome: Problems and possible solutions. *Research in Developmental Disabilities*, 30, 827-838.
- Obholzer, A. & Roberts, V, Z. (1994). *The unconscious at work: Individual and organizational stress in the human services*. London: Routledge.
- Olanshansky, S. (1962). Chronic Sorrow: A response to having a mentally defective child. *Social casework*, 43, 190-193.
- Orsmond, G. I., & Seltzer, M. M. (2000). Brothers and sisters of adults with mental retardation: Gendered nature of the sibling relationship. *American Journal on Mental Retardation*, 105, 486–508.
- Oyebode, J. (2009). Grief and bereavement. In: Downs, M. & Bowers, B. (eds) *Excellence in Dementia Care: Research into practice*. Buckingham: Open University Press, pp. 379-394.
- Prasher, V. P. & Filer, A. (1995). Behavioural disturbances in people with Down's syndrome and dementia. *Journal of Intellectual Disability Research*, 39, 432-436.
- Pruchno, R. A., Patrick, J. H., & Burant, C. J. (1996). Aging women and their children with chronic disabilities: Perceptions of sibling involvement and effects on well-being. *Family Relations*, 45, 318–326.
- Pulakos, J. (1987). Brothers and sisters: Nature and importance of the adult bond. *Journal of Psychology*, 121, 521–522.

- Rubin, S. S. & Malkinson, R. (2002). Parental response to child loss across the life cycle: Clinical and research perspectives. In: Stroebe, M. S., Hansson, R. O., Stroebe, W. & Schut, H. (eds) *Handbook of bereavement research: Consequences, coping and care*. Washington, DC: American Psychological Association, pp. 219- 240.
- Satre, J. P. (1948). *Existentialism and Humanism* (P. Mairet, Trans.). London: Methuen.
- Schleiermacher, F. (1998). *Hermeneutics and Criticism and Other Writings* (A. Bowie, Trans.). Cambridge: CUP.
- Smith, J., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, method and research*. London: Sage.
- Soliman, A. & Hawkins, D. (1998). The link between Down's syndrome and Alzheimer's disease: 2. *British Journal of Nursing*, 7, 847-850.
- Speck, P. (1994). Working with dying people: On being good enough. In: Obholzer, A. & Roberts, V, Z. (eds). *The unconscious at work: Individual and organizational stress in the human services*. London: Routledge, pp. 94-100.
- Sweeting, H. N. & Gilhooly, M. L. (1990). Anticipatory grief: A review. *Social Science and Medicine*, 30, 1073-1080.
- Tyrell j., Cosgrave, M., McCarron M., McPherson J., Calvert, J., Kelly A., McLaughlin M., Gill M. & Lawlor B. A. (2001). Dementia in people with Down's syndrome. *International Journal of Geriatric Psychiatry*, 16, 1168-1174.
- Watchman, K. (2003). Critical issues for service planners and providers of care for people with Down's syndrome and dementia. *British Journal of Learning Disabilities*, 31, 81-84.
- Watchman, K. (2008). Changes in accommodation experienced by people with Down syndrome and dementia in the first five years

after diagnosis. *Journal of Policy and Practice in Intellectual Disabilities*, 5, 65-68.

Zigman, W., Schupf, N., Sersen, E. & Silverman, W. (1995). Prevalence of dementia in adults with and without Down syndrome. *American Journal on Mental Retardation*, 100, 403-412.

Zigman, W., Silverman, W. & Wisniewski, H. M. (1996). Aging and Alzheimer's disease in Down syndrome: Clinical and pathological changes. *Mental Retardation and Developmental Disabilities Research Reviews*, 2, 73-79.

PUBLIC DISSEMINATION DOCUMENT

The experiences of carers of people with Down syndrome who develop
dementia

PUBLIC DISSEMINATION DOCUMENT

The experiences of carers of people with Down syndrome who develop dementia:

This document provides a summary of the research conducted as partial fulfilment of the Doctorate in Clinical Psychology at Birmingham University. The research was supervised by Dr Jan Oyebode, Dr Liz Kent and Dr David Rose.

Literature Review: Exploring the dementia and learning disability literature to support an understanding of the experiences of caring for someone with Down syndrome who develops dementia.

This literature review draws together, reviews and evaluates studies that may help us understand carers' responses to having a relative with Down syndrome who develops dementia. There is very little published research directly exploring the experiences of carers of adults with Down syndrome and dementia, therefore the review draws on research relating to diagnoses of, and living with, learning disability or with dementia and draws out the implications for having a relative with both conditions.

Issues raised are:

- Families may not have had a positive experience of receiving a diagnosis of their child's learning disability.
- Families better able to cope with a subsequent diagnosis of dementia, due to their long-term caring experiences.
- The needs of people with dementia may differ from those of other family members and therefore should be assessed separately.
- Differences between carers are highlighted and cultural differences need to be taken into account.
- Paid staff carers need support and training to help them manage the changing needs of those they care for.
- The review also demonstrates that more research is needed into the experiences of people who care for adults with Down syndrome and dementia.

Research study: Family member and professional carer perspectives on caring for adults with Down syndrome and dementia.

People who have Down syndrome are more likely to develop dementia than the general population. To date, little research has investigated what

carers understand about the diagnosis of dementia and what their thoughts and feelings are about caring for a person with this diagnosis. The majority of the research has been quantitative and not directly about the effect that caring has on the carer. . The research does not often make the distinction between those who are employed carers and those who are family carers and what difference this has on the emotional impact of caring for the person and the way carers view the person. The aim of the research was to explore paid staff carers' and family carers' experiences around caring for an individual with Down syndrome and dementia and look for similarities and differences in their accounts.

Design: The qualitative methodology interpretative phenomenological analysis, IPA (Smith, Flowers, Larkin, 2009) was employed, as the researcher was interested in the professional carers' and family members' experience of caring for those with Down syndrome and dementia. IPA allows the researcher to explore how events, processes or relationships are understood.

Participants: Caregivers were contacted by the clinical psychologist working within a Community Learning Disability Dementia Service. The clinical psychologist approached paid staff carers and family members. A total of ten participants took part, over the course of 8 interviews. A sole staff member was interviewed regarding their experiences with each

person with Down syndrome, and corresponding family members were either interviewed alone or in couples.

Method: Interviews were conducted using a topic guide based on broad questions about the person's experiences of caring for someone with Down syndrome and dementia. The topic guide acted as an aid for the researcher to cover various areas during the interview, but also gave the participants the opportunity to reflect on their experiences. Interviews ranged from 30 to 100 minutes. All interviews were audio taped to allow for accurate transcription and for the researcher to focus on the interview and participant rather than on taking notes.

Analysis: The interviews were transcribed by the researcher and all identifying information removed. After the interviews copies of the transcripts were sent to participants and any text they wished to be excluded from the analysis was removed. The transcripts were read and re-read several times and initial notes were taken. After this some key themes for each participant were developed, then connections were identified across the themes to identify over-arching themes. This process was completed for each participant in turn. Then the themes were brought together and thought about in terms of themes for family members and themes for staff carers.

Findings: There were four over arching themes that emerged for families and four for paid staff carers. For families they were:

1. Dementia and understanding: Family members described their understanding of the meaning of dementia and how they struggled to understand the diagnosis.
2. Emotional containment: Families described the difficult emotions they feel and these are contained and managed.
3. Relationships: Families described the relationship they had with their relative, which appeared to be respectful of the person; they described how they felt the relationship was reciprocal and they also described how they had difficult relationships with external care systems.
4. Difficulties endured: Families described loss and sacrifice, as well as how they felt that both they and their relative had suffered unjustly. They also described a fear of things to come.

For paid staff members the themes were:

1. Dementia meaning: Paid staff members described their understanding of the meaning of dementia and also expressed a desire to understand the person's inner world.

2. Containment: Staff members highlighted how working with people with dementia made them think about dementia within their own lives; they expressed some difficult emotions; discussed the importance of trying to keep emotional distance and also how it was important to them to feel they were doing a good job.

3. Witnessing others suffering: They talked about witnessing the losses for the people they worked with and their families; how unjust the suffering of them was and how they saw the future for the person and their family as bleak.

4. Person-centred: Staff members expressed ideas about person-centred care and how they tried to practice these principles.

Conclusions: Similar themes emerged for family members and paid staff carers. The main difference was the emotional content. Family members were immersed in the experiences and it was a painful part of their lives, whereas staff carers talked about the experiences from an observer position. Possible reasons for this difference are discussed in terms of psychodynamic defences and attachment theory. It is suggested that possible reasons for these differences be explored further. The importance of emotional containment for both groups is also highlighted

and how this can be developed further within service delivery to help prevent distress.



Family member and professional carer perspectives on caring for adults with Down's syndrome and dementia

Participant Information Sheet

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. **Please read this information sheet carefully.**

Talk to others about the study if you wish. Ask us if there is anything that is not clear.

The aim of this study is for the researchers to try and develop an understanding of what it is like to care for someone who has Down's syndrome and dementia, from the points of view of relatives and paid staff carers.

Why Have I Been Invited?

You have been invited to take part in this study because you are either a relative or a paid carer of an adult with Down's syndrome and dementia who is being cared for within Dudley.

Do I Have to Take Part?

It is up to you if you want to join the study. Angela Foster (the researcher) will describe the study and go through this information sheet. If you agree to take part, she will then ask you to sign a consent form. You are free to withdraw at any time up until you have reviewed the transcript of what you have said, without giving a reason. This would not affect the standard of care your relative/ client receives. It will not affect your employment in any way. If you withdraw the interview you provided will be withdrawn from analysis and destroyed.

What will happen to me if I take Part?

You will be asked to take part in an interview with Angela Foster (Trainee Clinical Psychologist) who will ask about your experiences of what it is like to witness and provide care for someone who has Down's syndrome and has developed dementia. The interview will take between 45 and 90 minutes and will be conducted in a place that is convenient for you.

Expenses

You will be entitled to claim back any travel expenses you incur taking part in this study.

What Are the Possible Risks/ Disadvantages of Taking Part?

You may become distressed during the interview as you are talking about someone you know, who has dementia. This could bring up different emotions and issues for you. You will have the opportunity to speak to either David Rose (Clinical Psychologist) or Jan Oyebode (Clinical Psychologist) to discuss the research experience and any difficult emotions that the experience has brought up for you.

What Are the Possible Benefits of Taking Part?

Please be aware that this study will not help you directly, but may contribute to an understanding of carer perspectives. Through developing an understanding of the experiences of family members and carers we can make recommendations about how best to support people in the future.

What if there is a Problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (please see the bottom of the form for contact details). If you do not wish to speak to the researchers you can contact the Head of the School of Psychology, Chris Miall, on 0121 414 2867.

Will my Taking Part in the Study be Kept Confidential?

All information given in the interviews will be anonymised and identifying information, such as names, will be changed. All interviews will be recorded and then transcribed into a written document, so that the interview can be analysed.

During analysis Angela Foster (trainee clinical psychologist), Jan Oyebode (clinical psychologist), David Rose (clinical psychologist) and Liz Kent (clinical psychologist) will have access to the transcripts.

Jan Oyebode at the University of Birmingham will hold electronic copies of the transcripts for 10 years after the report on this research is

published. These will be anonymised and password protected. The audiotapes and paper records will be stored at the University of Birmingham, by Jan Oyebode, within a locked cabinet for one year after the study is completed and then destroyed.

The final research report will involve the use of direct quotations of parts of the conversations that were recorded during the interview. Whilst your information will be anonymised, it may be possible that the other carer taking part in the study could identify you. You will be given an opportunity to review a transcript of the interview and then be asked if there are parts of your interview that you would not like to have quoted.

Everything you say/ report is confidential unless you tell us something that indicates that you or someone else is at risk of harm. In this case we would discuss this with you before telling anyone else.

What Will Happen to the Results of the Study?

The information will be in Angela Foster's thesis, as part of her Clinical Psychology Doctorate. The thesis will be held at the University of Birmingham library. The results will be presented to you and all other participants after the completion of the study. You will be asked if you would like a copy of the results. If so, this will be sent to you. The researchers would also hope to submit the report to a peer reviewed journal for publication and present the results at a conference.

Who Has Reviewed the Study?

This study has been reviewed and given a favourable opinion by the University of Birmingham Ethics Committee and the Social Care Research Ethics Committee.

If you require further information about this study please contact one of the researchers below.

Jan Oyebode (Clinical Psychologist)
0121 414 4904

David Rose (Clinical Psychologist)
01384 361247



Family Member and Professional Carer Perspectives on Caring for Adults with Down's Syndrome and Dementia

Consent Form

This information is being collected as part of a project concerned with the views of relatives and paid carers of adults with Down's syndrome and dementia. It is being collected by the School of Psychology in the University of Birmingham in collaboration with Black Country Partnership NHS Foundation Trust. The information which you supply will be entered into a filing system or database. This will only be accessed by people with the authority to do so. The information will be held by the University of Birmingham and will only be used for the project and audit purposes. By supplying this information you are consenting to the University storing your information for the purposes stated above. The information will be held by the University of Birmingham in line with the Data Protection Act 1998. No identifiable personal information will be published.

Please tick as appropriate

	YES	NO
I confirm that I have read and understand the participant information leaflet. I have had the chance to ask questions and am satisfied with the answer.		
I understand that taking part is voluntary and that I am free to withdraw without giving any reason anytime up until I have reviewed the transcript of what I have said. If I withdraw my information will be removed from the study and will be destroyed.		
I agree to the interview being audio-recorded.		
I would like a copy of the final results of the study.		
I understand that my personal information will be held for the purposes detailed above, in line with the Data Protection Act 1998.		

Based upon the above, I agree to take part in this study.		
---	--	--

Name, signature and date

Name of participant.....

Date..... Signature.....

Name of researcher/individual obtaining consent.....

Date..... Signature.....

A copy of the signed and dated consent form and the participant information leaflet will be given to the participant and one retained by the researcher to be kept securely on file.

Appendix 6

Interview Schedule: Family member and professional carer perspectives on caring for adults with Down's syndrome and dementia.

Development of Dementia

1. What does dementia mean to you?
2. How did you know that [name of person with Down's syndrome and dementia] had dementia?
3. What was your understanding of dementia before?
4. What is your understanding of dementia now?
5. Can you describe to me your experiences since [name of person with Down's syndrome] developed dementia?
6. What did you think/ feel when you were told that [name of person with Down's syndrome] had dementia?
7. What do you think/ feel now about [name of person with Down's syndrome] having dementia?
8. How much do you think about the diagnosis of dementia when you think about [name of the person with Down's syndrome]?
9. How much do you think about [the name of the person with Down's syndrome] having dementia?
10. How has [name of the person with Down's syndrome] having dementia affected you?
Prompt: behaviourally, physically, emotionally, within relationships.
11. How has [name of the person with Down's syndrome] being diagnosed with dementia affected you?
Prompt: behaviourally, physically, emotionally, within relationships.
12. How would you have described [name of person with Down's syndrome] before they developed dementia?
13. How would you describe [name of the person with Down's syndrome] now?

Implications

14. What is your understanding of what the future will hold for [name of person with Down's syndrome]?
15. How do you think [name of the person with Down's syndrome] having dementia will affect you in the future?

16. How do you think the diagnosis will affect you in the future?

17. On a day-to-day basis how do you deal with [name of person with Down's syndrome] having dementia? [for family members not caring for the person themselves ask only about emotional and relational impact]
Prompt: behaviourally, physically, emotionally, within relationships.

18. On a day-to-day basis how do you deal with the diagnosis of dementia? [for family members not caring for the person themselves ask only about emotional and relational impact]
Prompt: behaviourally, physically, emotionally, within relationships.

Appendix 7

Interview Transcript- John and Claire

1. AF: It's recording now. Ok, so we'll start off with what does dementia
2. mean to you?
3. J: Erm, what it means to me? Er, loss of memory. I think, I think that's
4. how most people think about it, ay it?
5. AF: Ok.
6. C: Er, yeah, that's how I look at it. Er, not knowing what's going on
7. around you.
8. AF: How did you know your brother had dementia?
9. J: We didn't until they told us at [name of home]. We noticed a change
10. in him before they told us he'd got dementia. Er.
11. AF: What was that?
12. J: I wouldn't say it was..
13. C: I don't think it was anything to do with his mind that we noticed. We
14. noticed he couldn't walk, didn't we?
15. J: Yeah. He came out. It was actually the last time he came here. He
16. was very, very unsteady on his feet and er, a big shock from the way
17. we seen him the last time. But I think that's when they said that they
18. discovered that he'd had, like, these mini strokes, or. We didn't really
19. know he'd got dementia until they said or said that he's been
20. diagnosed or that they diagnosed him with vascular dementia, so.
21. AF: So was it quite sudden then?
22. J: Er.
23. C: Yeah.
24. J: To us it was, yeah. I mean time goes that quick now. It seems like
25. only yesterday, but it's been quite a while, hasn't it, since he's been
26. diagnosed with it. Er, but yeah, it was sudden.
27. AF: Ok.

28. J: We noticed a big change very quickly.

29. AF: Ok, what was your understanding of what was going on at the
30. time?

31. J: I don't know really, er. It's, I don't know, it's only cause I don't see
32. him every day obviously. I only see him every other week. I've been
33. seeing him more regular, since he's been, since he's been bad. Erm,
34. you know, it's just a shock. Er.

35. C: Yeah, cause we didn't know what was going on did we, cause the
36. first change we saw in him was his walking.

37. AF: Right, ok.

38. C: When I actually passed a comment at [name of home]. I said why
39. can't he walk? Cause I was so shocked, that he was. He wanted to, but
40. he couldn't.

41. AF: Ok.

42. C: And I said why can't he walk. And that was, it just went from there
43. really.

44. AF: Ok and over what period of time was that happening?

45. C: Six to twelve months. To me that's quick.

46. J: He was walking and, er, I say, he came here and wanted to go to
47. the toilet on a regular basis, and he was taking ages and I says to you,
48. I said to C, he ay so steady on his feet and he was shaking. And we
49. mentioned it when we took him back, didn't we. And they said, yeah,
50. he has been having a few problems and they took him to the doctors,
51. but he was still doing normal things.

52. AF: yeah.

53. C: But a lot slower.

54. J: But a lot slower. And then it was. The he was.

55. C: And then they were sort of having to lead him, weren't they?

56. J: Yeah.

57. AF: Right.

58. C: And he could walk and then suddenly it just stopped.

59. J: And then he was admitted to hospital. He had a turn.

60. C: Yeah.

61. J: And that was the first time that give us something, that there might

62. be something that might be. C said he'd had a stroke. Before that it

63. was said that, cause C works at the hospital as well. Er.

64. C: I met him in A&E and I worked in A&E, so I was talking to the

65. doctors in A&E and they said, well they examining him and I said he

66. suddenly stopped walking and it all went from there really. And that's

67. why he used to be independent and walked about. He's always looked

68. after himself. To a certain degree obviously. And, er, I was telling the

69. doctors what I thought, you know. I said he just suddenly can't do it.

70. AF: Yeah.

71. C: He wanted to but he couldn't.

72. AF: And what did you tell the doctors that you were thinking?

73. C: Well I asked them if he'd had a stroke.

74. AF: Yeah.

75. C: And that was what they diagnosed at first, yeah.

76. AF: Ok and then it went from there?

77. J: I don't think they actually used the word stroke did they? They said

78. it's a process of mini seizures, if you know what I mean. They never, I

79. don't think, even, [psychologist, nor [psychiatrist] have actually said

80. stroke have they?

81. C: No.

82. J: They just say seizures. To me that's a stroke though. That's how I

83. look at it anyway.

84. AF: Ok. What was your understanding of dementia before your brother

85. got dementia?

86. J: I never, I never really give it any thought, cause I never known
87. anybody, or known anybody with dementia, so can't say that I, that I've
88. known them before and then after, so I suppose I just had the same
89. perception as everybody else, er, you know, loss of memory, ay it. Just
90. what you read. I've never actually experienced it.

91. AF: Ok. Have your views on dementia changed since your brother
92. developed it?

93. J: No. Probably no. Like I say, I might go and see me brother, I
94. some, I think he don't recognise me. Everybody says he does. The
95. carers say he does and you say he does, don't ya. He probably does,
96. but it's hard getting no reaction out of him. He sits there and sorta erm.
97. I sorta can't get a reaction out of him. We've been up together, ay we
98. and we don't go no reaction do we? Whereas the carers will. So er,
99. they'll sorta walk in, or somebody's walked in and he has sorta smiled,
100. which I never get, I know I'm never gonna get.

101. AF: And what's that like for you?

102. J: Well it's hard, but er, I just accept it [laughing].

103. AF: Right, ok. Erm, what have your experiences been since your
104. brother developed dementia?

105. J: Erm.

106. AF: What's it been like for you, what's been happening, has
107. anything changed?

108. J: Nothing to us has it? Er.

109. C: Things have changed. You've got to be honest about it
110. haven't you, because you didn't used to see him so often, but
111. your more concerned about him now. You wasn't so concerned
112. about him five years ago.

113. J: [laughing] No.

114. C: Don't say things haven't changed.

115. J: The only reason, you know yourselves, he's been up
116. there....

117. C: Twenty-five years.

118. J: Twenty-five years. It's his home. [home] is his family. I mean, I
119. know he's my brother, but them at [home] and everybody,
120. they'm more his family, than, than I am. Er, so, I don't know. I
121. am concerned about him, but my biggest concern and you, and
122. you know it, is I don't want him to leave [home]. That's my
123. biggest concern. My, my, my concern is if he gets that bad
124. where they can't look after him, cause it's not a nursing home.
125. And, er, if he's got to go somewhere else. That's more my
126. concern.

127. AF: Is that on the cards?

128. J: Well, not at the moment, no. [home] always state, don't they,
129. they'll do everything and keep him as long as possible. Er, so,
130. for, how I've changed is I'm more concerned and I see him more
131. often. Not the fact I get any information out of A, but if I ask the
132. carers how he's been going, this, that and the other and we
133. have meetings don't we.

134. C: See, when A was well and we used to go and see him, he'd,
135. he'd walk away from me, wouldn't he. It was a standing joke. Giz
136. me chocolate, I'm off. You know, but I think that's why you see
137. him more regular now, cause he can't walk away from us. He
138. always used to do it and he's done it all his life.

139. J: O, yeah. He greets ya...

140. C: He greets ya.

141. J: Five minutes and that'll be it.

142. C: He's off.

143. J: We spent half hour, three quarters of an hour, sorta talking

144. to the carers or somebody else and just say to our A ok I'm
145. going now. He was more, you know, interested in what was
146. going on in the house, cause he was always active. He was
147. always involved. And, er, I don't know. I don't know. Well, we
148. thought he used to get frustrated, really frustrated, but I think
149. he's got to the stage now where he's probably frustrated, but he
150. can't..

151. C: Can't show it like.

152. J: Can't show it.

153. AF: Ok, why's he frustrated?

154. J: Well, I think it was, well, I don't, we don't know, I'm just
155. assuming, because he can't, couldn't do anything, cause I say.

156. C: He's always been independent.

157. J: Yeah. I mean not so much now, cause they, they say he's
158. levelled off now. It's never going up, it's always going down, but
159. they, they [psychologist] and [psychiatrist] said he has sorta
160. levelled off. It ay just, drop, drop, dropping all the while, it sorta
161. reaches a plateau and then levels off and then. But we first
162. started, when they first diagnosed him, he was, he was really

163. C: He was angry.

164. J: But saying that, they found out, they said he'd got gall
165. stones and he was, cause he used to be screaming and lashing
166. out and this, that and the other hadn't he. It was that, and we
167. thought he was frustrated in the fact he couldn't move. Er, but
168. they've diagnosed with gall stones now and they've upped the
169. medication and that's, that's completely stopped.

170. AF: Ok.

171. J: So, you know, they have sorta. He was obviously in pain, so
172. if he just, er. You know, as I say, but as, the way I changed

173. through all this, is I see him more than I used to. I mean it could
174. be two or three months sometimes, hadn't it. It's the way things
175. happen, you know. But, as I say, it's normally every other week I
176. go up. Well I've been up the last two weeks. I went up not last
177. week, but the week before and he was asleep. And I must be
178. honest, if I walk and the carers say, o, Christ, he's only just
179. dropped off, you know, and I'll just sit there and see he opens
180. his, see if he wakes up. I won't wake him, because, I don't know,
181. too many, because I think if he's asleep the carers have got a
182. little bit of a break. And I would hate to think that, you know, er,
183. but it's just the way it is.

184. C: And you went up last week.

185. J: I went up last week and he was asleep again. So, so, I'll
186. come up earlier next time. No, the carers are marvellous. They
187. always have been, ay they.

188. AF: Ok, so that's why your worried about him moving from the
189. home?

190. J: Yeah, you know, cause as I say, they said as long as they
191. can keep him there, they'll keep him there. He's got lots of
192. things to accommodate him. Hoist, new bed. He just had a new
193. bed last week. But, er, I don't know how he would react, er. I
194. don't know, er, surely he would know if he was moved out of
195. [home]. I don't know how bad, I don't know how bad his
196. dementia, do they know their environment. Do they know their
197. surroundings?

198. AF: I mean, I don't know, cause I don't know G, but it's usually
199. best for people to stay in familiar safe surroundings.

200. C: I don't think they'd move him anyway.

201. J: No, I don't think they would. I mean there's other people

202. besides our A there.

203. AF: It does sound like it's a concern for you.

204. J: I say, I say that's my biggest concern, if they move him out

205. of [home].

206. AF: What did you think when he was first diagnosed?

207. J: I don't know to honest with you. Er, I can't really say I

208. thought anything. I don't know.

209. AF: Was it a surprise?

210. J: Well, yes it was a surprise. Er.

211. AF: Did it make sense to you?

212. J: No it didn't make sense, no. I don't think it makes sense to

213. anybody. I mean, to me, I'm, I'm, I'm probably, you can probably

214. say I'm cold. You got no quality of life.

215. C: you're not cold you're honest.

216. J: No, no, I mean he'd been admitted a couple of times even.

217. Then they rung and said A's back in hospital, and I'd ask was it

218. a seizure like last time and they'd say, o, yeah, yeah a seizure,

219. he'd bit all his tongue and everything. I mean honestly, I was

220. hoping that that would be it. To me, but everybody don't think

221. like that. I mean when he was able bodied he had fantastic

222. quality of life. Even though was Downs he....

223. C: He had better quality of life than us. His social life and that.

224. AF: Really, what sorts of things was he doing?

225. C: Swimming. Yeah, swimming. Clubs on a night-time. He was

226. always out singing, dancing. He'd go to the pub. He had quality

227. of life. Holidays. Three or four a year.

228. AF: Ok, so what's he doing at the moment.

229. C: Nothing.

230. J: Nothing. He's got up. He's sat in a chair.

231. C: He'll go to sleep. That's it.

232. J: They used to take him over to, er, cause I always tend to go
233. up, go up on a Thursday and they have a, they have a music
234. man come in on a Thursday for them and they have all the
235. residents over and they have a sing-song. He used to love that
236. and they still used to take him over. When he first, in the early
237. stages when first got diagnosis, he had used to do it and they
238. had used to give him a mic and he had used to attempt to sing. I
239. don't know if he knew what he was singing, but they used to put
240. his favourite on, Tom Jones, and he was singing, but then, as
241. time went on, he just, you could see he weren't interested in
242. that, so they stopped taking him over, didn't they. The carers
243. said, we don't think he's actually, cause they said. [psychologist
244. and [psychiatrist] said he needs stimulation and he needs this
245. and he needs that and the other, but they said they don't think
246. it's doing him any good. He'd sooner be in the living room, which
247. is why, er and he sorta. He, he was aware what was going on
248. around him like, but now he tends to just. He tends to sleep a lot
249. more than he ever does. As I say up the home I have to catch
250. him. It's very rare I go up and catch him or he'll wake up, but
251. that's how. He does sleep a lot. Rather than sorta, involved with
252. anything, you know. He just sorta got up. Ay, saying the staff
253. ain't involved with him. They am involved with him. They try and
254. stimulate him in other ways, but his not involved in anything as
255. times gone on. Not because trying, but because he can't.

256. AF: How's that been for you?

257. J: Well, it's hard. It's hard, it's hard seeing him as he is, cause
258. we know him as totally active. That's how we know him best.
259. It's, it's just hard to see the life of him now. I say, he used to

260. come out every Christmas to us, but that's stopped. He stopped,
261. that stopped a long before he was diagnosed with dementia,
262. before he was took ill, weren't he. For the simple reason, he was
263. bored when he comes here, ay he.

264. C: There wasn't enough going on here though, I don't think.

265. AF: Right. Ok.

266. J: He'd come, or the staff would talk him in, r, go and see and
267. o, going, yeah. And he'd come. They'd pack his bag. When they
268. go out and go and fetch him, cause he always spent Christmas
269. day in [home]. He didn't want to come to our Christmas day, so I
270. used to fetch him boxing day and he'd stop two or three days
271. away, or however long he wants and he started getting, er.

272. C: He started hiding from us.

273. J: I used to go up and I was like where's A and they couldn't
274. find him. He didn't want to come. He didn't want to come.
275. Perhaps, he's got to have done. He's got to have done. And he
276. come and he'd have his dinner and his presents and you could
277. see, can I go back. He wanted to go back. All his friends are at
278. the house. Them that don't go out, there's activities and that
279. going on. That started happening three or four years ago, didn't
280. it. Before he was took bad.

281. C: Then, then, he'd just come for a cup of tea then. That's the
282. only way we could get him here. Say, just come for a cup of tea
283. and a piece of cake.

284. J: Then he'd come.

285. C: So, then he would just come for a cup of tea. Once he had
286. his cup of tea and cake, can I go now?

287. J: He didn't take his coat off.

288. C: No. I'm not taking my coat off. There was too much going on

289. in [home], he didn't want to sit here with us. You know, he
290. probably though, boring old farts [laughing]. Erm, and that's how
291. it started with his not coming here.

292. J: I'll, I'll be honest. We don't actually know a great deal about
293. what actually goes on at [home], in a sense of what they actually
294. do with them, cause they do that much. I mean, I mean, you
295. sorta know about things that you see, or that they tell you about,
296. or, or he used to come and say he'd done so and so. There's
297. always something going on, ay there. Because, now it's like,
298. they've closed that many centres down, [home] is a centre for all
299. centres that have, so there's all the outsiders coming in as well
300. all the people that's.

301. C: Yeah, cause they've got their great big communal area.

302. J: They've got like a community centre thing, which is, cause
303. of the closure and cut-backs, they actually bring other Down's
304. into the [home], so there was always an influx. There was
305. always something going on, you know. But, er, no, it was too
306. boring when he come here, cause I mean we'd both been at
307. work and Christmas being your holiday, you just want to sit
308. down and relax and you just suddenly sitting and you talk with
309. him and laughing with him and he'd be saying, r, I wanna go
310. back, you know. But, er. That's the er. It's just hard seeing the
311. way he is now, cause knowing what he was. He was always
312. chasing the lady carers at [home].

313. AF: Really? Bit of a ladies man then?

314. J: Yeah. But they all knew one another didn't they.

315. C: He's been there that long hasn't he.

316. AF: You say he's been there twenty-five years.

317. J: Yeah, me mom and dad's been dead..

318. C: Twenty-five years.

319. J: Twenty-five years.

320. C: He actually went in before then.

321. J: Yeah, before me dad died. Because me dad...

322. C: He wanted to plan for the future didn't he.

323. J: Yeah. Actually he hadn't died, but he actually arranged to

324. sorta. He was looking forward, because, don't forget, they

325. soughta told mom and dad that A wouldn't live that long.

326. Obviously medicine and quality of life has got better, hasn't it?

327. And he started planning for that before he was took ill, didn't he.

328. C: And he used to go of a weekend.

329. J: Yeah, he just used to go for a weekend occasionally.

330. Obviously, when dad died, he was took up permanent, but he

331. used to come home every Friday night and stop with his mom,

332. till Monday and then he used to get the coach from home to the

333. centre and the centre would drop him off at [home] on the

334. Monday night and that went on for...

335. C: For four years.

336. J: For four years.

337. C: Till his mom had a massive stroke and died.

338. J: Before that, her had to go in the nursing home.

339. C: That'd be a bout nineteen years ago, yeah.

340. AF: Gosh, that sounds like lot happening at once.

341. J: Yeah.

342. C: Yeah it was.

343. J: I mean, I mean, we couldn't have had A stop with us or

344. spend that much time with him, because obviously, we got two

345. young kids then. And we were both at work, er. I got me mom in

346. a nursing home. But A used to see his mom nearly every day

347. hadn't he.

348. C: Yeah, but he used to go to the bus stop.

349. J: Cause where the nursing home that we put my mom in, the

350. day centre he used to go everyday of the week, was only about

351. half, about five hundred yards on the same street.

352. C: So he used to walk up and see his mom.

353. J: He used to walk up and see his mom every day. So he did

354. see his mom every day. Er, until she died.

355. AF: He was very independent then?

356. C: Yeah, he was. He was very.

357. J: O, r, yeah. Yeah, they used to let him come out the centre

358. and he'd walk up...

359. C: To the nursing home.

360. J: To the nursing home and take over in the nursing home

361. [laughing]. He'd take over. He had used to take over. He took

362. over didn't he? That's the way he was. He was always helping

363. out in the kitchen. He was always doing this. Always on the

364. move. That's the hardest part, seeing, erm, seeing er.

365. AF: Erm, what's your understanding of what the future's going to

366. hold for him?

367. J: I don't know.

368. C: I don't think you've got any understanding. I don't think you

369. know what's gonna happen.

370. AF: Ok, is that something you'd like to have?

371. J: I mean, in what way?

372. AF: Has anyone told you what's going to happen in the future?

373. J: Well, no, er, I think they have. [psychologist].

374. C: Our next meetings the 13th January.

375. J: 12th January.

376. C:12th.

377. J: And,er, it's er.

378. C: About the end of life.

379. J: End of life. They've dropped some hints the last couple of

380. meetings, ay they, but they've sorta said we don't really need to

381. broach on that, but I think they'm pussy footing around it for me,

382. but to honest with you, they don't need to pussy foot around. Er,

383. I mean, it's like I said, A ay got no. I know people could

384. disagree, but to me A's got no quality of life. Not now.

385. AF: IS this something you worry about?

386. J: No. I mean, me personally I think it would be a positive thing

387. for A. Some people might say I'm callous.

388. C: You've got to say what you feel haven't you.

389. J: I mean the A I'm seeing now, ay the A I know is it.

390. C: No, he's not your brother is he.

391. J: No, no. That's, that's, how I, how I, look at it anyway. I

392. mean, as I say, some people might say I'm callous and that, but

393. C: He always used to ask about his nephews didn't he. I mean,

394. I don't think he's mentioned them in a couple of years, as he.

395. J: I mean I have tried. They keep on, they've got, er, they've

396. developed all these key codes and that and picture things for A

397. like, for people to try and rub his hand or communicate with and

398. that. And, I, I, don't really, really does anything.

399. C: I don't think it does.

400. J: I don't know. I mean we got photos and I sorta try and talk. I

401. keep saying [names] and keep showing him photos and that, but

402. I mean, I get no response. He don't even look now. Er.

403. C: But we don't know if he remembers us.

404. J: Well, well, this is what I say, I don't know, I don't know, this

405. is what I say, I don't know, which is what I say. I don't like going
406. into the sense of what it actually does.

407. AF: Yeah.

408. J: I don't know. We don't know.

409. C: No we don't.

410. J: You've got your mom, ay ya, and she's got friends who've
411. got dementia and they don't really know what they say.

412. C: Yeah, but people who I know, my mom's friends who've got
413. dementia, they're not off their feet. They might get confused and
414. do the same thing ten times over, but they still walk and make a
415. cup of tea. You know what I mean. To me dementia is up here
416. [pointing to head], not this [pointing to legs]. So how do they
417. diagnose dementia?

418. AF: Has anyone ever explained it to you?

419. C: No.

420. AF: Right. Is that something you think might be helpful for you?

421. C: How have they diagnosed it?

422. AF: Is that a question to me?

423. C: Yeah, it's a question. How do they diagnose it?

424. AF: Well, erm, usually it's do by a multi-disciplinary team, so
425. you've got erm. Whose the psychiatrist? Is it [psychiatrist]?

426. C: O, I've forgotten his name.

427. J: [Says a name].

428. C: What's his name?

429. J: [Says a name].

430. C: No, not S.

431. J: [Says a different name].

432. C: No he's the social worker isn't he.

433. J: Well, I only know S, MS and DR.

434. C: Whose S, the coloured chap? He's a psychiatrist.

435. AF: The psychiatrist or a medic would have looked at the

436. medical side of things and excluded any other medical causes of

437. the symptoms and [psychologist] would have, erm, done some

438. erm, tests and asked people around some questions, er, to see

439. what he was like before the decline and, erm, what he was, er,

440. like, like after. They er, would have thought about his falls and

441. stuff, cause there's different types of dementia.

442. J: I think they have explained that. They was talking about

443. that.

444. C: It must have been one meeting when I couldn't go.

445. J: They have explained things to me, but half the time, you

446. say, yeah, yeah and you forget, or you just don't quite

447. understand it. It ay very nice is it.

448. C: No.

449. J: They said that at the moment, that it seems to hit a bit of,

450. it's levelled off, but it could drop suddenly, you know, not just,

451. very, very steeply. I don't see.....

452. C: When they say that, that, that it levels off now. That's how

453. they do it isn't it. He's up her and he's down here and then he's

454. gone up and levelled off again. What happens at the next drop?

455. J: Well say how much worse can it get?

456. C: How much worse can it get?

457. AF: Is that something that might be helpful to discuss with

458. someone?

459. J: Yeah, I think we're going to ask next time, cause I mean...

460. C: Cause our understanding is.. We're not ignorant, we just

461. don't understand.

462. AF: Would it have helped for you to have more information?

463. C: Well it won't change anything will it.

464. J: See, I. We've always, we've always said and we, we've said
465. it to [home] and to everybody else, cause I mean they ask
466. sometimes, o, we need your permission to, your, your in charge
467. of it.

468. C: Well, by law they still have to ask you.

469. J: Well, they keep saying, but I don't know why, because they
470. know him 100 times better than I would ever know him. I only
471. really know him, know A as me brother, when he lived at home,
472. before he went into [home]. After he went into [home]. It ay like.
473. He wasn't, he wasn't part of the family was he?

474. C: No. Because he settled so well and he loved everything he
475. was involved in and doing.

476. J: When mom was alive, he was part of the family, because
477. obviously mom wanted him out at home as much as her could,
478. so he was out every opportunity her could have him at home,
479. before her was bad. He was at home wasn't he. We had a
480. caravan. We used to take him down. We used to go to the
481. caravan. We had holidays together. We did everything. When
482. mom went and he lived in [home] permanently, like I said, we
483. ain't got the time to spend with A, as he had had before. So he
484. wasn't part of the family. [home] became his family and that's
485. how it went on. And of course it went on year after year and they
486. became more his family. So up till that stage, yeah, no I did
487. know him, but after that really it's actually [home] that know him
488. better. They know more than I'll ever know.

489. AF: And are you ok with that?

490. J: Yeah, yeah. I mean anything and they'll notify you straight
491. away or they'll ring. And we've been happy with that.

492. C: Yeah, cause we we're bringing up our own family. You
493. know, it's difficult isn't it.
494. AF: Yeah.
495. J: And now we've sort of been away from him. He looks that
496. lost.
497. C: He's just not A anymore is he.
498. J: No, no. He's not the A who we know is he.
499. C: No.
500. J: I mean if was took bad. Say when we had used to go up,
501. he'd greet you, there'd be kisses and that, then two or three
502. minutes after sitting down you wouldn't see him again. I mean
503. you had to go and find him to say ta-ra. It was ok ta-ra see you
504. soon and that was it wasn't it. But, er, um. It got to the stage
505. where I might not see him for two or three months, had I, when
506. we'd go up, he'd be just the same. He'd sit there and tell you
507. what you asked, he'd be like, I've been on holiday and I've done
508. this, that and the other, but after he told you, that would be it and
509. he'd be off. And you know....
510. C: It was a standing joke up there wasn't it.
511. J: Yeah. So probably, it was my guilt that I used to go up and
512. see him, because I thought, well, he's my brother, I ought to go
513. up and see him. But then, you go up and see him, and you're
514. like, he ay too bothered, so I'll [both laughing]. That's how it
515. went on though. I've probably seen him more in the last 12
516. months than I probably have in the last ten year, ain't I.
517. AF: So why is it that you feel you have to go more now?
518. J: Probably guilt again.
519. C: That's being human though isn't it?
520. J: Ay?

521. C: That's just being human.

522. J: Yeah, C you used to say, didn't you, the staff ay bothered,
523. but I suppose sometimes I think the staff think, his brother don't
524. come and see him. I don't know. But, er. Yeah, I'll go up and see
525. him, but like I say I'm just sitting there.

526. C: But you feel better cause you've been.

527. J: Yeah.

528. AF: Do you feel better when you've been?

529. J: Yeah, yeah. Because as I said it had used to be long
530. breaks, ay it. It could be two or three months before I see him
531. and then I think, o, I better go up and then I think it's his birthday
532. next month and I'll go up before his birthday, so, er. We didn't
533. worry about him. We never worried about him at all, cause as I
534. say, the staff are marvellous. I mean most the staff have been
535. there since...

536. C: Since they were teenagers.

537. J: Since they were teenagers. I mean K was only a carer, I
538. mean she's the manager now. I mean, you know, she was only
539. like a young kid when our A moved in. We've sort of seen them
540. grow up and. There's new staff come and go, but every time I go
541. up them that friendly. They, well, there marvellous. And that's
542. why. I mean that's, that's now my biggest worry. I mean, you
543. used to work in nursing home before you worked at the NHS
544. and a nursing home ay a place. I would hate him to go in a
545. nursing home.

546. AF: What is about nursing homes? Why would you hate him to
547. go there?

548. J: I don't know.

549. C: I think, I think they don't understand Down syndrome and I

550. suppose it's normal people that work in nursing homes.

551. J: I mean C's had. I mean, I've always been fortunate when

552. A's been taken to hospital. They've rung me straight away.

553. When A's been into hospital, either C's been I'm on tonight or

554. I'm on this afternoon and you've gone in. I mean last time and

555. the time before, I mean you was in A..

556. C: A&E

557. J: A&E and then they moved him onto the EAU and all they

558. could do was call you down from upstairs, because, because

559. they're not used to dealing with Down syndrome. And, o, what's

560. the matter with him, what's the matter with him?

561. C: Why's he shouting? Why's he doing this, you know. Cause,

562. cause they're not used to dealing with them.

563. AF: So what's that like for you when you have to do that?

564. C: It doesn't bother me, you know. I just worry that my gaffer

565. might say, well, where you going again, you know. Don't bother

566. me. They only have to ring me on the ward and I'm down there.

567. I'll go straight away, you know. Cause I think, well I'd rather be

568. there than the doctors and nursing staff getting frustrated,

569. because they don't know what's the matter with him or what he

570. wants. Whereas I do, you know.

571. J: You see, A, A, the biggest problems he's got no, he can't

572. talk. He couldn't talk when he was normal. You know, you get

573. someone who'd say hello and he couldn't have a conversation

574. like me and you could. Our A, he got his own language.

575. C: We understood it.

576. J: We understood it. Certain things he could say, which were

577. the right words, but other than that he'd got a word for

578. something that was totally different. You know, and unless you

579. know him you wouldn't know what he was on about. We knew,
580. we knew what he was on about when he lived at home with his
581. mom, er, because we used to see him every day. It's like the
582. staff knew, knew what he wanted, but when he goes to an
583. outside environment, it's just, it's just gibberish to anybody else.
584. Cause, he used to, he' only tell you once or only ask once,
585. cause if you didn't get it you were in trouble.
586. C: He wouldn't tell you again.
587. J: You know, you should understand me. That was his
588. attitude, wasn't it. I mean, if you didn't get it first time, he might,
589. he might give you a second chance. If you didn't get it second
590. time, no. Woe betide.
591. AF: Really?
592. C: This is why we see such a big change in him you see.
593. AF: It sounds like he's really different from how he was.
594. C: O God, yeah.
595. J: So, obviously, that's what I was saying. When he went to
596. hospital, he couldn't say what he felt or. He just had a seizure or
597. had a fit and was took in and them trying to find out what's the
598. matter. Why you got this? Well he can't say I've got a pain here,
599. I've got this and this. So he used to scream and fight and lash
600. out. Then C used to, you work upstairs. We've been lucky that
601. way, ay we.
602. C: We have been lucky that I've either been at work or I'm on
603. my way to work, so I've sort of gone straight there.
604. J: But you ay gonna get that in a nursing home. That's cause
605. it's only a nursing home, They ay gonna understand it. They
606. understand it at [home].
607. C: That's, that's the big difference to me.

608. AF: Ok, so you don't think anywhere else would be able to meet
609. his needs.

610. J and C together: No.

611. J: I wouldn't say they wouldn't meet his needs, but I wouldn't
612. like to put it to the test, you know what I mean. Er, I ay gonna
613. say all nursing homes are bad.

614. C: You're not saying that though.

615. J: No, they'd cater for his medical and stuff like that, but his
616. personal needs. You know, er, er, that, that would frighten me.

617. AF: It's just lucky that you've been at the hospital when you
618. have been. What's going to happen if you're not?

619. C: Well I'd go anyway. It's just, what we meant by lucky is that
620. I've already been there or on my way.

621. J: I mean the last two times he's been in there you've either
622. been there already or on your way for your shift. Or I'll pop in the
623. home, don't worry I'll go down and see A.

624. AF: It's just lucky you work that at all.

625. C: [laughing] It is, yeah.

626. AF: What if you worked somewhere totally different?

627. C: Of course, I know it's a stupid thing to say, but it helps
628. because I know the staff. You know, and if you know the doctors
629. and the nurses. It's a big help. It helps. Ring C if she's on
630. upstairs, so I have been lucky that. But we go anyway. Even if I
631. wasn't at work. It's just been fortunate that I've either been on
632. my way or I've already been at work when they've phoned.

633. AF: Is there anything else that you want to say, or anything else
634. you can think of that you want to say?

635. J: No, not really.

636. AF: Ok, I'll switch this off then.

EMERGENT THEMES

Dementia as memory loss

3. J: Erm, what it means to me? Er, loss of memory.
87. I suppose I just had the same
88. perception as everybody else, er, you know, loss of memory,

Dementia as lack of awareness

6. J: Er, yeah, that's how I look at it. Er, not knowing what's going on
7. around you.

Didn't recognise dementia

9. J: We didn't until they told us at [home]. We noticed a change in him
10. before they told us he'd got dementia. Er.
18. We didn't really
19. know he'd got dementia until they said or said that he's been
20. diagnosed or that they diagnosed him with vascular dementia, so.
35. C: Yeah, cause we didn't know what was going on did we, cause the
36. first change we saw in him was his walking.

Never thought about dementia

85. J: I never, I never really give it any thought, cause I never known
86. anybody, or known anybody with dementia,
205. J: I don't know to honest with you. Er, I can't really say I
206. thought anything. I don't know.

Life with dementia isn't worth living

210. J: No it didn't make sense, no. I don't think it makes sense to
211. anybody. I mean, to me, I'm, I'm, I'm probably, you can probably
212. say I'm cold. You got no quality of life.
215. Then they rung and said A's back in hospital, and I'd ask was it
216. a seizure like last time and they'd say, o, yeah, yeah a seizure,
217. he'd bit all his tongue and everything. I mean honestly, I was
218. hoping that that would be it.
381. I mean, it's like I said, A ay got no. I know people could
382. disagree, but to me A's got no quality of life. Not now.

Acceptance of death

377. J: End of life. They've dropped some hints the last couple of
378. meetings, ay they, but they've sorta said we don't really need to
379. broach on that, but I think they'm pussy footing around it for me,
380. but to honest with you, they don't need to pussy foot around.

384. J: No. I mean, me personally I think it would be a positive thing
385. for A.

Worry about what others think

211. you can probably
212. say I'm cold.

381. I know people could
382. disagree,

385. Some people might say I'm callous.

389. J: No, no. That's, that's, how I, how I, look at it anyway. I
390. mean, as I say, some people might say I'm callous and that, but

520. J: Yeah, C you used to say, didn't you, the staff ay bothered,
521. but I suppose sometimes I think the staff think, his brother don't
522. come and see him. I don't know.

Trying seems futile

393. J: I mean I have tried. They keep on, they've got, er, they've
394. developed all these key codes and that and picture things for A
395. like, for people to try and rub his hand or communicate with and
396. that. And, I, I, don't really, really does anything.

398. SH: I don't know. I mean we got photos and I sorta try and talk. I
399. keep saying [names] and keep showing him photos and that, but
400. I mean, I get no response. He don't even look now. Er.

522. I don't know. But, er. Yeah, I'll go up and see
523. him, but like I say I'm just sitting there.

Mind/ body disconnect

13. C: I don't think it was anything to do with his mind that we noticed.
14. We noticed he couldn't walk, didn't we?

38. C: When I actually passed a comment at [home]. I said why can't he

39. walk? Cause I was so shocked, that he was. He wanted to, but he
40. couldn't.

71. C: He wanted to but he couldn't.

413. To me dementia is up here

414. [pointing to head], not this [pointing to legs]

Shock

16. was very, very unsteady on his feet and er, a big shock from the way
17. we seen him the last time.

34. you know, it's just a shock. Er.

39. Cause I was so shocked, that he was.

Confused about dementia

77. C: I don't think they actually used the word stroke did they? They
78. said it's a process of mini seizures, if you know what I mean. They
79. never, I don't think, even, [psychologist], nor [psychiatrist] have
80. actually said stroke have they?

402. C: Well, well, this is what I say, I don't know, I don't know, this
403. is what I say, I don't know, which is what I say. I don't like going
404. into the sense of what it actually does.

410. C: Yeah, but people who I know, my mom's friends who've got
411. dementia, they're not off their feet. They might get confused and
412. do the same thing ten times over, but they still walk and make a
413. cup of tea. You know what I mean.

443. J: They have explained things to me, but half the time, you
444. say, yeah, yeah and you forget, or you just don't quite
445. understand it. It ay very nice is it.

450. C: When they say that, that, that it levels off now. That's how
451. they do it isn't it. He's up her and he's down here and then he's
452. gone up and levelled off again. What happens at the next drop?

458. C: Cause our understanding is.. We're not ignorant, we just
459. don't understand.

Draw own conclusions

81. J: They just say seizures. To me that's a stroke though. That's how I
82. look at it anyway.

Understanding won't help

461. C: Well it won't change anything will it.

Sudden

24. J: To us it was, yeah. I mean time goes that quick now. It seems like
25. only yesterday, but it's been quite a while, hasn't it, since he's been
26. diagnosed with it. Er, but yeah, it was sudden.

27. AF: Ok.

28. J: We noticed a big change very quickly.

45. C: Six to twelve months. To me that's quick

68. And, er, I was telling the

69. doctors what I thought, you know. I said he just suddenly can't do it.

Need to check him

32. I've been

33. seeing him more regular, since he's been, since he's been bad

128. for, how I've changed is I'm more concerned and I see him more

129. often.

134. You know, but I think that's why you see

135. him more regular now, cause he can't walk away from us.

141. J: We spent half hour, three quarters of an hour, sorta talking

142. to the carers or somebody else

170. You know, as I say, but as, the way I changed

171. through all this, is I see him more than I used to.

Highlighted difficulties to get action

42. C: And I said why can't he walk. And that was, it just went from there

43. really.

Loss of independence

66. And that's

67. why he used to be independent and walked about. He's always
looked

68. after himself. To a certain degree obviously.

143. He was more, you know, interested in what was

144. going on in the house, cause he was always active. He was

145. always involved.

Hard to think he doesn't recognise me

92. J: No. Probably no. Like I say, I might go and see me brother, I
93. some, I think he don't recognise me. Everybody says he does. The
94. carers say he does and you say he does, don't ya. He probably does,
95. but it's hard getting no reaction out of him.

Wants to be with others not me

96. I sorta can't get a reaction out of him. We've been up together, ay we
97. and we don't go no reaction do we? Whereas the carers will. So er,
98. they'll sorta walk in, or somebody's walked in and he has sorta
smiled,
99. which I never get, I know I'm never gonna get.

132. C: See, when A was well and we used to go and see him, he'd,
133. he'd walk away from me, wouldn't he.

137. J: O, yeah. He greets ya...
138. C: He greets ya.
139. J: Five minutes and that'll be it.
140. C: He's off.

259. that stopped a long before he was diagnosed with dementia,
260. before he was took ill, weren't he. For the simple reason, he was
261. bored when he comes here, ay he.

271. J: I used to go up and I was like where's A and they couldn't
272. find him. He didn't want to come. He didn't want to come.

275. He wanted to go back. All his friends are at
276. the house. Them that don't go out, there's activities and that
277. going on. That started happening three or four years ago, didn't
278. it. Before he was took bad.

285. J: He didn't take his coat off.
286. C: No. I'm not taking my coat off. There was too much going on
287. in home, he didn't want to sit here with us. You know, he probably
288. though, boring old farts

305. Christmas being your holiday, you just want to sit down and
306. relax and you just suddenly sitting and you talk with him and
307. laughing with him and he'd be saying, r, I wanna go back

498. Say when we had used to go up,

499. he'd greet you, there'd be kisses and that, then two or three
500. minutes after sitting down you wouldn't see him again. I mean
501. you had to go and find him to say ta-ra. It was ok ta-ra see you
502. soon and that was it wasn't it.

Dementia has increased concern

110. your more concerned about him now. You wasn't so concerned
111. about him five years ago.

The homes his family

117. J: Twenty-five years. It's his home. [home] is his family. I mean, I
118. know he's my brother, but them at [home] and everybody, they'm
119. more his family, than, than I am.

312. J: Yeah. But they all knew one another didn't they.

313. C: He's been there that long hasn't he.

467. J: Well, they keep saying, but I don't know why, because they
468. know him 100 times better than I would ever know him. I

479. When

480. mom went and he lived in home permanently, like I said, we ain't
481. got the time to spend with G, as he had had before. So he
482. wasn't part of the family. home became his family and that's how it
483. went on

535. J: Since they were teenagers. I mean K was only a carer, I
536. mean she's the manager now. I mean, you know, she was only
537. like a young kid when our A moved in. We've sort of seen them
538. grow up

Don't want him to leave home/ lose family

120. concerned about him, but my biggest concern and you, and you
121. know it, is I don't want him to leave [home].

188. J: Yeah, you know, cause as I say, they said as long as they
189. can keep him there, they'll keep him there. He's got lots of
190. things to accommodate him.

198. C: I don't think they'd move him anyway.

199. J: No, I don't think they would. I mean there's other people
200. besides our A there.

Frustration

145. Well, we
146. thought he used to get frustrated, really frustrated, but I think
147. he;s got to the stage now where he's probably frustrated

Dementia levelling off

155. J: Yeah. I mean not so much now, cause they, they say he's
156. levelled off now.

447. J: They said that at the moment, that it seems to hit a bit of,
448. it's levelled off,

Getting worse

156. It's never going up, it's always going down

448. but it could drop suddenly, you know, not just,
449. very, very steeply.

Understanding behaviours

162. J: But saying that, they found out, they said he'd got gall
163. stones and he was, cause he used to be screaming and lashing
164. out and this, that and the other hadn't he.

169. J: So, you know, they have sorta. He was obviously in pain, so
170. if he just, er.

Difficulty understanding needs

191. I
192. don't know, er, surely he would know if he was moved out of
193. HH. I don't know how bad, I don't know how bad his dementia,
194. do they know their environment. Do they know their
195. surroundings?

236. I
237. don't know if he knew what he was singing, but they used to put
238. his favourite on, Tom Jones, and he was singing, but then, as
239. time went on, he just, you could see he weren't interested in
240. that, so they stopped taking him over, didn't they.

241. [psychologist] and [psychiatrist]
242. said he needs stimulation and he needs this and he needs that
243. and the other, but they said they don't think it's doing him any
244. good. He'd sooner be in the living room,

Feels in the way

178. I won't wake him, because, I don't know,
179. too many, because I think if he's asleep the carers have got a
180. little bit of a break. And I would hate to think that, you know, er,
181. but it's just the way it is.

Good care

184. No, the carers are marvellous. They
185. always have been, ay they.
292. cause they do that much. I mean, I mean, you sorta
293. know about things that you see, or that they tell you about, or, or
294. he used to come and say he'd done so and so. There's always
295. something going on, ay there.
531. We never worried about him at all, cause as I
532. say, the staff are marvellous.

Loss quality of life

218. To me, but everybody don't think
219. like that. I mean when he was able bodied he had fantastic
220. quality of life.
226. AF: Ok, so what's he doing at the moment.
227. C: Nothing.
228. J: Nothing. He's got up. He's sat in a chair.
229. C: He'll go to sleep. That's it.
248. He does
249. sleep a lot. Rather than sorta, involved with anything, you know.
255. J: Well, it's hard. It's hard, it's hard seeing him as he is, cause
256. we know him as totally active. That's how we know him best.
308. It's just hard seeing the way he is
309. now, cause knowing what he was.
360. That's the way he was. He was always helping
361. out in the kitchen. He was always doing this. Always on the
362. move. That's the hardest part, seeing, erm, seeing er.

Don't know what home does

290. J: I'll, I'll be honest. We don't actually know a great deal about
291. what actually goes on at HH, in a sense of what they actually do

292. with them,

Lived longer than expected

322. sorta. He was looking forward, because, don't forget, they

323. soughta told mom and dad that A wouldn't live that long.

Things better now for people with LD

324. Obviously medicine and quality of life has got better, hasn't it?

I have my own life

341. J: I mean, I mean, we couldn't have had A stop with us or

342. spend that much time with him, because obviously, we got two

343. young kids then. And we were both at work

490. C: Yeah, cause we we're bringing up our own family. You

491. know, it's difficult isn't it

Don't understand/confusion about future

366. C: I don't think you've got any understanding. I don't think you

367. know what's gonna happen.

Person gone

387. J: I mean the A I'm seeing now, ay the A I know is it.

388. C: No, he's not your brother is he.

493. J: And now we've sort of been away from him. He looks that

494. lost.

495. C: He's just not A anymore is he.

496. J: No, no. He's not the A who we know is he.

497. C: No.

Guilt/ obligation

509. J: Yeah. So probably, it was my guilt that I used to go up and

510. see him,

515. AF: So why is it that you feel you have to go more now?

516. J: Probably guilt again.

Nursing homes are bad places

540. I mean that's, that's now my biggest worry. I mean, you

541. used to work in nursing home before you worked at the NHS
542. and a nursing home ay a place. I would hate him to go in a
543. nursing home.

People don't understand Down syndrome

547. C: I think, I think they don't understand Down syndrome and I
548. suppose it's normal people that work in nursing homes.

555. J: A&E and then they moved him onto the EAU and all they
556. could do was call you down from upstairs, because, because
557. they're not used to dealing with Down syndrome.

565. I'll go straight away, you know. Cause I think, well I'd rather be
566. there than the doctors and nursing staff getting frustrated,
567. because they don't know what's the matter with him or what he
568. wants. Whereas I do, you know.

593. J: So, obviously, that's what I was saying. When he went to
594. hospital, he couldn't say what he felt or. He just had a seizure or
595. had a fit and was took in and them trying to find out what's the
596. matter. Why you got this? Well he can't say I've got a pain here,
597. I've got this and this. So he used to scream and fight and lash
598. out.

602. J: But you ay gonna get that in a nursing home. That's cause
603. it's only a nursing home, They ay gonna understand it.

Need to know him to understand him

572. Our A, he got his own language.
573. C: We understood it.
574. J: We understood it. Certain things he could say, which were
575. the right words, but other than that he'd got a word for
576. something that was totally different. You know, and unless you
577. know him you wouldn't know what he was on about.

579. It's like the
580. staff knew, knew what he wanted, but when he goes to an
581. outside environment, it's just, it's just gibberish to anybody else.

Need to cater for emotional needs

613. J: No, they'd cater for his medical and stuff like that, but his
614. personal needs.

Super-ordinate themes

Don't understand dementia

Confused about dementia
Didn't recognise dementia
Never thought about dementia
Don't understand/ confusion about future
Difficulty understanding needs
Mind/ body disconnect
Draw own conclusions
Shock

Struggle to see role

I have my own life
Feels in the way
Worry about what others think
Wants to be with others not me
Hard to think he doesn't recognise me

Home as family v Others don't help

The home is his family
Don't want him to leave home/ lose family
Good care
People don't understand Down Syndrome
Nursing homes as bad places
Highlight difficulties to get action

Life not worth living

Loss of quality of life
Life with dementia isn't worth living
Acceptance of death
Getting worse
Trying seems futile
Understanding won't help

Person-centred

PwD Frustration
Understanding behaviours
Need to know him to understand him
Need to cater for emotional needs

Meaning of dementia

Dementia as memory loss
Dementia as lack of awareness
Dementia levelling off
Sudden

Loss

Person gone

Loss of independence

Concern v Guilt/ Obligation

Need to check him

Dementia increased concern

Guilt/ obligation

Appendix 8

Self-reflexivity and the positions the researcher has brought to the research:

I am a 30-year-old woman from the North West of England. I was brought up in a seaside town with a high concentration of care homes, by a mother who has worked for the majority of my life, within older adult care, as a care assistant. I have heard stories of both positive and negative experiences of being a paid staff carer. Many of the care homes my mother has worked within were private organisations that paid her very badly and worked her extremely hard. The role is a very stressful one and I think many times she has felt unsupported and often exploited by organisations that are more interested in profit than people. On the other hand, she also worked for many years caring for elderly nuns and she had a very positive experience. This role was unusual, as she was working within a community of nuns, where those that needed support were not separated from those that did not require it. My mother's job was to help support the more elderly nuns to maintain their roles within that community. The relationship was also reciprocal, in that each nun was assigned a carer and their family to pray for each day.

I myself started working in older adult care homes when I was a teenager and was quite upset by the experience. My working conditions were poor, my training was non-existent and my responsibilities were great for a person of such a young age. I lasted a week initially at this job. When I went to university, due to financial necessity, I began work in a

different home. Whilst I was a couple of years older, I was still a teenager, but managed to contain my distress better and worked on and off for three years. I was still quite emotionally affected by what I saw and would go home and cry.

I think having these experiences has coloured the way I view care organisations and I often expect the worst from them. I was curious to see what paid staff carers would say about their positions within the organisations. Paid staff carers did not really mention the wider organisation and when they did, it was to say how supported they felt. I am glad that staff did have good experiences and feel that there may have been changes within the system since the 1990s, with the introduction of a minimum wage and an increase in training. However, it has left me wondering if they were able to be honest about their positions and has made me wish that I had explored it more.

I am also curious about their emotional experiences, as I was quite traumatised by the experience of seeing people so unwell. I wonder whether that was because for me it was a 'holiday job', so I could allow myself to be emotionally affected by what was happening around me, as I knew that it would come to an end. Within the research I was focusing on the emotional experiences and wonder if I was drawn to this due to my own experiences?

Within my own family, currently my Grandad is carer for my Auntie who has dementia and he supports her within her own home, with help from paid carers. It was very difficult for my Grandad to be able to obtain

this support and we managed to access support through seeking advice from a social work colleague of mine who supported us in negotiating the system and letting us know what we were entitled to. My Grandad is in his late 80s, has literacy difficulties, is registered blind and was brought up to have reverence to those who were seen as his betters, so when the GP was reluctant to help this was something that he accepted. This has left the whole family frustrated at a system that is difficult to negotiate.

The family system I grew up within has strong beliefs around caring for those within the family. I have personal experience of being in a family carer position, as my mother has ongoing health problems. The majority of the time she manages well, but there have been aspects of life that she has struggled with, which has also put a strain on my own life and that of my siblings. Over the years my family have developed a more trusting relationship with external support, as my mother has accepted help and this has gone some way to mitigating my families mistrust of external support.

That some families struggle to trust others and believe that others outside their families could have their best interests at heart, is familiar to me, but also working within the system that is offering support has helped me see things from both sides. I recognise that the system is not perfect and never could be, but I also recognise that many people are left to struggle with very difficult situations and feel incredibly frustrated. I also understand that sometimes families struggle to continue to be there all the time for one another, as the strong expectations within my family that

'families care for each other', has left me with some difficult feelings of obligation.

My position as a trainee psychologist within an adult psychotherapy service and a child and adolescent mental health service that works from a psycho-dynamically informed position, may have influenced the way I viewed and interpreted the transcripts. I think it is obvious from the themes that have developed, that psychodynamic and attachment ideas are strong influences, even though I did not consciously look at the data through these lenses. I wonder if I had been working somewhere else what themes would have emerged?

I like to think that I have been able to bracket off my own personal life experiences and take each account on its own merits. I do worry that I was quick to highlight the negatives within the system, but the research team were there to help me think about these issues and believe that my themes are sound. However, I feel that main influence has been a theoretical one and I have drawn upon ideas that I am currently exposed to rather than thinking of alternative explanations.